

Experiences of blind children caregivers

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ABSTRACT

Background: Teachers, parents and foundations should become objective-oriented for children with visual impairment so that learning and sensitization of necessary knowledge and skills for the behaviors of these children are assisted. Where there is impairment in the relations of children caregivers, their emotional security is disturbed and its effects will appear in their behaviors. Therefore, strong dependence on parents, teachers and other adults is the characteristics of most of the children with physical problems including blind children. Since use of the experiences of caregivers of these children increases their efficiency and life skills, this study was conducted aiming to understand the experiences of blind children caregivers in Isfahan.

Materials and Methods: This study was a qualitative study with a phenomenological approach to investigate the experiences of blind children caregivers including mothers and teachers. Four mothers of blind children and four caregivers of blind children were purposefully selected and interviewed from 2007 to 2009. Data were collected through interviews which were recorded on cassette tapes. The obtained data were analyzed using Collizzi method.

Findings: The experiences of the blind children caregivers were divided into two groups of challenge and role.

Conclusions: The results of this study showed that upon diagnosing the child's blindness, the parents suffer from mental stress. At first, they deny the problem, but then they begin to come along and accept the blind child. At this time, they analyze the effective factors in keeping and educating the child. At the same time, they act in response to the child influenced by several factors including the role of the society.

Key words: Caregivers, blind, phenomenology.

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INTRODUCTION

Family has a considerable role in interventional programs and development of its disabled child. Besides, teachers, psychologists and social advisors should also participate and play roles in providing services, education and interventional programs for disabled individuals so that the pressures imposed on the families are reduced and in this way they contribute in the progress of these children as well as meeting their needs.^[1] On the other hand, Seligman and Darling believe that low visual acuity in blind children is an important factor for parent's reactions towards the child. Delayed growth of social skills as well as abnormal behaviors observed in children is the main stressing factor in the family.^[2] Furthermore, most of the studies have addressed the negative effect of a disabled child on the family and different performances of this family as compared to the families of non-disabled children. In this regard, Burack et al. believes that these children often impair or delay the evolution of families.^[3] Furthermore, the first contact of neonates with outside world is formed within the framework of strong social interactions with their caregivers. These mutual processes involved in the primary interactions strongly depend on vision.^[4]

In 2002, world health organization (WHO) announced

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the number of world's blind people to be 45000000 people. Currently, each five minute one person becomes blind in the world.^[5]

It is important to consider that people with special needs, regardless of the type of their disabilities, usually face with problems such as self-concept and damaged self-esteem, poor confrontation skills, poor communication and social skills, poor cognitive function, low ability to solve problems as well as problems in the motivation system due to functional restrictions, disproportionate life conditions in general and educational conditions in specific and also due to the feedbacks that they receive from their environment. Therefore, psychologists have put an emphasis on children's relations with those who are responsible to take care of them and have considered these mutual actions as the major base for emotional, cognitive and social growths.^[6]

Since most of the exceptional children are always faced with rejection and failure, they need a desirable relationship. They need someone to listen to them, to help them determine their present and future goals, to guide them improve interpersonal relations and maybe the most importantly, to help them find their self-concept and self-confidence. Whenever the relationship between caregivers and children is impaired, children's emotional security will be impaired. This impairment manifests itself in their behaviors.^[6]

Human's different senses are considered as the gates of his knowledge and wisdom due to their importance in sensation, perception and understanding of the things. The most important senses include vision and hearing. Generally, learning and educating activities are broadly associated with vision and hearing senses. Considering that method of communication has a vital role in the social and personality growth of an individual, blind people seem to face more problems during life including their social lives.^[7]

Therefore, strong dependence on parents, teachers and other adults is the characteristic of most of the children with physical problems including blind children.

Moreover, blind children are considered as a heavy burden for their families and their parents feel that their blind children cannot help themselves and their societies like other children.^[8] There are almost 5.9 million disabled children in the United States most of who are cared at home. There are several indications that poor care giving leads to frequent hospitalizations of children outside their homes. The importance of child care has led

to new arrangements and strategies planned to care disabled children.^[9]

Eisenberg stated in his study that disabled children are often unable to establish social and mutual relations with their peers and adults and are not supported by them due to physical problems and the resulting deprivations. Therefore, their future emotional and social adaptations will be difficult.^[10] This is why caregivers can have a considerable role in establishing these relations and can assist them in obtaining social skills.

Taking care of these children entails different experiences. In addition, the experiences, beliefs and interpretations of individuals have a considerable effect on all the aspects of their lives and applying the experiences of these children's caregivers will increase their efficiency and life skills. Therefore, the present study was designed aiming to understand the experiences of blind children's caregivers.

MATERIALS AND METHODS

This study is about the experiences of caregivers with a qualitative and subjective nature. There is limited information about that and it cannot be measured by quantitative methods. Therefore, a qualitative method with a phenomenological approach was considered for this study. The questions include 1) The problems of blind children's caregivers, and 2) the effective factors in taking care of children.

Research society included those who had the experience of taking care of blind children at home or educational centers and included four mothers and four instructors working in Ababasir blind children education center in Isfahan, Iran from 2007 to 2009. Mothers were selected because they were responsible to accompany the children in commuting to school and had more comprehensive experiences about taking care of their children. Instructors also had a major role in educating and guiding the children during the active hours of life. The mean age of children was 8 years and the mean work experience of instructors was 10 years.

In order to collect data, efforts were made after contacting each of the studied individuals to obtain their consent for cooperation and participation in the study and for recording the interviews. This was done by providing explanations about the nature and goals of the study and its method.

The participants were then interviewed in a deep and non-structured fashion. The thoughts, insight, values and

beliefs of the participants were obtained by recording the interviews. The researcher noted any non-recordable as well as their non-verbal gestures by observing during the interviews. Participants were assured of the confidentiality of the information.

The interviews were made in a calm environment at the time proposed by caregivers. Each interview took 20 to 40 minutes. Sampling continued until reaching data saturation, i.e., until no further new concept was set forth by study subjects.

After recording, each interview was transcribed word by word and was once again compared to the recorded data. It was then read by the researcher for several times and in case any additional explanations were required, the participant was called for clarifications.

To determine the accuracy of data, the four criteria of reliability were used. For this purpose and to ensure data credibility, after analyzing each interview, the participants were contacted to confirm the accuracy of the information or to make the necessary changes. To determine confirmability, the researcher tried not to enter his previous presumptions in the data collection and analysis process as much as possible. To achieve reliability, which is the sufficiency of data analysis and decision making processes, the researcher used the advice and supervision of experienced professors and the final results were then returned to the participants. To analyze the data, Collizzi method with the following stages was used: In order to empathize with participants, all the transcriptions were carefully read and important expressions were extracted. In the next stage, the meaning of each expression was explained and encoded. Then the codes were classified. These classifications were referred to primary protocols for validation. Finally, the results were combined as a complete description of the studied phenomenon and were reviewed to achieve clear themes. At the end, the findings were returned to the participants for validation.

FINDINGS

Eight people including four mothers with blind children and four female child caregivers working at schools were enrolled and interviewed. The mean work experience of the caregivers was 10 years and the average age of the children of the participating mothers was 8 years old. The findings of this study are as follows:

I. Challenge: Challenge is one of the main themes obtained from mothers' experiences, the way that

families and especially mothers show their feelings and emotions upon becoming aware of their children's blindness. At first, they deny the problem and try to accept and accord with its cause by controlling that. Then, the family shows different functions based on the conditions, thoughts and viewpoints as follows:

a) **Denial:** One of the mothers says about the denial and non-acceptance of her husband: *"At first, it was very difficult for him and it is the same right now. He always hopes that when he wakes up, God has cured him (the child), like he (the child) turns his eyes and gets cured".* (Participant No. 2)

In this regard, one of the instructors says, *"Information of the blind children is very little since their families try to deny that they have a blind child and they do not let them attend public meetings and places. They hide their blind children from people." "When a mother finds that her child is blind, she frequently asks why God has given such a child to her. How she has hurt (others) that God gave her such a disabled child",* he continues. (Participant No. 6)

b) **Compatibility:** Statements of the participants on the compatibility and reflection of the unpredicted problem:

"During the first year, I always cried. It was very difficult for me. I thought that only my child was blind. I couldn't accept that. When I took him to the welfare office, I found that there were several other children worse than my child. Then, I gradually faced the reality and came along with that." (Participant No. 1)

In this regard one of the instructors says, *"Well, if the same situation occurs for us, it is difficult to accept that. Some people accept the problem more easily and some will never accept that. Anyone who has accepted this problem easily, her child will be more sociable and more capable. But anybody who does not accept the reality always hides her child and never takes him outside. In this way she wants to ignore the child. This will increase the child's problem."* (Participant No. 5)

Another participant says, *"At the beginning, I always sat in a corner and cried. I didn't want to talk to anyone. My husband was really disappointed and got older than before our child was born. Then I thought it had happened and we could not do anything for it. I asked God to give me patience. I*

talked to my husband several times and he got well, too.”(Participant No. 8)

- c) Interaction and performance is another theme obtained from the actions of the families. In this regard, one of the participants says: *“Some families show too much pity for their (blind) children. They put food into their (children’s) mouth, they take their (children’s) hands. They think that they (children) are less capable than what they are. But this is wrong and such children will never grow.”*(Participant No. 5)

“We have a family with five blind children, but they (parents) have accepted the reality and now their children have successfully achieved university education. We have also another family with one blind child. They have decided not to have any other children for they fear (they may have another blind child). They do not take much care of their blind child. I mean they do not believe him.”(Participant No. 6). People look at the blind as disabled people.

Families expect too much. They are very disappointed too. They may provide everything for their healthy child at home, but they ignore their blind child and don’t do anything for them. Of course, there are several families that really understand their blind children and their educational progress is highly important for them. Some of them ask me to leave notes in their children’s notebooks about their progress as well as their homework. Those families who pay attention to their children make it easier for us. (Participant No. 5)

2. **Role:** Role is another main theme that we achieved in this study. The role of society is an important factor in adaptation of family in a new condition and is highly important. The society plays different roles that form our subthemes for this theme as follows:

- a. **Supportive role:** One of the participants says, *“From social viewpoint, people must understand to treat them like ordinary children. They shouldn’t pity for them and shouldn’t say “May God give you patience”. People should improve their culture and should understand our situations and our children’s situations.”*(Participant No. 8)

Another participant says, *“Now they are treated well. When people see a blind person walking in the*

street with a white stick or working, they have a better viewpoint than before. They no longer think that blind people cannot do anything and should stay at home until the end of their lives.”(Participant No. 3)

Participant No. 4 says, *“If joint cultural and artistic programs are held for blind and non-blind children and if they perform programs jointly, that will certainly affect their spirits and they will progress.”*

- b. **Lack of support:** In some cases, the society does not support these children. In this regard, one of the participants says, *“For example, we have a mother here who reports that her sister says, “I don’t want your child to come to my house every day. My child is very clever and has learned the things your child does.” This is why I believe that education should become extensive so that the rest of the family understands that this child is not different from other children. He has no infectious diseases. He has a good mind and a good understanding and you should help him so that others behave such that his mother is not forced to hide him and not to take him to a party fearing that others may suppress him.”*(Participant No. 3)

“They have not informed people of the comprehensive project that (blind) children go to ordinary schools. The principal, his assistant or even the main authorities of the school and even the society is not informed. Today, when we take our children to the street, people look at them and say, “Gee, look. He is blind. How you come along with this? God bless you.”(Participant No. 6)

“We shouldn’t have such a reaction when we are with these children so he may ask, “What’s wrong with me?””(Participant No. 6)

Another mother says, *“It was very difficult for me to tolerate other people looking at me. They all tortured me. They said ‘May God cure him’ with their looks. They made me cry.”*(Participant No. 1)

“Healthy children don’t play with them. These children try to communicate with healthy children but they do not accept them.”(Participant No. 1)

“Some people unconsciously compare their children with mine when they see me and say, “Thanks God”. They think that they are very fortunate to have

healthy children.” (Participant No. 4)

“I become disappointed to let my child study in an ordinary school as I see people pity or other children make fun of blind children.” (Participant No. 4)

Lack of information in the society leads to such behaviors with these children and their families and develops another subtheme called Mother’s Stress. In this regard, one of the mothers says, “I don’t want them to pity for my child. We only suffer from society. It does not matter if they only ask questions. But some of them look and say, “May God cure him.” What problem does it solve? It is clear that they are blind. What is the question for? They only get under our skin. We have to explain for an hour.” (Participant No. 1)

c. The role of media: Media have an important role in informing people and the families of disabled children. Participant No. 6 says, “The most important thing in the society is to give information, which does not happen. On the international day of people with disabilities we see that a disabled person is shown on the TV and is asked to talk about the problems. That’s all.”

“If mass media would talk more about them, people would think they are different but that is not true.” (Participant no. 6)

“Many families don’t know. I mean they haven’t been introduced to a successful blind person. If a successful blind person was introduced on TV, the families would be more hopeful.”

“We want to know why people look down on welfare offices. If there were no such centers, we couldn’t do anything for our children in the society. TV should take footage of these centers for poor people in remote areas so they would realize there are such centers.” (Participant No. 8)

d. The role of municipalities: “There should be markings in the streets for the blind so that whenever they want to cross the street, they would not need any help.” (Participant No. 7)

“In other countries, when a blind person wants to get on the subway, he/she knows what to do and where to go since all the routes and directions have been written in Braille. All the cans have Braille writing too. Pits and ditches are another issue. Today, municipality makes a hole here without

installing any notice to notify the blind.” (Participant No. 6)

“The city should provide special passage ways and commuting service for these children. They should fill and remove the pits in the streets so that we don’t see them bruised and injured all the time, or don’t witness their death after accidents.” (Participant No. 3)

DISCUSSION

The themes obtained in this study include two main issues, one of which is challenge. Family shows some reactions in response to the problems they face with. Challenge includes three subthemes, namely denial, compatibility, and interaction and performance. Another theme is role which consists of four subthemes, namely supportive role of the society, lack of any support, the role of municipality and the role of media.

The findings of the study indicate that the effect of a disabled child on the families is different and that families show different reactions to the challenge they face. Those disabilities that are more apparent and can be seen result in more stress to the families and can be defined. Furthermore, the disabilities that are socially apparent and attract the attention ruin self-image.

Since the presence of an exceptional child can be somehow stressful, mothers in this study denied their children’s disability at first. Then, they took recourse to God and Imams and expected a miracle and wanted to change the incident. After that, most of them coped with the problem and showed different reactions. One of the obtained subthemes in this study is denial. In this regard, Gilbert believes that parents use patterns called confrontation methods to overcome stress and to adapt with problems. These methods are useful but if they include negative and denial behaviors, they will not be useful.^[11]

Amiri Majd quotes Cohen (1964) and Lambros (1980) about frequent denial of disability by parents: “Of course parents naturally love their children, but they are not able to accept the reality of their children’s disability and disorder. It is certain that identification and emphasis on the child’s disability effects on child’s attachment and other aspects of parents-child relation.^[12]

Amiri Majd quotes Summers (1944): “There are four types of feedback made by parents in relation to their children’s visual impairment:

1) Considering visual impairment of the child as a form

of punishment for parents;

- 2) Fearing others think that their child's blindness is the result of his parents' disease;
- 3) Feeling guilty due to negligence or breach of some social and ethical regulations;
- 4) Feeling shameful and dishonored.

Summers also identified 5 patterns for parents' adaptability with their child's disability:

- 1) **Acceptance:** In this condition, parent accepts the child honestly and sincerely and has a realistic approach toward the disability.
- 2) **Denial:** Parent denies the disability and its importance and is unable to accept the fact that his/her child is different from other children in one aspect.
- 3) **Extreme support:** In this condition, the parent tries to extremely and unreasonably support his/her disabled child.
- 4) **Hidden rejection:** Parent hides his/her negative feedback by showing extreme kindness to the disabled child.
- 5) **Apparent rejection:** Parent torments and annoys the child and blames others for the disability of the child.^[12]

Adaptability is another subtheme of challenge. In this regard, Maleki Ranjbar says, "The birth of a blind child blows painful hits on the bodies of family members and it takes a long time for the parents to cope with that and to remove its mental effects."^[13]

In the study by McCarty et al., mental stress and family performance were investigated in the parents that had a child with fragile X syndrome. The results showed that the parents experienced a high degree of mental and family stress. Fathers and mothers experience similar levels of such stresses, but they adapt to them over time.^[14]

Family interaction and performance is another subtheme of challenge that can have a role in booming their talents and achieving social skills. In this regard, Talebian made a study on emotional reactions of parents with children suffering from visual impairment. He stated that these parents had a realistic behavior with their blind children. They were prospective, active and independent and they do not consider blindness a serious problem. Those who

patiently adapt themselves with a series of adjustments, adaptations and tolerance of problems and live quite naturally, they enjoy physical sufficiency, self-confidence, financial independence and social status.^[15]

Shahi and Jadidi believes that correct behavior of parents and other family members is very important for a blind child since his birth because it will help his correct growth and natural evolution.^[16]

Furthermore, role is another finding of this study and one of its main themes. It is a very important factor in the family adaptation with a new condition. Appropriate communication and behavior and social support have a positive effect on family adaptation. Media have an important role in the society's understanding of the problem and supporting the blind children and will make the society aware to support the children and their families. Lack of knowledge in the society about the problems of these children and their parents will lead to non-supportive and sometimes destructive social reactions which can be followed by mother's stress and affect her performance in caring her child. Municipalities will cause peace of mind for the parents and will reduce their stress by providing suitable conditions for the social life of these children. Yektakhah has explained in her paper about the supportive role of the society that "Exceptional children and paying more attention to the mental health of these children and their families has attracted the world in recent years. Several days have been named as the international commemoration days for these people to emphasize their importance in the society and to help in removing their problems."^[17] In this regard, Movalli says, "Each blind child has the right to have a high quality life and to enjoy the supports of other people".^[18] One of the subthemes is lack of any support. Movalli believes that caregivers look for social support and use this solution to obtain the information or emotional support of others. They accept other people's cooperation and social support leads to acceptance of responsibility and one's role in facing with the problems. This is while lack of social support will lead to avoiding problems. Caregivers seek an imaginary world and imagine what they want in the real world. The role of media is another subtheme. In this regard, Ghasbeh made a study in which he states that the parents of disabled students need some information about caring for, educating and behaving with their children to plan for them. Information especially through media is very important to meet these needs. The role of municipalities in providing facilities for these people is another subtheme. In this regard, Ademola-Popoola et al. made a study in Nigeria found that blind children receive no mental care and that most of the blind people have

stopped their relations with their societies and families due to adaptation problems. They are deprived of professional education and economic movement and face several problems in streets and at schools. They also lack social, educational and rehabilitation facilities and most of them lead a low quality life.^[19]

Eftekhar *et al.* believe that if the families of blind children as well as authorities cause less stress in providing individual and social transportation facilities for the blind, this will lead to their healthy movement and transportation.^[20]

The supportive role of the society helps the caregivers to wisely solve the problems. Their orientation will be toward removing the problem and changing the situation. Their attentions will be turned toward children's needs and they will try to improve their future by helping them in obtaining social skills and independence. All these scales have religious meanings as well.

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