

We have Neglected “Ourselves”; A Qualitative Study on Iranian Parents of Children with Aphakia

Abstract

Background: Contact lenses play a substantial role in the management of childhood aphakia. However, the use and care of the lenses can be challenging. Despite its prevalence, the phenomenon of living with children with aphakia is not explained in Iran yet. The aim of this study was to illuminate the lived experience of the parents of children with aphakia. **Materials and Methods:** This hermeneutic phenomenological study was conducted on the parents who have been referred to Farabi Eye Hospital of Tehran, Iran in 2019, whose children were diagnosed with aphakia, and the condition was corrected with contact lenses. Qualitative semi-structured interviews were conducted with 20 parents of children with congenital cataract. Analysis was based on the framework of Diekmann enabled data interpretation and elaboration of shared themes. **Results:** The 20 parents involved in the study consisted of 12 women and 8 men. The participant’s experiences were classified in 4 categories: Self-Ignorance, Troubled mind, Self-Regulation, and Coping with the problem while hoping for the future. **Conclusions:** “Self-Ignorance” and “Troubled Mind” indicates that because of the risk of burnout in the long-term process of treatment, the psychological support of parents is necessary. Psychological support will continue until the parents acquire the ability of self-regulation. Giving a realistic hope to families is a core element in psychological support.

Keywords: *Aphakia, contact lenses, parenting, qualitative research*

Introduction

The prevalence of congenital cataract is about 4.88/10000 in Iran.^[1] Intraocular Lens (IOL) is the first choice for aphakia (absent lens) optical correction in adults.^[1,2] Aphakia is the most frequent indication for fitting young children or infants in contact lenses.^[3] Contact Lenses (CL) are used for young children (under two years old). This is a common consensus between ophthalmologists, and reliable studies confirm it.^[2-5] Using CL has some complications include poor cooperation from children in CL replacing, CL expenses, loss of CL, and risk of bacterial keratitis,^[6-9] that affect the visual outcome. It can act as a barrier to achieving the best visual outcome, especially in unilateral aphakia cases. About 16-18% of children suffer from a chronic disease or condition such as anemia, cerebral palsy, thalassemia, seizure, type 1 diabetes, and cancer.^[10] Because aphakia involves the visual system for several months/year, it is considered

a chronic disease and impacts children’s function. According to the child’s age, they need long-term, close, and continuous parent aid to do their daily activities, which places a heavy burden on their families.^[11]

In addition to parenting experiences, in some studies, the quality of life of children with chronic diseases (such as congenital cataracts) from the child’s and his parents’ aspect was assessed and compared with a control group.^[12,13] In most cases, the general quality of life, as well as the physical, emotional, and social quality of life, were significantly different. Their health-related quality of life is similar to that of children with congenital heart disease who have undergone liver transplant.^[14] To the best of our knowledge, most of the studies on this subject are quantitative. Qualitative studies approach was grounded theory,^[15] and parents’ experiences were assessed in a few studies. The phenomenon of living with children with aphakia is not explained in Iran yet. It seems the phenomenon of living with these children needs more clarity, and

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a hermeneutic phenomenological approach would help to explain it.^[16] The best way to reach a clear perception of peoples' experiences is to have a face-to-face interview in which they talk about their thoughts, emotions, and concerns, and to analyze them. It could help expand the knowledge in this field and improve healthcare providers' ability to detect and solve these families' problems. The phenomenon of living with children with aphakia is a long term process. These children need continuous parental support, which may affect their families' mental health and happiness. Nurses, as the closest people to the parents' of these children, need to perceive their experiences to help them in this winding road.

In 2019, about 300 children (0 to 10 years old), for a variety of reasons including congenital, traumatic and concomitant retinal problems were examined in the Contact Lens Unit of Farabi Eye Hospital. In this study, we aimed to elucidate the lived experience of the parents of children with aphakia, who have been referred to Farabi Eye Hospital of Tehran, Iran in 2019.

Materials and Methods

This qualitative study was conducted between June 2019 and August 2019 in Farabi Hospital, in Iran. A Heideggerian hermeneutic phenomenological approach enabled us to disclose and explore the meaning of the experience^[17] in relation to the phenomenon of living with a child with congenital cataracts. We consider the nature of language and meaning in lived experiences in depth.^[18] Phenomenology was the selected approach and it has been used in similar research.^[19] Dikelmann's approach was adopted for this study as it describes the participant's experience in their own words, that is, to gain insight into the meaning that people describe as their experience.

Purposive sampling was used to recruit 20 parents of children with congenital cataract regardless of the stage of their child's illness. The main criterion for inclusion was the experience of living with a child with congenital cataracts; the phenomena under study.^[20] Other criteria for parents included admission to Farabi Hospital for congenital cataracts of their child, the ability to converse with the researcher, and agreeing to be interviewed to share their experiences.

Recruited participants were interviewed in Farabi Hospital during a convenient time when they had referred to see a doctor to examine their child. All interviews were conducted in Persian as conversational in-depth interviews by the second author. All participants who provided consent (written or verbal) were interviewed. By expressing the subject of study, each interview was begun. Participants were offered the opportunity to tell their story using a non-directive opening question. For all participants, this was, "Please tell me about your experiences in relation to living with a child with congenital cataracts."

It was continued as, "Can you talk about your concerns?" Subsequent questions used the trigger and clarification formats to prompt amplification of participants' responses in uncovering their life experiences of living with a child with congenital cataracts. After initial responses, probes and reflective expressions were used to support experiential specificity.^[21] The number of interview sessions was between 1 and 2. Interviews were audio taped with each lasting between 25 and 65 minutes. Extracted codes were managed using MAXQDA 10 software.

Data analysis was started during data collection, via active listening of the audiotapes during interview and reading of the interview transcripts,^[22] analysis of entangled reflection, clarification, and intuiting.^[19] Diekelmann's approach was used to seek the data,^[23] with the overall trigger of convergence between participant-generated data and the researchers' interpretations (expert readers), leading to an in-depth perception of the phenomenon itself.^[24] Diekelmann's approach includes 7 stages. In the first stage, researchers read all transcriptions for complete understanding. In stage 2, researchers evoke implicit and explicit meanings. A hermeneutic story was developed after each interview (stage 3). In stage 4, sub-themes and themes were expanded. Themes were clarified by returning to the transcripts or re-interview with participants (stage 5). Fundamental patterns identified link themes in stage 6. Using participants' quotes, the final written report will be completed. This framework enabled the appraisal of the rigor of the data.

Initially, each interview content was considered as a whole to gain an overall comprehension (stage 1). Possible common meanings were then recognized, using portions to support the interpretation (stages 2 and 3). Next, the research team compared their explications for similarities and differences at a meeting, reaching further clarification and consensus considering the original text (stage 4). All texts were then re-read to confirm expanding themes (stage 5). Finally, a constitutive pattern was identified that described the interrelationship among themes across all contents (stage 6).

For Trustworthiness, a broad range of criteria of rigor for interpretive phenomenology is evident. Some researchers recommend a traditional qualitative framework, using criteria such as trustworthiness.^[25-28] We used authenticity and credibility^[23] that were addressed by the second author, three academic colleagues, and the first author as expert on congenital cataracts and a research supervisor, independently interpreting the data; a meeting was then held to discuss the consistency of the identified themes. Also, credibility was maintained by applying the member-check method to some transcripts of the interviews. In this method, transcripts are returned to the participants with a request to revise any words or sentences that do not accurately reflect the participants' meaning or intent.

Conformability was achieved by separately interviewing participating fathers and mothers, which confirmed what had been learned from the other parent.

Ethical considerations

This study was approved by the Tehran University of Medical Sciences Ethics Research Committee (Code number: IR.TUMS.MEDICINE.REC.1399.670). Potential participants were informed about the objective, the approach of the study, and its importance. Participants were informed that their participation was voluntary and confidential. After the study was explained by the first and the second authors, the informed consent for participation and the permission to record the interviews were verbally obtained from each participant. According to the obtained consent, we were allowed to record the interviews, and all the personal information would be confidential within the research team. In addition, they may choose to withdraw from the study at any time during the process.

Results

The 20 parents involved in the study consisted of 12 women and 8 men. Eight parents had a college education, six had a high school diploma, three had some high school education and two had primary education. The age range of the children was between 1 and 9 years old [Table 1]. The data analysis revealed 4 categories: Self-Ignorance, Troubled mind, Self-Regulation, and Coping with the problem while hoping for the future [Table 2].

Self-ignorance

One of the most important and fundamental facts in this study was the Self-Ignorance. In this case, four sub-contents emerged from participants' experiences: "Prioritize the sick child," "Ignoring one's hobbies and interests," "No delight in life," and "Self-Neglect."

Prioritize the sick child: A 28-year-old mother said, "I quit my job because I wasn't able to patch her eyes in time." "I was running a shop which I later abandoned and came to Tehran ... my child is more important," 39-year-old father said.

A 30-year-old mother pointed to her negligence of other significant persons in her life and said, "I have an older child, but if I didn't, I would've never thought about having another baby because all I care about now is this child."

Ignoring one's hobbies and interests: A 38-year-old mother said: Having fun has become a memory for me. My husband likes to go to the beach but I do not accept.

No delight in life: A mother said: Nothing in my life makes me happy.

Self-Neglect: Another 38-year-old father talked about self-neglect and said, "My wife is not even visiting her parents because she believes that her child won't patch

Table 1: Study participants' characteristics

| Variables | Frequency |
|----------------|-----------|
| Gender | |
| Mail | 8 (40%) |
| Women | 12 (60%) |
| Education | |
| College | 8 (40%) |
| Diploma | 6 (30%) |
| High school | 3 (15%) |
| Primary | 2 (10%) |
| Children's age | |
| 1-3 | 5 (25%) |
| 3-5 | 7 (35%) |
| 5-9 | 8 (40%) |

Table 2: Parents' experiences of living with children suffering from congenital cataract phenomenon

| | Main Theme | Sub-theme |
|--|---|--|
| | Self-Ignorance | Prioritize the sick child |
| Parents' Experiences of Living with Children Suffering from Congenital Cataract Phenomenon | Troubled Mind | Ignoring their own hobbies and interests |
| | | No delight in life |
| | | Self-Neglect |
| | | Confusion |
| | Self-Regulation | Self-blame |
| | | Grief |
| | | Guilty Feeling |
| | Coping with their problem while hoping for the future | Hopelessness |
| | | Stress Handling |
| | | Self-Controlling |
| | | Helpless |
| | | Hope |
| | | Acceptance |

his eyes in her absence. Our child is uncomfortable with having patches while others are around. He doesn't like communicating with others."

Troubled mind

"Confusion," "Guilty Feeling," "Self-blame," "Grief," and "Hopelessness" are the five sub-contents that shaped the "Troubled Mind" theme.

Confusion: A 36-year-old father found the reason for their confusion is the difference between ophthalmologists' opinions and said, "We visited several doctors. One said your child is fine. Another one said they could not do anything until he was 3 or 4 years old. The next one said we should operate on him immediately. Most of them believed that our child was fine. After one month of going from one doctor to another, we came here and realized that our child would be blind by the time he was four years old if we did nothing." "One day, we came back home and saw

a white fragment in the child's eye. I took our child to a doctor immediately, and the doctor said there's a portion of cataract left in your child's eye, and he must go under surgery. I was worried that something would happen to my child's vision. Then we came here, and they said the child is fine." A 42-year-old father talked about the doctors' different opinions.

Self-blame: A forty-three-year-old man was blaming his wife and said, "We didn't need a child and it was my wife's fault because a child is a heavy responsibility for her/his parents."

Grief: A twenty-eight-year-old mother described her grief as "We noticed that our child's eyes did not align. Sometimes when our child was not around, I cried. It was so tough."

Guilty Feeling: A fifty-six-year-old father said, "Deep down I have a feeling of guilt that this might affect my child's future. Maybe we didn't take care of our child as we were supposed to, for example, hold the lenses on their eyes for a little longer or patching the eyes more precisely." A 28-year-old mother said: "I'm worried that my child blames me for giving birth to them and considers me as the one responsible for this inconvenience." Another 35-year-old mother added, "My main concern is my child's happiness and self-confidence. I'm doing all I can to make this happen, but my main concern is not their eyes. I want to raise my child as a strong person who can live with this situation."

Hopelessness: A thirty-two-year-old mother said, "After this child, I had an unplanned pregnancy which I aborted because I was unwilling to have another child with the same problem. I thought, what if the next one has this problem in both eyes. I've seen children with the problem in both of their eyes."

Self-regulation

One of the most critical aspects of participants' experiences was "Self-Regulation." Two sub-contents, including: "Stress Handling" and "Self-controlling" shaped this theme.

Stress Handling: A father described his handling of the stress as, "At first we didn't have any information about this, and during the final 17 days prior to the surgery, my beard turned gray because it was our first and only child and we loved them so much. I was extremely nervous during these times." Another father said, "I cannot sleep well at night because of the stress. I lose my temper easily, and I want to see a result after all the expenses. I come a long way only to hear that my child's eye is getting better. I want these days to pass." A mother mentioned, "I have four kids. I came here four months ago, and despite all the pressures and expenses, I was hopeful. I worked hard and paid for the contact lenses and the solution, but the treatment procedure is very slow and disappointing. I think

I haven't gotten the result I wanted. I want this to end soon, but it seems like it will never be over. Not with this disease."

Self-Controlling: A mother talked about losing control with her child and said, "I've lost my temper. I cannot be patient. I can't control myself. I don't beat my child, but I yell at them a lot."

Coping with the problem while hoping for the future

One of the aspects that appeared in participants' experiences was coping with their problem while maintaining hope for the future. Each of the patients pointed to this theme in different ways. "Helpless," "Hope," and "Acceptance" shaped this theme.

Helpless: A mother said: "We'll do whatever they tell us to do. We have no choice. If there were a simpler way, I would've chosen that one."

Hope: Another mother described her hope for the end of these days as, "I tolerate it because things will change. I should stick to my child till he is able to use contact lenses all by himself. Sometimes when contact lenses hurt my child's eyes, their teacher sends him to me, and I take them out. I put a teardrop in the eye, and after 5 minutes, I send my child back to class." A father talked about his hope for the future, "human is always hopeful. Hope helps us continue. Maybe someday there will be a new cure for this condition." A mother described her hope for her child's eye surgery as, "I wish we could've operated my child's eye earlier. Sometimes I worry a lot when I look at her eyes." A father described his hope by saying, "Even if they tell me there is no cure for your child, I'll bring them here again. There is hope in disappointment. I believe my child will be fine, but something will eventually go wrong either in school or college."

Acceptance: A 50-years-old father mentioned his belief in destiny as a reason to accept this problem "It is God's will, and we should accept it."

Discussion

In this study, parents' perception of living with children who suffer congenital cataract phenomenon appeared in 4 themes including; Self-Ignorance, Troubled mind, Self-Regulation, and Coping with the problem while hoping for the future.

"Self-Ignorance" indicates that it is necessary for the parents to be psychologically supported because the risk of burnout in the long-term treatments is high. A study on parents of children with autism participants described the difficulty of balancing the needs of the family with the needs of the child.^[29] Burn out syndrome can lower the participation of the family in treatment, and consequently, has a negative effect on children's health. As some researchers have mentioned, family activities and vacations often had to be curtailed.^[30-32]

“Troubled mind” is one of main themes that appeared in our study as well. Troubled mind refers to “living with agitation before final diagnosis.” In another study, all mothers and fathers expressed being shocked, worried, and anxious when they learned of their neonates’ admission to the NICU.^[33] In a study^[34] performed on 21 parents of children with thalassemia, one reported theme was living a hectic life. “Troubled mind” in our study was similar to this study’s main theme too. The researchers concluded, designing a supportive plan to reduce parent’s problems is necessary.

Also “Self-Regulation” and “Coping with the problem while hoping for the future” were other names for “Coping with the problem during children’s treatment” and, “Accepting the responsibility of their children’s visual development” in Lima *et al.*’s study.^[35] “Coping due to hope for the future” is in line with “Feeling hopeful versus feeling hopeless,” a sub-theme in Abuidhail *et al.*’s study (2017), too. However, “Self-Regulation” and “Coping due to hope for the future” indicate that parents have accepted their children’s visual development responsibility and could cope with the problem.^[33] The reason for themes difference in our study and the above study is related to the different names of the themes. In a study^[36] on 21 parents of children with cancer, hope for the future was an obtained category. “Coping strategies to deal with the problems and hope for the future” theme in our study was similar to the “Hope for the Future” theme in that study. This hope is the result of the effective interaction between the families and the treatment team. Problems such as being concerned about children’s future, the possibility of a more effective treatment that the parents are not aware of, and confusion can be managed by increasing parents’ knowledge.

A study was performed on 23 children diagnosed with congenital cataract in Sweden in 2018,^[15] all of the parents followed what they were supposed to in order to achieve the best visual outcome. From the researcher’s view, it was a self-controlling act. In our view, parents’ “Self-Regulation” and their self-controlling act was a compliance mechanism. Furthermore, in a study, the authors have mentioned self-regulation in the form of two sub-themes. These two sub-themes are: “Caring for our child and handling the situation” and “Staying in contact with the outside world.”^[37] Also, the theme “Power and control oriented ritualization” in Dutta *et al.*’s study refers to parent’s self-regulation.^[38]

Some parents stated that observing other children in hospitals increased their hope for a cure. It should be noted that seeing other children with almost similar problems has a contradictory effect on the parents. Being together in this procedure can help them feel better. Meanwhile, watching others going through a tough patch and ending with satisfying results could encourage them to follow the treatment more thoroughly. It appears that having group

discussions with other parents in a similar situation, either in person or on social media, or seeking consultation through a psychologist will benefit these families. Creating pamphlets with inspiring and successful experiences could be useful as well.

Ophthalmologists, as the leaders, should inform every member of the treatment team about parents’ issues, and delegate specific responsibilities of the treatment procedure. To achieve the best visual outcome, nurses should acknowledge that parents’ mental support is as vital as the therapeutic skills. Besides seeking psychological consultation, financial support and planning should be considered. The present research is a qualitative study. Participants’ experiences were collected in this research. However, participants’ number is low in the qualitative research, and this matter along with data collection from only one referral hospital can constrain the results generalizability and the authors acknowledge this limitation in the present study.

Conclusion

The phenomenon of living with children suffering from aphakia is a long term process. These children need continuous parent support, which may affect their families’ mental health and happiness. Nurses will play an essential role in this regard. According to the code of conduct, physicians and nurses need to be trained for well-advised empathy and proper consultation. Giving realistic hope to families is a core element in professional consultations. To achieve the best visual outcome, healthcare personnel should acknowledge that parents’ mental support is as vital as the therapeutic skills.

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Conflicts of interest

Nothing to declare.

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