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Exploring the psychological problems of mothers having the experience of death of children with untreatable genetic disorders: A qualitative study

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Abstract:

BACKGROUND: A newborn with an untreatable genetic disorder could disrupt a family and affect parents' mental health, psycho-social interaction, and parent–child relationships. This study was conducted to explore the psychological problems of mothers having the children with untreatable genetic disorders.

MATERIALS AND METHODS: This qualitative study was performed using the conventional content analysis method on 15 mothers having the children with untreatable genetic disorders selected by purposeful sampling. In-depth and semi-structured interviews were used to collect data. The recorded interviews were transcribed verbatim immediately and imported into MAXQDA10 software. Lundman and Granheim's content analysis method and Guba and Lincoln's proposed criteria for assessing rigor of the results were used.

RESULTS: Overall, 1067 primary codes were extracted from the interviews and after the integration of similarities grouped into 19 sub-categories and three major categories including psychological reactions before diagnosis, after determined diagnosis, and after the child's death.

CONCLUSIONS: The results showed that having the child with untreatable genetic disorder is considered as a notable psychological trauma and causes painful psychological reactions in parents. In this regard, the following approaches are recommended to health professionals: continuous monitoring of mental health of these families, developing a family education program, emotional and psychological support, and genetic counseling.

Keywords:

Birth defects, genetic diseases, mental disorders, qualitative research

Introduction

Birth defects are any abnormalities that affect the structures or functions of the body and are diagnosed at birth or after birth; the cause of 50% of birth defects is unknown.[1] Approximately 20% of deaths in children under 1 year old are due to congenital anomalies.[2] Rare diseases of genetic origin have a chronic and debilitating nature and sometimes threaten the life of the child and require special treatment.[3] Currently, the focus is on non-communicable disorders such as genetic diseases, which account for nearly the highest proportion of mortality among children under the age of 5.[4] The frequency of consanguineous marriages in Iran is reported to be 74%, which increases the incidence of recessive autosomal diseases.[5]

Given that the family is a structure, the performance of each person in this system

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will affect the continuation and survival and change in the behaviors of other family members. Therefore, impairment in the physical or mental health of one member affects the function of other organs and can eventually lead to dysfunction of the entire system.[6]

Having a newborn with a rare genetic disease can disrupt family order and be very stressful; the burden of care that a child with a genetic disorder imposes on the family is lifelong and requires extensive changes in the roles and responsibilities of family members, economic status, and work patterns.[7]

Parents play a variety of roles in each family, and parents of sick children have the role of a care coordinator, medical expert, supporter, ambassador, and child representative. In general, parents of sick children experience higher role pressure, levels of stress, and burnout than parents of healthy children in relation to the parental role, division of labor, and expectations.[8]

Crowell *et al*. (2019) state that parental stress is a factor that not only overshadows their physical–psychological condition but also delays the process of recovery of the sick child.[9]

Mothers interact with the child more than other family members and experience more problems and anxiety than other members. The mother–child relationship is intertwined, and their relationship is very important in psychology and each other's change affects the other. Therefore, in mothers whose children have genetic disorders, stress levels and psychological problems increase.[10,11]

In the process of the child's illness, mothers play a more active role because they are culturally the main caregiver of the sick child and consider themselves obliged to be completely devoted to the child and deprive themselves of activities such as recreation, employment, and socializing that they did before the child became ill.[12]

Despite access to studies based on the diagnosis, there is insufficient knowledge about the consequences that such disorders can have for the sick child and the family.[13] In general, studies on genetic diseases and their types have been able to introduce these diseases to the community to some extent. However, despite all the efforts made, the importance and necessity of prevention have not yet been able to be effectively institutionalized among the thoughts and ideas of society. Also, the distribution of facilities according to children's diseases in the country is not fair, which increases the problems of families.[14,15]

Due to the nature and complexity of genetic disorders, parents of children show relatively high levels of anxiety, depression, stress, and other psychological problems, and these people are highly vulnerable to various mental and physical disorders.[16] This is despite the fact that there are moderating factors between parents' psycho-social pressures and children's disorders. In this regard, the results of some research indicate that some factors play an effective role in reducing the amount of stress and discomfort experienced by parents of affected children.[17] Therefore, according to some different results in different studies, the present study qualitatively explained the psychological problems of mothers with children with incurable genetic disorders.

In this regard and in order to promote a prevention-oriented approach at the community level and to create the basis for collective thinking about the need for prevention and its development strategies, qualitative studies are needed to be able to write down the thoughts and ideas of those involved in problems related to genetic diseases, especially severe ones and by revealing the undiscovered dimensions of the problems and disorders of these families, give a new perspective on the life of this group of people to society, and thus try to promote preventive attitudes and behaviors about genetic diseases. Therefore, the present qualitative study was conducted to investigate the psychological problems of families with children with incurable genetic defects.

Methods

Study design and setting

The present study was conducted with a conventional content analysis approach. Conventional content analysis is used in studies that aim to describe a phenomenon. This approach is usually appropriate when existing theories or research texts on the phenomenon are limited. Researchers avoid using pre-formed classes and instead allow classes and their names to flow from the data.[18] The available evidence for the psychological consequences that incurable genetic disorders leading to child death can cause for parents is very limited and was considered as the aim of the present study.

Study participants and sampling

The population studied in this study consisted of mothers of children with incurable genetic defects in Ardakan city in Yazd province, for example, parents of children with metabolic genetic diseases such as Crigler–Najjar syndrome, butterfly disease, familial dysautonomia, spinal muscular atrophy, chromosomal and multi-gene genetic disorders (which cause complications such as cleft palate, cleft lips, and cerebral palsy), and Mucopolysaccharidoses, who were willing to participate voluntarily in this research and spoke fluent Persian. Families were selected to participate in the study in which at least one of their children died of a severe

genetic defect. These parents should also be able to express their feelings and points of view and be able to address their inner feelings in terms of personal and social life experiences. The members of the research team had sufficient knowledge of mothers due to their extensive knowledge of families; the first author, who is from the city of Ardakan, works in the community health center and has experience living in the heart of the research community. Exclusion criteria were the inability to express their feelings, the mental and cardiac perceptions about the health, illness and death of the child, and the unwillingness of parents to continue participating in the study. Also, travel and absence in the region geographically were considered as criteria for exclusion.

Ethical considerations

In this study, principles such as stating the objectives of the study to the participants, confidentiality of information (explained to the participants that the recorded interviews are listened to only by the interviewer and after transcribing them on paper are deleted as well as their alias or code used to report the results), obtaining informed consent for interviewing and recording the conversation, providing the results to the participants upon request, and having the right to withdraw the participants from the research at each stage were observed. This study was approved by the ethics committee of Shahid Sadoughi University of Medical Sciences in Yazd with the code IR.SSU.SPH.REC.1397.070.

Data collection

Semi-structured individual interviews were conducted with 15 participants, with each interview lasting between 45 and 60 minutes. Before conducting the interview, the research team coordinated with the participants and, while explaining the objectives of the interview, determined the time and place of the interviews based on their preferences. Interviews were conducted during the day (morning or evening) at the participants' homes. An attempt was made to keep the interviews in a suitable atmosphere, without prejudice and direction (the researcher kept all his ideas and assumptions according to the principle of bracketing in qualitative research and did not allow their interview or analysis questions to skew the research). In this study, first, by inquiring from the provincial welfare organization, Ardakan Genetics Laboratory, the names of children who had died due to severe genetic problems in the last 5 years were extracted. Parents were then allowed to be visited and interviewed by telephone. Some parents refused to be interviewed and participate in the study due to severe psychological trauma. They were also thanked and proceeded to contact the people who agreed to the interview. Participants (mothers whose at least one child died of a severe genetic defect) were purposefully selected. Based on the coding and analysis of the first interview, planning for the next interview and interview questions was done.

The initial framework of the interview questions was designed by reviewing the texts and experts aware of the subject. To begin the interview, an open-ended question such as "Please talk about your pregnancy and what happened after your baby was born" was used as a guiding question to clarify the main issues. Subsequent questions were formulated and asked based on the participant's response. To clarify the concept, follow-up questions were asked based on the information provided by the participants.

Probing questions such as "Can you explain more?" or "Give an example" were used to get deeper information, for example, when the first participant talked about the time when her child was hospitalized and the type of her illness was still unknown: "I was just crying there. I was doing nothing but crying." The interviewer asked her to explain more or what they meant by their comments. "I wish there was no such child for me, I wish this child was not mine," she admitted.

Simultaneously with the interview, important statements made by the interviewees were noted, which helped to retrieve and relate a summary of the important points made at the end of each interview session to confirm their meaning by the interviewee. In cases where there was ambiguity after rewriting the text of the interview, the interviewee was contacted again and new data were added to the text of the interview by conducting additional interviews. Data collection continued until the saturation stage, that is, until no new findings were obtained and all domain areas were covered.

Data analysis

Immediately after each interview, on the same day, the recorded material was implemented verbatim and entered into MAXQDA10 software. Data analysis was performed simultaneously with data collection. After collecting the data, the data analysis process was performed based on the proposed steps of Granheim and Landman (2004).[19] In this method, the following five steps are performed for analysis:

1. Word-for-word interviews and studying them several times to get a general feel.
2. Dividing the text into summarized semantic units.
3. Abstraction of summary semantic units and labeling by codes.
4. Separating the codes in the sub-themes by comparing them based on similarities and differences.
5. Setting themes as an indicator of hidden textual content.

The members of the research team reviewed the whole interview several times to get a general sense of the textual data, and after identifying the analysis unit and semantic units, they performed the coding process. The primary codes were compared, and similar codes were sub-divided. Then, the notes were replaced within the main classes by constantly comparing the sub-classes based on their appropriateness and similarity.

With the addition of each interview, the analysis process is repeated and the codes and classes are modified. During the interview analysis process, the research team tried to maintain close contact with the data. In this study, to report aspects related to the field and method of study and the results of their analysis and interpretation, COREQ criteria have a standard 32-item checklist and are in three dimensions: "Research and Reflection Team", "Study Design", and "Analysis and Results" are adjusted and considered.[20]

To achieve the trust worthiness of the data, the criteria of credibility, transferability, confirmability, and dependability[21] were considered. To verify the credibility, items such as allocating sufficient time, rewriting as soon as possible, and rereading the entire data were considered. The results were made available to three faculty members outside the research team (faculty members of the Pediatric Nursing and Genetics Department) to assess the credibility of the results and verifiability.

Targeted sampling with maximum diversity (mothers with different demographic characteristics, i.e. age, level of education, socio-economic status) was used to help generalize or transmit the findings. Also, the research team tried to increase the dependability of the research by participating and interacting with the participants, collecting valid information, and confirming the information from the participants.

Results

In the present study, three participants lost two children and 12 participants lost only one child due to a severe genetic disease. Six of them now had another healthy child, and nine had no children. Ten of the parents had a university education. The average life expectancy of the children was one and a half years, and they were ten girls and five boys. The family relationship between spouses was reported in 53% of cases. Demographic information of the participants is presented in Table 1.

During the qualitative analysis of the content of the interviews, 1067 initial codes were extracted, which were classified into 19 sub-categories and 3 main categories. The titles of classes and sub-categories along with the number of related codes are presented in Table 2.

Psychological reactions before diagnosis

This category includes seven sub-categories, including three general categories related to pre-exposure symptoms and four post-exposure categories.

The joy of having children

Participant No. 15 says about her pregnancy time: "My husband loves children very much because this child was also given to us by God a few years later. I had a very hard time in my pregnancy and we did not think that it would be a problem at all."

Participant No. 8 was pregnant after a long time, while she had previously been told that it was not possible for her to become pregnant naturally and that she could use IVF-assisted pregnancy. Now she goes to the doctor and hears that she is pregnant: "And what good news! She said you are pregnant, and you are entering the fourth month, and everything is in order."

Participant No. 11 talks about how important the ultrasound was to the baby's head and weight and inquired about this to the doctor several times. "In the ultrasound that resulted in us, I checked myself that it was not a problem, but the doctor said that everything was standard."

Feeling confused

This feeling is caused by a kind of ignorance and the lack of information about the disease. Participant No. 3 says about the cause of death of her child: "Now we do not know if it was from an anesthetic needle that was given to me before delivery, or from a counterfeit drug. We do not know anything. This baby of ours did not get well anymore."

Self-deception

Participant No. 7 was constantly deceiving herself about her first child who had an incurable disease: "I always said it would be fine, I said, 'Doctors make mistakes.' I always hoped it would get better. I said that the doctor misunderstood and now it will get better, and I asked them later, 'Didn't you see?'"

Participant No. 5 says: "Our one-year-old child started walking. Our one-year-old daughter started walking. It is not late for her yet. But this child did not walk even at one year old."

Self-harm

Participant No. 2 felt so out of control that after a while she would beat herself up so that she may heal: "Some days I hit myself two or three times a day, what should I do with this child now?"

Participant No. 4 states: "I thought that by hurting myself, my problems would be solved, and my child would get better."

Table 1: Demographic characteristics of the study's participants

Participants' code	Age	Education	Job	Being blood relatives among parents	Number of dead children	Number of healthy children
P1	38	Associate degree	Housekeeper	Yes	2	0
P2	41	Bachelor	Teacher	Yes	2	0
P3	48	Primary	Housekeeper	Yes	1	2
P4	50	Primary	Housekeeper	Yes	1	2
P5	41	Bachelor	Housekeeper	Yes	1	1
P6	31	Bachelor	Housekeeper	No	1	0
P7	36	Diploma	Housekeeper	No	2	0
P8	30	Bachelor	Housekeeper	No	1	0
P9	30	Bachelor	Housekeeper	No	1	1
P10	29	Bachelor	Worker	Yes	1	0
P11	34	Primary	Housekeeper	Yes	1	0
P12	36	Bachelor	Worker	No	1	1
P13	32	Diploma	Housekeeper	Yes	1	1
P14	32	Bachelor	Housekeeper	No	1	0
P15	38	Bachelor	Worker	Yes	1	0

Table 2: Categories and subcategories extracted from the analysis of interviews

n	Main Category	Subcategory
1	Psychological reactions before diagnosis	The joy of having children
		Feeling confused
		Self-deception
		Self-harm
		Feeling frustrated
		Coming to its knees
2	Psychological reactions after a definitive diagnosis	Commitment and habit of caring
		Social isolation
		Symbolic death of a child
		Avoid useless treatments
		Avoiding attachment
		Trust
3	Psychological reactions after death	Acceptance of death
		In search of the lost child
		Preserve and record the child's memories
		Expecting to be understood by those around you
		Indifference to the events around
		God willing in sickness
		Doubts about childbearing

Feeling frustrated

Participant No. 8, despite performing all the pregnancy tests and getting the desired feedback from the doctor after delivery, encounters a baby who has a cleft lip and has many other problems with its appearance. She unconsciously rejects the baby: "This baby that when they brought him in and I saw him, I said, 'Wow! He has no lips? He has no palate?' I fainted there. I did not understand anything else. I said this is not my baby."

"I was just crying there. Everyone was crying," says Participant No. 1 about when her child was hospitalized, and her illness was still unknown. On the other hand, looking at the appearance of her child, who does not promise a carefree life, she wishes she did not have such a child: "I was sad. I said, 'I wish it were not mine.'"

Coming to its knees

Participant No. 1 says: "When I saw the pediatrician, I could not even ask her what is wrong with this child. I told my husband! 'Pray she has bone marrow cancer. This disease is being cured.'"

The husband of participant No. 13 experiences the same feeling when looking at his daughter: "I said to myself, 'What do I want to happen now?' You do not want to be alive anymore. This is a big problem."

Participant No. 11 thinks when he sees pigeons flying on the roof in the hospital, free from grief: "Pigeons were flying from the roof of the hospital, at the time, I wanted to be like them. I want to be released from this prison."

Psychological reactions after a definitive diagnosis

After many ups and downs and going through the previous stages, the child's illness is diagnosed, and palliative care is started according to the doctor's instructions. At this stage, parents experience a variety of unique feelings.

Commitment and habit of caring

Despite the contradictory feelings and thoughts, what is certain is that the child was a member of the family and an important part of the parents, and the mother provided for her daily needs. Participant No. 1 says in this regard: "I always had to give Fatima food first. Then I would sit at the table and eat. Although her food was now through the nasopharynx, I could not do anything else. So, I would feed her and make sure she is full then I would sit down and eat."

Participant No. 3 tells the doctor who warned her that she may not survive the risk of liver donation surgery: "I said, 'I want to die but my baby will be fine,' and she simply preferred her son's life to her own and accepted an organ donation."

Social isolation

Parents of children with incurable genetic defects, subconsciously and under the influence of the circumstances, are less inclined to have social activities and attend family gatherings and busy gatherings. One way to bring them more peace of mind is to avoid dealing with people in the community. Participant No. 5 says "We didn't go anywhere at all. Only my wife's father's house once a month. We didn't want anyone to understand my son's problem. That is, until the last stage, no one knew. And in the end, we just told our family. I feel we were right that we did not want anyone to know my son was sick. I think it was right."

Participant No. 11 says, "The reason for my isolation was that I could not go anywhere because of my child's condition. I always had to be at home. Looking at me like what I know. Too bad. It breaks my heart. As you must have committed a sin that now this child has befallen you. I do not know. I can not say."

Symbolic death of a child

Parents, despite their efforts to improve their child's living conditions, little by little, become convinced that the early death of the child is inevitable. "We knew our child was going to die, but the biggest stress we had was how. In all the stress of how the baby would die, it bothered us a lot. I have always imagined how she would die."

Avoid useless treatments

"For example, the same drug that is said to have been invented when you cannot completely save a child is an extra effort. A torment that is now inflicted on parents" (participant number 6). "What matters is the end of these struggles. When there is no happy ending, all those efforts lose their value and importance. What good is it if it happened two years later? What is necessary? Well, for me, what could have happened the first night happened two months later. With the same cardiac arrest the first night. two months later he had a cardiac arrest. It made no difference" (participant number 6).

With this simple argument, parents who had lost a child felt that intensive care and supportive care were futile: "You have nothing left to lose. You have lost everything. What is more important than a child? You? Your dear child dies in front of your eyes and you cannot do anything. It hurts and you cannot do anything. You hurt him. You torture him. You know he is going to die and you torture him again." (Participant No. 7)

Avoiding attachment

Another concept obtained in this research is the concept of avoiding **attachment**. Participant No. 14 says, "As soon as they said another patient, I did not even think that he might be healthy. I'm glad I do not have it now. I did not want it at all. That's what all doctors say. Two bullets filled in front of your eyes and you could not do it. You could not like them. You could not mother them."

Trust

Relying on God gives parents an incredible sense of well-being so that they can withstand adversity and maintain their faith. Participant No. 1 says in this regard: "I trust in God. If God wants, he will give a healthy child. If he does not want to, he will give a sick child and take him again. It is not in my hands."

Participant No. 4 also says in this regard: "My friend comforted me, and in short, I went and took action and told myself that I will do my share. The rest is in the hands of God. Her share was the act of donating an organ by her wife to her child."

Psychological reactions after death

Psychological reactions after a child death are classified into six categories. These include expressing the feelings and behaviors that parents express after a child dies. The most important issue in post-mortem reactions is the unbelievability of the child's death and not using the words "dead child".

Acceptance of death

Participant No. 2 stated, "We were told he would not live any longer. I also knew that it finally happened. You know, our mental conflict was how this baby was going to die."

Participant No. 6 says, "Death was a blessing that could have been bestowed on him because of the pain and suffering my child had endured. That's why I feel when this happened to my child (inability to say the word death to the child), although it was very difficult for me. But I was still calm."

In search of the lost child

Participant No. 6 hopes to see her baby in her dreams every night; maybe she would calm down a little: "I hoped to see him while I was asleep every night. But I still do not dream. Or I dream that she is still in the hospital in the same bad condition. I have never had a good dream about him."

Preserve and record the child's memories

Participant No. 3 says of her child's memories: "All these memories that I describe are always with me. They never end. The memories of a year and a half of a child's life after five years are still very much alive and well, like it just happened yesterday."

Participant No. 7 laments: "I remember him moment by moment. I remember him every minute. Does one forget? Can he forget? It's all like a movie in front of my eyes. Waking up and sleeping. You always see him." This is 9 years after the death of the first child and 6 years of the death of his second child.

Expecting to be understood by those around you

Participant No. 2 says that a few days after the death of her child, her mother invited them and cooked for them, and she and her husband were upset. "Even though our child died they did not understand that we lost our child, and we are upset"

Participant No. 2 is deeply saddened that after the death of her child, her mother-in-law invited all the children and held a family party: "I wanted to kill myself then. How could they do this?"

Participant No. 6 states, "Even if I visit my child's grave and someone sees me and the news reaches my mother, she will feel bad. Even my mother does not understand her daughter. Even my mother! Even my mother, who is compassionate."

Indifference to the events around

Participant No. 13 describes this issue as follows: "We are no different since our son left. For example, they tell us that someone died! I say, well, he died, he died! We were the most important person, the dearest person"

Participant No. 6 expresses her feelings as follows: "For example, they used to tell me that someone had a miscarriage like this. I said, 'OK!' Didn't we have an abortion? Didn't our baby get sick? Didn't our baby die?"

Participant No. 14 believes that the reason for this indifference to the suffering of others is that the suffering of losing a child is too great to be described. "This suffering is so great for us that other sufferings are small in comparison. There is no greater suffering than that. Nothing. nothing."

God willing in sickness

Participant No. 14 states that she had no role in the illness and death of the child.

"Because I have no choice. God told us that you were not involved in these things at all. It was my wisdom".

Participant No. 7 says: "I just thanked God. The more you are ungrateful, the worse it will be for you. God wanted to give me a child and then he wanted to take it from me. You have no right to interfere. You had better just surrender."

Doubts about childbearing

Participant No. 7 was afraid of pregnancy due to the serious injuries she saw in the death of her children, and immediately after the pregnancy, at the doctor's discretion, she had an abortion: "At that time, I was so scared that I just wanted to have an abortion. Both of my children were sick. I was completely scared. Even if he is really healthy."

Discussion

The present study was conducted in one of the cities of Yazd province (Ardakan). The results of a qualitative content analysis of the interviews with participants were classified into three categories: psychological reactions before diagnosis, psychological reactions after definitive diagnosis, and psychological reactions after child death. Parents with children with rare diseases, including incurable genetic diseases, experience physical exhaustion, burnout, fatigue, loneliness, and distress. These parents feel that they have reached the end of the line and that caring for their child requires a lot of time and money, which exhausts them physically and mentally.[22]

Feeling lonely in the face of a child's illness can overwhelm parents over time. The mothers in the present study at this stage felt so confused that even the worst possible medical diagnosis could have calmed them down because they thought that with a definite diagnosis of the child's illness, there was an absolute or relative possibility of a cure. Waiting for a child's disease to be diagnosed can increase the risk of spreading stress and

depression in parents.[23] Detraux *et al*. (1998) state that parents prefer to diagnose the child's anomaly earlier and start treatment immediately[24] because they need to be informed about the viability and available diagnosis and treatment solutions.

Avoiding accepting illness and consoling oneself about the problems that have arisen is one of the ways for parents to do less damage to their body and soul and family. When they are not yet aware of the type of disease, they try to build a barrier between themselves and the disease by ignoring and not expressing the issues. After the diagnosis, the parents try to heal the wounds caused by the child's suffering with false hopes. These false hopes later turn into a deep and very damaging understanding of them that shatters the foundations of their parental feelings.

The prolongation of the diagnosis process has frustrated the parents participating in the study and left them exhausted and helpless. Therefore, in the present study, self-mutilation was reported as a traumatic measure to alleviate the psychological pain of parents. A deep feeling of helplessness and inability to deal with a problem that has suddenly arisen will not leave a person so soon; it plunges one into the abyss of utter despair.

Feelings of helplessness and severe depression in parents can lead them to suicidal thoughts; the results of the study by Canga *et al*. (2020) showed that 1% of the parents reported suicide attempts.[25] In the Weber (2016) study, which examined the experiences of mothers with children with the genetic disease fragile X syndrome, grief was expressed as an important sensory experience.[26] What can be deduced from this is that following the child being infected, these parents themselves have psychological problems and feelings such as chronic sadness, self-deception, confusion, frustration, anger, and self-harm. After a while, feeling tired can have a significant effect on the quality of the couple's relationship and eventually weaken the foundation of family unity. Parents hide these cases and refuse to seek mental health services; in this regard, mourning counseling is also necessary for parents whose child is still alive.[27] Parents of a child with a genetic disorder may respond to the crisis in two different ways once their child's diagnosis is confirmed: 1) reasonable confrontation to find solutions and help the child and commitment to providing care and 2) the crisis of symbolic death and the avoidance of useless treatments to prevent the child from suffering. In the present study, the parents, by accepting the complicated condition of the child until his death, committed themselves to him and provided him with daily care, thus keeping their conscience satisfied. Parents who accept their child's condition play the role of the caregiver as long as the child is alive.[28]

The treatment of the child takes precedence over any other issue. But this treatment is important for the parents as long as it is evaluated in order to improve or increase the quality of life of the child. For this reason, if the treatment does not save the child's life, it is an additional suffering imposed on the child and the parents. The crisis of symbolic death of a child occurs when parents feel all their hopes and expectations of the affected and disabled child are wasted and imagine his death; Visootsak *et al*. (2012) quote the statement of a parent who said, "I had a child with fragile X syndrome and I was devastated and felt that I was mourning a child who is still alive".[29] Therefore, in order to prevent an attachment with the child, they avoided creating a strong emotional bond with their child, while avoiding an attachment and imagining the death of the child can complicate the psychological condition of parents.

Parents of children with severe genetic defects are unable to explain the child's illness to others. They feel unable to repeat what the disease is and what they have done for the child. That is why they prefer to hide the child and his illness to avoid the hassle of explaining it. Anxiety about dealing with others is caused by mental conflicts with issues that depend on those around you. These surroundings are divided into two categories. Either they are sympathetic to their parents or they are alienated and in conflict with their feelings, and both groups somehow cause the parents to be upset. Feelings of "being different" lead to social isolation. Social isolation is another consequence of having a child with a genetic disorder. In this case, interaction with others is strongly affected. These parents do not want to participate in group activities or attend meetings and gatherings because they feel ashamed of having such a child. The child's abnormal physical condition can arouse the curiosity of those around him to ask questions. Social isolation can lead to pessimism and suspicion about others and overshadow the self-esteem and quality of life of parents.[30] In the study by Wagner *et al*. (2015), parents of a child with a genetic disorder that impairs the development of the nervous system stated that they had experienced isolation and that they tried to attend public meetings less to avoid social stigma.[31]

Relying on God is another concept that parents try to reduce their serious psychological damage. Trust in the strict sense of the word can be found in the painful moments of despair and loneliness of parents with severe genetic defects. While all the doors of hope and aspiration are closed to them, they continue on the rocky path of healing and breathtaking care of the child only because of the course of hope that they have closed to the power of God. These parents use faith and trust in God to cope with their child's stress. In the study of Alves *et al*. (2016), the parents of the study left the

child's future in the hands of God and believed that God would give the best result for the child (death or healing).[12] The treatment of spirituality and religion provides a framework for making sense of things and increasing resilience as well as social and psychological support for individuals.[32] Therefore, teaching spiritual skills to families can reduce their potential anxiety and stress about the progression of the disease, treatment, complications, and lack of recovery of the child and have a positive effect on communication with other family members and their quality of life.[33]

The most important issue in post-mortem reactions despite accepting the death of the child is its unbelievability. Parents strongly reject the death of a child. Even now, years after the death of the child, they are careful not to use the word "death" and try to avoid using the word as much as possible. For parents, the death of a child is a very painful and unbearable experience; when a child dies, the dreams of the parents will die with him. There are emotional parents with emotions such as lack of personal competence and power, loss of a part of existence, and loss of a valuable person whose characteristics have been part of the family system.[34] One of the major experiences of mourners following the loss of a loved one is to see vivid and meaningful dreams that reflect the process of mourning.[35] The mothers of this study missed their dead child and searched for him in their dreams and expressed that they are relieved to see the child in a dream.

Parents participating in online research face serious problems and challenges in having children; that is, while they tend to have another child, they are afraid that they will still have a child with a genetic disease as they did before the previous pregnancy because they have a defective gene that can be passed on to future pregnancies. In a study by Rivard *et al*. (2014), fathers with children with a genetic disorder stated that they were unsure about their next child and worried about their health.[36]

Limitations

One of the limitations of this study was access to information about the families of children with genetic diseases, and this took a long time. Genetic laboratories did not have an accurate database that determined the time and cause of a child's death, and some were reluctant to provide it to researchers for any reason. Accurate and complete information on the causes of death of children in hospitals is rarely recorded, and this makes it impossible to easily discover the root cause of death.

Conclusion

What can be deduced from the results of this study is that mothers of children with incurable genetic diseases experience psychological problems that can disrupt their quality of life and their relationship with their spouse, as well as they usually interact logically and correctly with their children. They have many problems that prevent them from adopting a desirable and logical approach. In new methods of health education and health promotion to such families, much emphasis should be placed on emotional, informational, and psychological support and genetic counseling before marriage and pregnancy. Emotional support, in addition to helping parents understand their feelings and actions toward the sick child, helps them better adapt to their children. Types of support in the above areas can include providing information about organizations, institutions, or associations that provide various educational, rehabilitation, and welfare services to parents, helping parents to identify conflicting feelings about their child, conducting group counseling with parents and self-help groups, anger management training, training problem-solving coping styles, and strengthening religious orientation. One of the limitations of the present study is that because interviews were conducted with parents who had a child with a genetic defect, the results of the study could not be generalized to other parents with a child with a chronic disease of non-genetic origin.

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Ethics approval and consent to participate

This study is part of the results of the master's thesis which was approved by the ethics committee of Shahid Sadoughi University of Medical Sciences in Yazd with the code IR.SSU.SPH.REC.1397.070. Therefore, the authors express their gratitude to the Vice-Chancellor for Research and Technology of Shahid Sadoughi University of Medical Sciences of Yazd for financial support and also to families with children with incurable genetic disorders who sincerely provided their valuable insights and experiences to the research team.

Author contributions

MK and AADT involved in the conception and designing the study. MKH wrote the manuscript and acted as corresponding author. MKH and NS performed the data analysis and interpretation. AADT, MKH, NS supervised the development of work, helped in data interpretation and manuscript evaluation. NS and MHD helped to evaluate and edit the manuscript.

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Conflicts of interest

There are no conflicts of interest.

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