

## Life experience of parents with amblyopic children in contact with health care providers

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**Objectives:** Amblyopia is the most common binocular vision anomalies. To comprise is decrease of visual acuity that doesn't remove by optical correction. Nowadays because of the psychosocial problem with amblyopia, is a functional disability. Awareness of parents of children with amblyopic life experience, when facing with curing system can provide effective for promotion of self-assessment, treatment and rehabilitation.

**Method:** To explore parent's experience in relation with health care provider utilize a qualitative study with phenomenological method. This study involving semi-structured on-depth interviews with 9 parents of child with amblyopia. Interviews were tape recorded. Data analysis was based on Van manen method.

**Results:** parents of children describe five subjects in relation with health care providers include: on time and correct diagnosis, consultation, therapist's behavior, change the therapist and visual screening.

**Discussion:** This study indicates that on time diagnosis and intervention, therapists appropriate behavior, consultation and prescribe an appropriate treatment can effect on parental and child acceptance and successful treatment.

**Keywords:** life experience, child with amblyopia, phenomenology, health care providers

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### Introduction

Amblyopia is most common cause of binocular vision anomalies among child, young and middle age adult (1). Amblyopia may be defined as reduced visual acuity not improvable solely by optical correction (2) and not caused by structural ocular and visual pathway abnormalities (3). Psychophysical studies indicate that binocular driven neurons don't grow up adequately and has shrinkage in lateral geniculate body (4). Furthermore the function of parvocellular system is abnormal (5, 6). Sensitive and critical periods (from birth to 8 years old) in the development of sensory-motor function are common to all neurobiological system in many species. The ultimate goal of guidance and intervention is to establish normal vision during the early of life (2). Treatment method for amblyopia strives to stimulate vision improvement in weaker eye by helping the part of the brain that manages vision to develop more completely (1). vision therapy for amblyopia

or rehabilitation in amblyopia as defined functional disability has 6 related stages, included: prescribe an appropriate prescription, implement occlusion therapy, prescribe an active vision therapy program to augment occlusion therapy, assess prescription power and VA with appropriate frequently, consider strabismus surgery when appropriate, monitor compliance and education the parent (2).

Epidemic of amblyopia in general population is so difficult, but we can suppose amblyopia involving up to 2-2.5% of general population (7). The studies argue that about 2.4-3.1% of Iranian population has amblyopia. More results show, there are some relation between amblyopia and increased lifetime risk of visual impairment as well as quality of life. In discussing the effectiveness of treatment for amblyopia, the possible functional disability related to unilateral amblyopia must also be taken into consideration and determine "Do the therapy decrease this disability?" (8).

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Amblyopia is associated with decreased stereopsis so can impact on children's school performance and sport activities (9). One reason for treatment of amblyopia can fail is due to poor compliance from the kids and/or their parents. The finding should lead to better compliance with treatment, less expensive treatment and improved quality of life for children with amblyopia (1). Our experience indicates that many parents have problems for compliance with treatment, because they can't control their kid's behavior. Some of parents don't take their child for follow-up. In other hand the amblyopic children with occlusion therapy sometime have problem to in communication with their peers, because the amblyopia affect their psychosocial wellbeing. The clinical manifestations of amblyopia didn't correlate with the social implications of the condition. However, children with strabismus were noted to have significantly greater conduct and externalizing problems (10). Health outcomes need to integrate both vision and psychosocial implications of treatment (11).

Although the therapists should strive to improve the Visual acuity and treat amblyopia, but should decrease the negative psychosocial impacts on treat. Finally the diligent parent is facing much true or untrue information in their community and even the therapists. Amblyopia therapists deal with issues concerning its raelly diagnosis and treatment. Their correct and timely diagnosis especially in anisometropic amblyopia, their appropriate prescription, present the information and consultation, visual screening and refer the patient are some causes of this notion.

In this study we try to survey the parent's experience with their amblyopic children in contact with health care presenters by a qualitative research and phenomenological approach.

#### **Method and Material:**

This study was approved by ethics committee in college of rehabilitation in medical science of Iran University. In this study, according to phenomenological research, we utilize a purposeful sampling. According to purpose of this study "deep understanding about the life experience of the amblyopic child's parents in contact with medical care takers" selects the samples. Informed consent we obtained from participants after explanation of the study. Semistructured interviews were conducted either in families' home or at clinic (according to parental preference) with nine mothers.

No father participated in our interviews. Interviews were tape recorded. The promote guide was used flexibly in response to the directions in which participants wishes to take the interview. Data analysis was based on Van monen method.

#### **Results:**

The results of this study about life experience of parents in contact with optometrist, ophthalmologist and visual screening conductor were revealed in 5 fields.

1) Timely and correct diagnosis is important for prevention, acceptance and treatment of amblyopia. Sometimes the parents receive the correct diagnosis by referring to the medical centers or a visual screening center, but occasionally this refers weren't useful. We notice that one of the reasons for mistreatment amblyopia was expertists' negligence.

"Her teacher told us; I think [ ] can't see clearly, she stands near the board for reading. After that we referred to an ophthalmologist, but he said [ ] is malingering. After a much time, I understand she really can't see and her new doctor said she has bilateral deep amblyopia." (Participant 9)

"I talked [ ] to a vision screening center and then an ophthalmologist, but they said he is normal, now, he has 11 years old and you say he is amblyopic. We feel guilty and we are upset. But we didn't know, we thought their diagnosis was correct." (Participant 2)

Although occasionally, some of parent didn't refer to medical or screening center for their kid's examination.

2) Consultation was another field in this survey. The parents incline to receive guidance from their child's doctors about amblyopia and its treatment. Sometime they get information from TV program, some brochures, newspapers, magazines and other's experience, but most of the time the parent's didn't receive guide and consultation from others.

"I expected to his doctor explains the problem for me, but he didn't say anything. I didn't know why? I needed his guidance." (Participant 3)

"I think the doctors don't want to guide us. I took [ ] to doctors very much, but they never counsel me." (Participant 6)

3) The therapist behavior is one of the important reasons which impact on kid and parent's acceptance. Sometime they don't have an appropriate behavior, so the parent's don't refer to them another time.

"As a matter of fact Dr... has a very bad behavior, he announced us in a rough manner. After that I

shocked and cried, I became depressed, I didn't know what to do, finally I said I don't accept him." (Participant 4)

Sometimes the parents change their child's therapist because of some reasons: lack of confidences to the therapeutic plan is an important reason and the therapist behavior was another reason.

4) Visual screening was an important field in this survey. This program is held in many countries for many years. The effectiveness or ineffectiveness is an important issue in universal challenge.

Sometimes vision screening provider aware the parents of their child's amblyopia. But sometimes they don't detect the kid's amblyopia and even guide the parents wrongly.

"I took [ ] to a vision center 2 years ago. He was three years old. But they didn't examine him and said he was very little and not cooperative. Then said you can refer him to an optometric center. The doctor don't accept him because [ ] is little." (Participant 4)

5) And occasionally the parents didn't take their child to these centers because of their previous undesirable experience.

#### **Discussion:**

The results of this study indicate that health care providers have an important role in diagnosis, prevention, determine the therapeutic program and periodic follow-ups. Usually amblyopia isn't diagnosed only with a specialist examination, so health care provider's behavior; their diagnosis and consultation are noticeable. Kannadel believes that many physicians don't have relation and supportive skills to announce the news to the parents about their child's disease (12).

Untimely and incorrect diagnosis of the amblyogenic Factors are one of the causes for decrease the chance of therapy. Menon says the therapy is simple and effective is started early (13). Based on Groaungard's study the certainty of the diagnosis was central for the parent's experience. First the emotional reaction of the parents is highly influenced by the diagnosis process. Second needed possibilities for taking action and third they found difficulty in coping uncertain future (14).

One of difficulties which parents confront with they can't receive information from providers. The importance of self-efficiency and past behavior suggest that consultation with parents experiencing higher levels of success with patching may elicit be shared with parent's experiencing difficulties with

patching(9, 15). There is parent to parent consultation solely in amblyopia. We think the parents afraid of stigmatization. But parental performance should be considered when we have a prescription or when occlusion is planned, if compliance is needed to be improved (16).

Our participants said they often feel awkward, anxious or sad when interacting with this problem. They tried to find a way to compensate for their discomfort, e.g.s to change the therapist. It's necessary that the optometrist and ophthalmologist be aware of their behavior's impact on kids and parents. Tannila says that when the parents find a way to cure a therapy for their child, their stresses will decrease (17). Although they sometimes change the therapist thinking that their child does not have any disease.

Vision screening is one of the health care provider's duties the cost –effectiveness of vision screening is an issue in international. Nowadays in scientific literature there are many questions about these programs effectiveness (18).

Many researchers are trying to highlight the importance of effective follow-up programs for all children especially of families with limited recourses, because there are relationship between social deprivation and compliance (19, 20, 21). But Wender believes the prevalence of uncorrected significant refractive errors is high enough to justify a regular school eye screening programs (22). The result of Jamali and his coworker's study in Iran emphasize the need for adequate diagnostic and therapeutic eye care services for preschool children (23). In other hand Marsh's work in USA indicate national efforts to reduce preventable vision loss from amblyopia are hampered because children are not available for screening and because providers miss many opportunities to screen vision at school age (24).

Screening program for amblyopia is held in Iran with disburse many and advertising for timely diagnosis the amblyopia and strabismus. But the results of semi-structured on- depth interviews show sometimes providers don't examine the child exactly, so the amblyopic child are not detected .we think, we need to train the parents and screening providers for receiving to the purpose of program.

In other hand it's clear that low income, minority, uninsured families are at high risk of not utilizing vision screening .direction of available resources to these highest risk will create the greatest return on such efforts. Castanes expressed that ignorance remains major problem at all levels so improvement

in the distribution of information and education are needed and should yield improvement additional finding is necessary to pay for this remedies (25).

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