



Living in the shadow of shame and stigma: Lived experience of mothers with deaf children

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ABSTRACT

Congenital deafness is one of the most common childhood disorders and every year many children are born with permanent hearing loss. The present study was carried out to understand the experience of mothers with deaf children. This study was conducted with a qualitative approach. The participants were 35 mothers of children with congenital deafness who were selected by purposive sampling. The data was collected through semi-structured in-depth interviews and analyzed using thematic analysis introduced by Braun and Clarke. Data analysis revealed 3 themes and 9 sub-themes including social stigma (prying eyes, pity aversion, feeling of discrimination, taunt from people), internalized stigma (feeling of inferiority, feeling of shame and embarrassment), and reaction to stigma (turning to concealment, cautious disclosure, and marginalization). Shame and stigma were the major experiences of Iranian mothers of deaf children that shadowed their lives. These experiences lead mainly to ineffective coping mechanisms such as avoidance of using hearing aids and concealment of the child's hearing loss. In addition, to cope with perceived stigma, mothers isolate and marginalize themselves and pursue secrecy strategies. Therefore, our findings are important for health professionals who are working with families having children with hearing loss. They need to aware of the problems faced by the families and should advocate necessary support.

Keywords: Deaf child, Mother's experience, Shame and stigma, thematic analysis, Qualitative research, Lived experience

INTRODUCTION

Congenital deafness is one of the most common childhood disorders. Globally, 1-3 of every 1000 children are born with permanent sensor neural hearing losses (SNHL). This occurrence is a critical life event with intense effects on parents and the family members [1]. Usually mothers view the presence of a congenitally disable child as a tragedy which cause substantial personal and social challenges [2]. Today, parents are informed about congenital

abnormalities of their children. Hence these parents have to live with children with hearing deficiency for many years [3].

From the perspective of family health, early childhood deafness is one of the most complex sensory impairments which expose parents to permanent stress. [3, 4] and may influence different aspects of family life and children’s participation in the family and in the community.[5] Evidence shows that physical and psychological needs of these children, as well as the required time and energy needed to care for them, is different compared with healthy children. These differences impose heavy challenges for their parents, especially for the mothers [6, 7].

The mother is the first individual who communicates directly with her child and is informed about the child’s impairment. Emotions like feeling of sin, fault, frustration, and deprivations due to the impairment of child can cause maternal isolation, disinterest to communicate, and sorrow resulting in low self-esteem, depression, and consequently disruption of mother’s mental health. [8] The result of a qualitative research showed that children’s disabilities lead to a painful process and creation of conflict, so mother does not see herself ready for motherhood and feels guilty giving birth to a disabled child. For a mother, birth of a disabled child is a failure to achieve the expected motherhood [9].

Although deaf people form a small group in the community, but unfortunately, judgment of individuals on this group is associated with negative prejudices [10]. Studies have shown that negative valuation of societies of disabilities may result in formation of tarnished and devalued identity for disabled people and their families [11]. Negative reactions of people to the deaf child in the community may severely annoy their mothers, leading to their isolation, keeping away from people, and cutting some connections. Although certain mothers cope with their children’s hearing loss, most of them are saddened from the attitudes of family and community towards their deaf children [3]. Furthermore, the current body of knowledge in Iranian and Muslim society regarding the experiences of mothers with deaf children is not sufficient. Hence, in-depth and greater understanding of the lived experience of mothers with deaf children is necessary for successful management of deaf children and providing an appropriate rehabilitation program. This study aimed to gain a deep understanding about the live experiences of mothers with deaf children in the family and in the society.

MATERIALS AND METHODS

A qualitative approach was used to conduct the study. While the qualitative approach played an umbrella-like role in the overall process of the study, thematic analysis helped the researchers to understand the lived experiences of the mothers with deaf children. Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data. It is seen as a foundational method for qualitative analysis [12].

Participants and setting

The participants were mothers who had a deaf child, registered in Welfare Organization of Ardabil Province, Iran. Thirty five mothers with deaf children participated in semi-structured interviews. All mothers had normal hearing and were relatively stable physically and mentally. All were from Azeri ethnicity and Muslim with an age range of 21-50 years. Based on health care documents in the welfare organization, mothers who had severe physical or psychiatric problems were not included in the study. In addition, all participants were in a stable marital status and were living with their husbands and children. Hearing loss was the only health issue of their children and their age ranged from 6 months to 10 year (Table1).

Table 1: Demographic characteristics of the participants (n=35)

Characteristics	Number/Year
Mean age of participants	29.8 years (minimum 21, maximum 50)
Educational level	7 illiterate, 18 diploma, 10 bachelor
Employment status	8 employed, 27 housewife
Family history	12 yes, 23 no
Children’s gender	16 boys, 19 girls
Children’s age	6 month to 10 year

Data collection and Analysis

Fieldwork and performing the interviews took place between December 2014 and November 2015. Data was collected through in-depth semi-structured interviews. At the start of the interviews, an open question was asked to

stimulate the mothers to speak about their experiences of living with their children: Please tell about your child and living with her/him. In the rest of the interviews, I tried to ask specific questions helped us to extract the lived experiences of the participants. All of interviews were performed by the corresponding author. The interviews took place in a private room in the language training center for children with hearing loss. The language of communication was Turkish (Azeri). The interviews lasted for 50-70 minutes and were tape recorded. After listening a few times, all conversations were immediately transcribed verbatim into texts and were analyzed using qualitative thematic analysis introduced by Braun and Clarke. [12] The phases of thematic analysis and its use in the current study is shown in table 2. The qualitative text analysis software, MAXQDA (ver. 10) was used to manage and coding the participants' stories.

Table 2: Phases of thematic analysis and its application in the current study

Phase	Application in the current study
Familiarizing yourself with your data	Transcribing data, reading and re-reading participants' stories, perceiving initial ideas
Generating initial codes	Coding word by word and line by line
Searching for themes	Condensing the codes into potential themes
Reviewing themes	relating themes with each other, with extracted codes and the entire data set
Defining and naming themes	Ongoing analysis, refining themes, generating clear definitions and names for each theme
Producing the report	Final analysis, moving between transcripts and themes, selection of vivid stories for each theme, conducting the report

Trustworthiness

Some strategies were used to improve the quality of the study. First of all, the main researcher attended in the health center which provides health care services for children with deafness and their family. A primary session was conducted with each participant to make an acceptable trust and effective communication. Participation of the researcher in the caring environment and in the preliminary sessions with the participants helped the researchers to meet the rule of long-term interaction. For maximum variation we tried to select the participants from different social class, age group and severity of hearing loss in children. To immersion in the data, researcher read the interviews at least 2 times and thought on the stories of the participants and tried to capture the message or meaning which were hidden in the data. Above all, researcher considered the research question at any point of the study. In addition, the main theme and its structure were given to 4 participants and they confirmed that the findings properly reflect their lived experience. [13]

Ethical Considerations

Ethical approval obtained from the Ethics Committee of Tabriz Medical University. In addition, the below activities were done for ethical considerations: Describing the objectives and the method of the study for participants, obtaining written informed consent in a preliminary session, ensuring confidentiality of information, informing about the right to withdraw at any time of study.

RESULTS

Stories of the participants and their experiences were condensed in three main themes include social stigma, internalized stigma, and reaction to stigma; their constituent sub-themes are shown in Table3.

Social stigma

An important part of experiences of the participants with deaf child belongs to their social interactions. Social stigma subtheme emerges from meaning units of prying eyes, pity aversion, imposed discrimination, and taunt from people.

Prying eyes

The participants stated that people are curious when facing with their deaf children. The second participant, a 29 years old mother said: "When walking in the street or when in the bus, some people look so as if they met an alien. The fifth participant told: They zoom on my child, sometimes without blinking and I do not like it." Another example of prying eyes about deaf children is their annoying looks. People's strange looks and behaviors are difficult for mothers of deaf children, and heavy looks of people annoys them. The Fourteen participants said: "When we ride the bus or go somewhere, I feel all thoughts and looks are toward my son's hearing aid. I don't know, perhaps I think that their first look is at my child hearing aid, maybe it's not true."

Table3: Categorization of themes, sub-themes and the preliminary themes

Main theme	Theme	Subtheme	Preliminary theme
Living in the Shadow of Shame and Stigma	Social stigma	Prying eyes	Attract attention and curiosity of people Too much questions from people Harrowing look of people People's gaze
		Pity aversion	Pity of people Discomfort and distress resulting from people's pity
		Imposed discrimination	Inattention to children among relatives difficulty in access to health facilities Inadequate social support of deaf children
		Taunt from people	Feeling reproach from people inappropriate behavior from relatives Notoriety from institutional support
	Internalized stigma	Feeling of Inferiority	Feeling of humiliated Inability to compliment the child Feeling invaluable near relatives
		Feeling of shame and embarrassment	Feel ashamed of having a deaf child Shame as the cause of secrecy of deaf child Shame as the cause of secrecy of hearing aid
	Reaction to stigma	Turning to concealment	Denying deaf child from people Hiding the child hearing aid Seeking treatment other than hearing aid
		Cautious disclosure	Hesitant to express child deafness to people Limited disclosure of child deafness
		marginalization	Distancing from the community Limiting the use of community facilities Difficult social interactions

Pity aversion

The sub-theme of ‘pity aversion’ means that the participants had an aversion to the pity or excessive compassion from other individuals in the society. In this regard, a participant said: “everybody looking with pity to my child. It is very painful for me” (p21). Also another participant said: “I don’t like the compassion of relatives. I don’t need their pity and sympathies” (p4). A 29 years old mother stated: “I don’t like people’s pity to a deaf child. I hate the compassionate look and words” (p 11).

Feeling of discrimination

Data showed that the participants perceive discrimination in many aspects. This sub-theme constituted of three primary codes of ‘inattention to children among relatives’, ‘difficulty in access to health facilities’ and ‘inadequate social support’. Mothers expressed that there is a significant discrimination between normal and deaf children among relatives. Usually more attention is given to healthy children. A participant said: “when I go ceremonies of relatives, I feel that people think my child is mentally ill” (p 11). In terms of difficulty in access to health services, a mother who was living in a town, expressed: “in our town or the near city there is no special service for deaf children. Sometimes my child’s hearing aids does not work so we should travel to a big city which is far from here [our town]” (p 5). In terms of inadequate social support a participant Said: “while the cost of rehabilitation and hearing aids is high we don’t receive an enough governmental fee to overcome the problems which mainly come from the problem of my child” (p 15).

Taunt from people

Participants felt reproach from people regarding the deafness of their children. People in the society may rebuke them: “I was thinking before why it’s happened for my kid? Somebody rebuke me for having a deaf child” (p2). Another mother said: “At first, I was disturbed because it was possible to get reproached. I felt that someone maybe is taunting me, or someone might say my child has a hearing impairment” (p 25). Participant 1 said: “Still the words of my sister-in-law sound like a hammer on my head. She taunted me because of my child” (p 1). Another participant said: “I’m not sad because of his/her difficulties, but when I remember their taunts and shames, I feel disturbed” (p 22).

Internalized stigma

Mothers’ experiences of deaf children suggest that perceived social stigma gradually becomes internalized in them. Internalized stigma consists of sub-themes including feeling of inferiority, and feeling of shame and embracement.

Feeling of inferiority

Data analysis showed that perceived stigma goes to be internalized in the participants through some mental processes. One is feeling of inferiority. The third participant said: “I felt more embarrassed at first; really a big wound. These somehow induce inferiority complex forcibly” (p 12). Another mother said: “Life is hard with a deaf child, very hard, when someone talks about her kid who can say Mom and Dad, you cannot talk about your kid near friends. You cannot say that my kid can say Mom and Dad. You are humiliated” (p 9).

Feeling of shame and embarrassment

Mothers feel shame for deaf children, and negative reactions of friends and neighbors lead to their more shame. A participant stated: “I am ashamed of people who know I have a child with hearing impairment” (p 19). “I am ashamed of the reaction of people against muteness of my child” (p 6 and 7). A participant said: “I’m tired of feeling shame; of being constantly in a position of weakness in front of others, and explaining always about his/her empowerment and speech” (p 13). The participants viewed the stigma as a cause of feeling shame and a major factor of social isolation. Some participants were concerned about their notoriety. That’s why they avoid communicating with others. In this regard, a participant said: “I hate communication with people. Attending in public with this child is shaming, some people are of low capacity and shout to all, then you feel notorious and I do not like” (p 10).

Reaction to stigma

Findings showed that the participants react to the stigmatized deaf child through ineffective ways. This experience condensed in the meaning units include turning to concealment and marginalization.

Turning to concealment

The participants did not like to talk about and took effort that nobody knows about their child’s disability. In response to the curiosity of people, they prefer to hide their child’s disability and show everything normal. Therefore, they try to keep their child deafness hidden from others and sometimes keep the child at home due to fear of people’s interpretation. (p 9). The participant 3 stated: “I removed the child’s hearing aid in weddings and parties to hide it from others. I am ashamed that it would be seen by my friends; what to say to them” (p 3). Another participant said: I did not want the relatives see and understand that ...is hard of hearing. I was Ashamed she is seen by my friends. What to say them” (p 12).

Later, most mothers try to hide the hearing aid of the child in any possible way to prevent attraction of attention and disgrace. In this regard, a participant said: “I tried to hide it from others. Even I did not remove her scarf to hide hearing aid” (p 20). Another participant said: “We bought the hearing aid but did not use it well because we felt ashamed. We had not seen in families so far, neither in our relatives. We did not want anyone to know” (p 2).

Marginalization

Distancing from entourage and community was another reaction of mothers to the negative experiences that mothers of deaf children are facing. They described that they were isolated and kept their children away from people after the diagnosis of deafness. Another participant said: “I did not go to the relatives’ houses. When I went to my father’s home, no one came there, even my sisters, because they knew that their presence bothered me” (p 23). Even some of them decreased their social interaction in order to alleviate these concerns, and even became happy for not invitation to a family ceremony. One participant stated: “Life is difficult with a deaf child. You can’t go to the community and for fun. We cannot just go somewhere, just once a month. I have a notebook in my hand and I have to train speech all afternoon. I should work always” (p 26).

DISCUSSION

The present study was conducted to explore experiences of mothers with deaf children. Thematic analysis of the data led to a central theme entitled “Living in the shadow of shame and stigma” consists of three subthemes of “social stigma”, “internalized stigma”, and “reaction to stigma”. The results showed that stigma is one of the bothering experiences that mothers of deaf children are facing in daily life. According to the participants’ life stories, one annoying experience was the look or taunt of healthy people to the disability of their children. In the other study same findings were reported. [14] In a study, mothers reported that there is no positive feedback in the society towards deaf children and they usually are stigmatized in the society. [15]

Based on the findings, excessive compassion of people are also unpleasant to mothers of deaf children. They stated that people look with pity and compassion to their children. In addition, compassionate looks of relatives to deaf children may emotionally hurt mothers and result in their withdrawal from society. In a survey have been also shown that mothers usually turn to some form of loneliness and social isolation due to pity from people, which reduces the level of intimate and social relationships. [16]

Mothers are taunted and blamed by people for having deaf child. A study revealed that more than half of mothers with disabled children are taunted and blamed by their husbands 'family. [17] The blame of entourage towards these families may be caused by emotional encounters and lack of sufficient knowledge about the experiences of these mothers.

The participants had numerous negative experiences, especially feeling of inferiority. The results of a previous study showed that families with disabled children experience embarrassment and inferiority that is consistent with the results of the present study. [18] Another study also showed that families of people with disabilities encounter various labels, reproaches, and sometimes ridicules in their life in the society which can lead to a sense of futility and worthlessness. [19] These factors could result in severing ties with family, distancing from relatives, and limiting the relationships which is consistent with the results of Plechat and colleagues. [20]

The findings showed that the mothers are experiencing shame and embarrassment in social interactions with other people. For this reason, they isolate themselves and pursue secrecy strategies. Jackson has also reported the feel of shame for having a deaf child. [5] Feeling of shame and embarrassment were reasons for these mothers to withdraw from community which is consistent with the results of other studies. Having a healthy child is perceived as self-importance for mothers and in contrast birth of a deaf child may initiate the feelings of shame and embarrassment, as well as rejection and social isolation. [21,22]

The results showed that like other stigmatized individuals, most mothers use secrecy, withdrawal from interactions, and cautious disclosures strategies for managing their stigma. For example, many of them hide the hearing aid which is a sign of hearing loss. Mothers' emotional and negative reactions mainly originate from lack of social approval and hiding child' disability is a technique for controlling information management, referred also in other studies. [22, 24] The completing subtheme of concealment was "cautious disclosure of child's deafness". Lived stories of mothers discerned that they gradually share their children's disorder with relatives. Likewise, the results showed that in early stages of diagnosis, the mothers with deaf children consider disability of their child as a stigma and use ineffective methods such as avoidance. In other words, stigma arisen from having a deaf child pushes them to separate themselves from the community or to reduce their social interactions. Several studies have also shown that the relatives of stigmatized people have more emotional stress and less social interactions. [25] A prior study also showed that following the diagnosis of deafness in children, mothers often fall in loneliness and social isolation, which reduces the level of social and intimate relationships. [16] The social life of most mothers with disabled children is usually limited, and mothers show different behaviors in such conditions including aggression, withdrawal, rejection, and social avoidance. [26,27]

Limitations of the study

The present study simply reflects the experiences of mothers of children with congenital deafness. Therefore, the findings may not be useful in the context of mothers of children with acquired hearing loss.

CONCLUSION

According to the lived experiences of the participants, the perceived shame and stigma in mothers of deaf children can be exacerbated by relatives or other people in the society. Consequently the stigma can be internalized in mothers of deaf children and may marginalize them in the community. Mothers of deaf children encounter with taunts, excessive pities, looks, and staring of entourage and occasionally discrimination from people. These may lead to feelings of inadequacy, inferiority, futility, and worthlessness. To cope with these issues, mothers usually use low-level coping strategies such as denial, avoidance and concealment. In addition, the negative experiences of mothers of deaf children such as social stigma and discrimination are intensified with visible hearing aids. Hence, using of implanted hearing aids can decrease the perceived stigma among deaf children and their mothers. In addition, teaching effective coping strategies, psychological interventions, and supporting these mothers socially seems necessary. Moreover, one of the responsibilities of healthcare professionals, who work with families of deaf

children, should be to promote their social relationships. We recommend additional emancipatory studies to decrease the challenges, limitations and social stigma perceived by deaf children and their mothers. Another study can be conducted to investigate the experiences of mothers of children with visible hearing aids versus implanted hearing aids.

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