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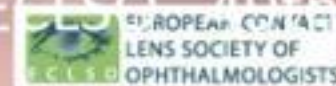
European Contact Lens and
Ocular Surface Congress

EUROPEAN CONGRESS
ON MYOPIA CONTROL

2 - 3
September
2022

Novotel Tour Eiffel

Paris - France



We have neglected “ourselves”; A qualitative study in Iranian parents with aphakic children

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Background

- Contact lenses play a substantial role in the management of childhood aphakia.
- The use and care of the lenses can be challenging.
- The aim of this study was to illuminate the lived experience of the parents with aphakic children.



Materials and Methods

- This is a qualitative research in Iran.
- Purposive sampling: 20 parents
 - Conducted on the parents attending in the contact lens clinic- Farabi Eye Hospital in 2019, whose children were aphakic, and the condition was corrected with contact lenses.
- Qualitative semi structured interviews



Materials and Methods

- The data collected were transcribed verbatim and analyzed using *“qualitative conventional content analysis”*.



Materials and Methods

- Through careful inspection and continuous comparison of the data, categories emerged by inductive reasoning.
- Deriving categories were identified from the first interviews and then tested and revised through analysis of succeeding interviews.



Materials and Methods

- The research design adhered to Lincoln and Guba's four major criteria for rigor in qualitative inquiry:
 - true value,
 - applicability,
 - consistency, and
 - neutrality



Results

- The 20 parents involved in the study consisted of 12 women and 8 men.
- The participants' experiences were classified in 4 categories:
 - Self-Ignorance,
 - Troubled mind,
 - Self-Regulation, and
 - Coping with the problem while hoping for the future



Self-Ignorance

Four sub-contents emerged from participants' experiences:

- “Prioritize the sick child”,
- “Ignoring one’s hobbies and interests”,
- “No delight in life”, and
- “Self-Neglect”.



Troubled Mind

The five sub-contents that shaped the “Troubled Mind” theme:

- “Confusion”
- “Feeling of Guilt”
- “Self-blame”
- “Grief” and
- “Hopelessness”



Self-Regulation

Two sub-contents, including:

- “Stress Handling”, and
- “Self-controlling”



Coping with the problem while hoping for the future

Each of the parents pointed to this theme in different ways. Referred stages were:

- Feeling Helpless,
- Hope and
- Acceptance



Discussion

- “Troubled mind” refers to “living with agitation before final diagnosis”

- “Self-Ignorance”

- Need for psychological support of the parents
- More chair time at the time of diagnosis
- Strategies such as support groups

- “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.



Discussion

- "Coping strategies to deal with the problems and hope for the future" theme in our study 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.



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 should continue until the parents acquire the ability of self-regulation.
- Giving a realistic hope to families is a core element in psychological support.



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