Original Article

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Stress Management Experience of Caregivers of Thalassemia Children: A Qualitative Research

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Abstract

Background: Children with thalassemia do not have favorable psychological health. Today, the use of different therapeutic regimes for caregivers with thalassemia has increased life expectancy; however, these patients have other various needs and requirements such as constant professional training. The aim of the present study was to explain stress management in caregivers with thalassemia children.

Materials and Methods: The method applied in this study was phenomenological qualitative research with conventional content analysis. This study was done in 2016-2017 in Shahrekord, Iran. A total of 15 participants, including 10 mothers, 1 grandmother, and 4 fathers participated purposely in this study. There were two sessions of interviews each of which lasted for 30 minutes. The content of interview was recorded and analyzed through conventional content analysis method after documentation.

Results: Following content analysis, three categories were obtained: seeking for hope included two subcategories of seeking for hope and trusting in God, seeking for information included two subcategories of seeking for information from parents and seeking for information from physician and nurse, and seeking for new treatment included two subcategories of seeking for new treatment and seeking for transplant.

Conclusion: This findings of the present study showed that planners and healthcare team can contribute caregivers of thalassemic children in coping with this disease using three adaptation approaches; that is, offering caregivers hope and providing them with proper information about the disease and treatments.

Key words: Caregivers, Stress Management, Thalassemia

Introduction

Thalassemia is a hereditary blood disease. This genetic disease requires specific medical treatment; and patients with thalassemia have to undergo repeated blood injections as well as chelating therapy (1). Unpleasant lengthy and repeated therapeutic regimes have unfavorable effects on the mental and general health of patients' family (2). These issues confer several social and psychological problems on the physician and healthcare team (3).

Thalassemic children, during all evolutionary stages of the disease, suffer from physical aspects (anemia, weakness, fatigue, etc.), mental aspects (self-image defection, counterpart rejection, etc.), cultural and social aspects (activity limitation, isolation, etc.), and spiritual aspects (feeling of purposelessness, powerlessness, and frustration) of thalassemia (4). Some studies reported unfavorable psychological health in patients with thalassemia (5, 6).

Parents of thalassemic children often suffer from lack of awareness about thalassemia, its treatment methods, the cause of the disease, and its long-term treatments as well as separation from child (7). The role of physicians and other people involving in treatment is to help

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patients and their families deal with problems occurring during treatment (8). Patient's training should be done with the cooperation of the family taking their hygienic needs, culture, and beliefs into consideration (9). Majid and Abidi (2013) held that it is necessary to do qualitative studies in families having children with thalassemia in order to specify their adaptation methods (10). Considering the fact that families with thalassemic children experience considerable stress, and no study has yet addressed this issue, the present study was conducted to explain stress management in caregivers with thalassemic child.

Materials and Methods

This study was approved by the Ethics Committee of Shahrekord University of Medical Sciences (Ethical Code: 93-8-17). Phenomenology has been practiced for centuries, but became formally established during the 20th century, thorough the work of Edmund Husserl, Martin Heidegger, and others. This study used conventional content analysis followed with open coding, classification, and abstraction (11). This study was done in 2016-2017 in Shahrekord, Iran. A total of 15 participants, including 10 mothers, 1 grandmother, and 4 fathers participated in this study. The selection of the participants was done purposefully. In this study, participants were continually selected until data saturation was obtained. Parents of children with definite diagnosis of thalassemia interested to participate in the study were included in the current investigation. Caregivers with clearly stated specific diseases such as depression and other chronic diseases for which they were under treatment and diseases that brought about specific needs and those who were not interested in cooperation at any stage of the project were excluded from the study. In this study, the main method for data collection was deep, semi-structured, face-to-face, and individual interviews. First, the researcher did some initial interviews to become familiar with unpredicted and possible problems. In semi-structured interviews, there are no pre-determined or fixed questions. They are devised based on the procedure of interview. Some of the following questions were used in the interview: Please talk about the time when your child was diagnosed with thalassemia? What were your problems after diagnosis? The interview was continued by asking explorative questions such as: Is there any other issue that needs to be mentioned? Can you explain more in this regard? The average time for interview was 30 minutes. For the interviewees' comfort, interviews were conducted in a quiet and private room.

All participants' statements were recorded using an MP3 recorder and were transcribed word by word and the content was analyzed and coded. Data analysis began with analyzing the text and an overview was found. Then, the texts were coded. After extracting concepts and codes, important paragraphs and sentences were classified based on similarities and differences. Finally, the categories were combined making a few main categories based on their relations (12).

In this study, the parents who were interested to participate were interviewed after being obtained a consent letter. Interview and data analysis were done simultaneously. After extracting concepts and codes from important sentences and paragraphs, they were classified according to the similarities and differences. Finally, the classes were combined based on their relationship and were decreased to fewer main classes. The following measures were taken in order to increase validity of data: repeated reading of the interviews and probing the data, using experts' point of views and complementary suggestions of colleagues in order to correct codes and extract classes, and returning some of transcribed interviews to participants after coding to get data transferability. Following the interview, the researcher

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reviewed conceptual codes with participants in order to check their reliability. The confidentiality and anonymity of participants as well as moral considerations were observed in the present study.

Results

Following data analysis, three categories of seeking for hope, seeking for information, and seeking for new treatment were obtained which will be explained in the following:

Seeking for hope

This category included two subcategories of seeking for hope and trusting in God.

Most caregivers were seeking for hope after informing about their newborn' disease and if they failed to receive a transplant, they trusted in God. In this regard, a mother said:

"*My child is small, it was very difficult for me if he would be injected Desferal. Thank God we give him tablets and he has no problem. Just phlebotomy bothers him but that's just once in a month. If it is God's will, he will receive a transplant. If not, we have to manage the situation. Let's see what God wants…*" (m1).

Another mother stated:

"*I sold my life possession for my child. I had one kilo of gold and I sold it and spent it for my child so that his appearance wouldn't change. I took him to Tehran to a doctor…*" (G1).

Seeking for Information

This category included two subcategories of seeking for information from others parents and seeking for information from physician and nurse. Most parents stated that they were seeking for information about the disease and its treatments from other parents, the physician, and the nurse. Most of them stated that they felt comfortable when receiving information. In this regard, a mother said:

"*I was always looking for new treatments. I have asked everyone and especially other parents if a new treatment has arrived for their child and what they have done for their child…*" (m6)

A father said:

"*While I was in the ward, I usually tried to obtain information about the disease, when the doctor was not busy. The nurse (B) had time and gave us information about thalassemia. Talking to nurses calmed us*."

Seeking for new treatments

This category included two subcategories of seeking for new treatments and seeking for transplant. Most parents were seeking for new treatments for thalassemia. Some were seeking for treatments such as Hematopoietic stem cell transplantation (HSCT).

In this regard a nurse said:

"*Most parents ask us whether there have been any new treatments for thalassemia. Their hope depends on new treatments. They expect a new treatment will be found. Most of them have undergone transplant; one or two of them have been refused*". (n1).

Another father said:

I went to Tehran and I spent money. Science is advancing.

I tried hard to find new treatments. The government should help. It's very difficult now if my child's appearance changes … (f2).

Discussion

Following data analysis, three categories of seeking for hope, seeking for information, and seeking for new treatments were obtained.

The results of the present study revealed that caregivers having a child with thalassemia were seeking for hope, new treatments, and information from other parents and had trust in God. The results of other studies also confirmed these findings. Gallo et al., (2007) revealed that healthcare personnel and nurses should give parents of children with thalassemia an opportunity to express their concerns.

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They should also apply required strategies and sources to support parents and families (13). Based on the findings of Ghazanfari et al., (2010), parents of children with thalassemia did not have sufficient information about their child's disease and needed high level training (14). Caocci et al., (2012) revealed that parents having a child with thalassemia needed psychological support throughout their life to prevent mental problems. One of the strategies was cognitive behavioral therapy (15).

According to Aziz et al., (2012), the chronicity of thalassemia and its life threatening nature for children throughout the course of their life give rise to stress for parents, and make them prone to psychological disorders. Thalassemia begins from infancy and has several psychological effects on parents. Lack of training can cause numerous social problems in parents (16). Ishaq et al.'s findings (2012) indicated that parents' knowledge about thalassemia and preventive measures were not enough; therefore, proper intervention in the form of programs for general health training with focus on target society is recommended (17). The results of the present study revealed that parents used approaches of seeking for hope and new treatments. These were also confirmed by the results of other studies. In this regard, Ali et al., (2012) suggested psychological support with the purpose of reducing parents' stress and both psychological distress and reinforcing adaptation strategies for a better life (18). Wacharasin et al., (2015) stated that empowerment programs for parents having a child with thalassemia can increase their ability and self-confidence (19). It is necessary to implement supportive programs. Family-based programs such as giving medicinal information to parents, family psychological support, and financial support are required to decrease parents' stress (20). Salehi and Morovati (2016) revealed that proper nursing intervention in parents having a child with thalassemia can promote adaptation behaviors (21).

Conclusion

Many studies have been carried out on life quality of patients with thalassemia, but appropriate planning to increase the quality of their life is impossible without enough knowledge about life experiences, the stress that their families bear and their adaptation method. The results of this study can guide planners and healthcare team to assist caregivers to adapt with the disease of their child. According to the result of this study, parents' adaptation approaches included seeking for hope, seeking for information, and seeking for new treatments. Therefore, healthcare team can help parents adapt with their children's disease by offering them hope and giving proper information about disease and treatment.

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Conflict of interest

There is no conflict of interest.

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