

## **THE STUDY OF GUILT, BLAME, STIGMA AND UNDERSTANDING OF INHERITENCE IN FAMILIES WITH CONGENITAL DEAF CHILDREN**

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*Abstract: Genetically inherited diseases have long been known to have medical as well as psychological consequences on both patients and their families. In this regard, families tend to worry about the future of the affected child but also feel stigmatized, guilty and blame the other parent. All these factors affect the ability to cope with the disease and the general situation. Several studies have measured the understanding of the genetic inheritance mechanisms and the reproductive risks but none of those have been standardized in order to present conclusions in a controlled fashion. Nevertheless, the psychological impact of a genetic disease is often higher on the parents, especially if only one of them is found to be the carrier of the mutated gene.*

*Keywords: congenital, deafness, stigma, guilt, genetic counseling, psychology*

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### **INTRODUCTION**

The rapid advances in molecular genetics and the decoding of the human genome have been a major step forward in clarifying at least some of the congenital deafness cases. It is clear now that about 50% of all cases have a genetic cause. This type of genetic conditions has been long proposed to have social and psychological consequences (worry about the health of the children, feelings of stigmatization and guilt) which could affect the family's ability to adjust to the condition.<sup>7</sup> After the birth of a child and the diagnostic of congenital hearing loss, most parents do not expect a genetic cause where there was no obvious family history for such pathology. The parent's conception about the cause of the deafness varies extremely and has been studied in several articles. The opinions on this subject include several factors such as: Fate, Use chemicals or pollution during pregnancy, Relevant family history in the father's family, Relevant family history in the mother's family, Medication during mother's pregnancy, Alcohol or drugs during mother's pregnancy, Accident during the pregnancy, A genetic variant in a gene or chromosome of parents, As a punishment, Child had an accident or injury in the neonatal period or childhood, Medical error, Either mother or father smoked during the pregnancy, God's will, History of deafness in the family, I do not know.<sup>12</sup>

Parents usually have a poor understanding of the genetic factor as the cause of their children's deafness as shown by the study of Rodrigues et al. in 2012. Abe et al. have shown that only 36% of parents were aware of a genetic factor as cause of deafness, prior to genetic counselling.<sup>1</sup> Kaimal et al. (2007) confirmed the need for clinical geneticists and genetic counsellors to be aware of and sensitized to the questions and reasons that bring parents to a genetic consultation.<sup>8</sup> Middleton et al. (1998) confirmed that any genetic counselling is only effective and appropriate when clinicians and counsellors take into consideration the prior beliefs of counselees.<sup>11</sup> Successful counselling is achieved when families receive accurate information and understand the

relevant information. In this sense, we evaluated whether the genetics knowledge of the participants improved after the impact of the genetic counselling.<sup>12</sup>

One of the most frequent emotions that has been studied in literature is the guilt. The majority of parents do not change their minds about the idea that they might have done something to prevent their child's deafness. Some studies report that parents do not appear to feel guilty about the clinical condition of their children.<sup>12</sup> Earlier investigations show that parents of children with a genetic condition identify less guilt than parents of children with mental retardation or multiple congenital anomalies of unknown etiology.<sup>9</sup> Nevertheless, in all of these cases it is important for genetic counsellors to provide an opportunity for parents to express their feelings (whether guilt or some other emotion) and to assure them that these feelings are common and normal.

### **PSYCHOLOGIC CONSIDERATIONS**

The sense of guilt is related to the propriety of empathy, to be able to feel what another person feels and to adapt one's behavior depending on what it feels. Guilt, shame, embarrassment and pride are designated as self-conscious emotions because they are the core of our conscience and regulate the interpersonal relationship. These are crucial for the development and maintenance of interpersonal relationships because they act as important social regulators by encouraging a balance between the individual's urges and the rights and needs of others."<sup>3</sup> In the overall scheme of emotions, guilt is in the general category of negative feeling states, which also include agony, grief, and loneliness, according to one comprehensive framework.<sup>4</sup>

The lack of these feelings is an important indicator of psycho-pathology, in the sense that a psychopath hurts his victims voluntarily and does not feel any remorse, regret or shame and it cannot understand or feel the suffering of its victim.

Early conceptualizations of shame and guilt claimed that shame was a public experience (in the presence of others and caused by their reactions), while guilt was a private experience (caused by internal conflict about morality).<sup>2</sup> Some modern commentators have argued that there are two types of guilt: "maladaptive, neurotic guilt" and "adaptive, pro-social guilt."<sup>13</sup> Following the logic of this research, adaptive guilt is focused on doing the right thing in the future and maladaptive guilt is focused on the past, on regret, but is not an acting attitude, so shame is generally a maladaptive emotion, while guilt is an adaptive one.

With regard to explanatory theories of the development of guilt, shame, embarrassment there are several variants: Freud's psycho-dynamic theory proposes that we build defense mechanisms to protect us from the guilt we would experience if we knew just how awful our awful desires really were. Specifically, Freud linked the feeling of guilt, and its related emotion of anxiety, to the Oedipal stage of psycho-sexual development. Erikson believed that guilt first emerges in life at about the age of 3-5 as the negative outcome to a period he called 'initiative vs. guilt'. Children develop a strong sense of guilt at this age as the polar opposite to playfulness. The cognitive explanation sees guilt as an emotion that people experience because they are convinced they caused harm. In cognitive theory, the thoughts cause the emotions, so the thoughts that cause guilt are negative or dysfunctional.

Susan Krauss Whitbourne (2012) describes 5 types of guilt:<sup>14</sup>

**1. Guilt for something you did.** This type of guilt may involve harm to others, such as causing someone physical or psychological pain – this has an external cause but can also be internal when guilt emerges because of the violation of one's own ethical or moral code, such as cheating, lying or stealing.

**2. Guilt for something you didn't do but want to.** It's similar to the first one, but in the other direction. You feel bad for not committing an act for someone, or for yourself, and thinking that if you had done it, the actual situation, the present would have been different.

**3. Guilt for something you *think* you did.** This is a more cognitive guilt and you can experience almost as much guilt from it as if you actually committed the act — or even more. You don't know for sure, but you ruminate negative thoughts for something that maybe happened, or maybe not.

**4. Guilt that you didn't do enough to help someone.** This type of guilt occurs when the results of what you did is not what you expected, so you think that maybe wasn't enough for that person.

**5. Guilt that you're doing better than someone else.** The experience of *survivor's guilt* is often encountered in war veterans who outlived their fellow troops or in people who lost family, friends, or neighbors in disasters themselves remaining untouched or, at least, alive.

These 5 types of guilt can be easily found in parents who have children with loss hearing. Often parents are thinking that maybe they did something wrong, or maybe they did not do that thing that probably would change the situation, or they think that what they've already done wasn't enough, or maybe they feel guilt that they can hear and their child cannot (for hearing parents).

Specifically for these types of parents, we can distinguish some particularly guilt types like: the guilt for doing something bad in their life and this child's problem is the punishment; guilt for not finding the best treatments, doctors, solutions for their child; guilt for child's physical and emotional suffering; guilt for the fact that people around the child treat him badly; guilt for the fact that if they have a sister or a brother in good health, they will have to take care of the sick one, after the parents death. Mothers tend to feel more guilt than fathers for their child's disease<sup>7</sup> and it's important to understand that a persistent guilt can lead to depression or other mental problems, so healthcare professionals must recognize these problems and be able to offer appropriate interventions.

A genetic test can provide a clear answer about the etiology of hearing deficiency, but the answer may generate different attitudes in parents. Studies show that some parents may feel relieved if they felt guilty for doing something bad, but others may feel more guilt because now they have the 'proof' that it's their fault. Even more, Deaf community fears that the use of genetic tests will reduce the numbers of deaf children born, having a direct effect of viability of their community. So more than 55% of the respondents thought that genetic testing would do more harm than good, while 46% thought that its potential use devalued deaf people, and 49% were concerned about new discoveries in genetics. When asked about testing in pregnancy, 16% of participants said that they would consider having prenatal diagnosis and, of these, 29% said that they would prefer to have deaf children.<sup>6</sup>

## **CONCLUSIONS**

Genetic counselors can provide an extremely important service by assessing the knowledge, experiences, beliefs, attitudes to these families, but they need to appreciate that some deaf persons may prefer to have deaf children. Genetic counseling service can be effective and appropriate only if clinicians and counselors take into consideration the beliefs and values of the deaf community at large.

The new-born hearing screening process is a process that begins with bedside audiometric screening of virtually all new-borns prior to discharge and proceeds to outpatient diagnostic audiological evaluation for a small percentage of infants. During this process, parents are in contact with many health care professionals, including obstetricians, paediatricians, hearing screeners,

audiologists, otolaryngologists, and early intervention teachers. Currently there is no formalized protocol for determining who should discuss the availability of genetic counselling and genetic testing to parents nor the timing of this discussion, although the pros and cons of initiating genetic testing at different stages in the process have been described.

In conclusion, as genetic testing for congenital deafness becomes more widespread, it should also be combined with psychological counselling for parents in order to avoid the inadvertent feelings of guilt, shame and blame that occur from the birth of a deaf child.

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