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Parental knowledge and attitudes towards hereditary hearing loss and genetic technology

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ABSTRACT

Introduction: The knowledge and attitudes about genetic hearing loss are essential to prevent more hearing loss incidences in societies. However, limited studies have compared the knowledge and attitude toward genetic technology between parents of normal and impaired-hearing children.

Methods: A descriptive, cross-sectional study was performed involving 105 parents with one or more children having a hearing impairment and 204 control parents with children having normal hearing. Parents completed surveys designed to investigate their knowledge and attitudes about the genetic basis of hearing impairment and recent technologies. Descriptive and inferential statistics were used to measure response differences between the two groups.

Results: Both groups shared the same level of knowledge, with the average knowledge scores of parents with normal-hearing children (9.53/19±2.56 points) resembling those of parents with hearing-impaired children (10.08/19±3.17 points; F(1, 307)=-2.17, p=0.14). Moreover, parents had limited information about the genetic basis of hearing loss, specifically in estimating the recurrence of congenital hearing loss (n=26 of 105, 24.76%)and misunderstanding inheritance paradigms (n=24 of 105, 22.86%). Regardless of having children with auditory issues, parents expressed positive attitudes towards genetic testing.

Conclusions: These findings suggest that more genetic specialists are needed to educate families of children with hearing loss about the genetic attributes of hearing impairment and the significance of genetic technology.

Keywords: genetic hearing loss, genetic testing, knowledge, attitude, prenatal diagnosis

INTRODUCTION

The ability to listen and comprehend information is influenced by genes [1]. Any hearing impairment is considered a serious issue that impedes human communication. Human genetics is vital for understanding auditory disorders [2, 3]. The progress in understanding heredity has contributed to recognizing over 6,000 mutations in over 150 genes triggering hearing loss [4]. This suggests that congenital hearing impairment is the most insidious developmental disease occurring among infants immediately after birth [5]. Hereditary hearing loss is approximately 200 per 100,000 births, exceeding other childbearing disorders, including low intelligence, cleft lip and palate, down syndrome, limb defects, spina bifida, sickle cell anemia, and phenylketonuria [6]. Being born with hearing impairment reduces intellectual abilities of children, creating a complex situation for them and their caregivers [7]. It was suggested that children with language disorders have challenges hearing and processing sounds that reach their ears [8]. These results of language impairment eventually affect the academic, psychological, and social capabilities of children.

The prevalence of non-syndromic autosomal recessive hearing impairment is 75-80%, whereas the prevalence of non-syndromic autosomal dominant hearing impairment is 20%. Similarly, the non-syndromic prevalence related to X chromosome and mitochondria is 2-5% and 1%, respectively [9]. To diagnose genetic hearing loss, a comprehensive understanding of clinical manifestations of congenital syndromes is crucial. Subsequently, following the American College of Genetics guidelines, newborns and infants diagnosed with hearing impairment should receive comprehensive assessments, including patient-focused medical and birth histories, three-generation pedigree tracking, family medical history, and physical examinations to explore any physical deformities. Individuals showing indications of syndromic hereditary hearing loss should undergo pre-test genetic counseling, detailed studies to determine if other organs are impacted, and appropriate short- and long-term screenings and inspections. Conversely, those without physical signs indicating a known syndrome should receive pre-test genetic counseling in combination with single-gene testing, particularly when collected information from their medical or family history, or hearing loss manifestations, suggest a specific etiology. Moreover, complementary tests,

including bone and soft tissue radiological imaging and nuclear magnetic resonance, could be conducted as a cross-check to confirm the presence of a hereditary mutation [10]. When examining the factors involved in hearing impairment, disorders are primarily associated with genetic and environmental factors, some may be out of control [11, 12]. Thus, affected individuals must manage symptoms during the onset and course of the disorder. Hearing impairment symptoms interfere with the ability to listen, communicate, and behave accordingly [13, 14]. Educating people about genetic hearing loss enhances their awareness and prompts seeking medical care for symptom control and life management. Additionally, this approach facilitates the establishment of short-term and long-term management systems for those dealing with the condition. Knowledge, attitude, and practice (KAP) survey is a method to reveal what specific groups of individuals know about certain topics and how they interact with them. KAP questionnaire has been extensively used by researchers in various health fields to evaluate the knowledge, attitudes, and practices of healthcare professionals [15-17], patients [18, 19], and caregivers [20-22]. In audiology, KAP approach is commonly employed to investigate diverse hearing issues, including harmful noise exposure [23] and neonatal and preschool hearing screening [24, 25]. KAP comprises three principal categories: knowledge, attitudes, and practice [26, 27]. For its simplicity, significance, and cost-effectiveness, KAP questionnaire is essential in implanting any health policy or plan [27].

Nearly all types and configurations of hearing loss have a genetic component encompassing conductive, sensory, and neural; syndromic and non-syndromic; sudden or progressive, high-frequency or low-frequency; mild or profound; and recessive, dominant, or sex-linked [28]. The issue faced by healthcare providers is the limited effectiveness of treatment options for certain genetic hearing impairments affecting the neural pathways of the auditory system [29]. An estimated 40% of auditory neuropathy cases have underlying genetic etiologies, which can be passed to offspring in both syndromic and non-syndromic deafness [30]. Reducing the incidence of genetic hearing impairment cases by raising population awareness through all educational means, including increasing public awareness about genetic hearing loss and reproductive program options, is considered the most beneficial method for addressing genetic diseases. Indeed, a population with a higher level of education about all aspects of hereditary hearing impairment is expected to reduce its influence and occurrence, which accounts for 50-60% of pediatric hearing loss cases in developed countries [31].

The current research compared knowledge and attitudes regarding genetic hearing loss and testing among families of children with and without hearing impairment. To our knowledge, few studies have discussed parental attitudes toward genetic testing; for instance, 96 parents with one or more deaf childeen were examined [32]. The study indicated that 96% of participants held an optimistic attitude towards PND. Parents showed a lack of knowledge about genetics, with 98% inaccurately predicting the possibility of recurrence of genetic hearing impairment and misinterpreting inheritance paradigms.

The current study aimed to survey Jordanian parents to determine whether genetic counseling is necessary to make them more accepting of genetic testing after understanding that it is necessary, not harmful, and designed to their advantage and support their reproductive autonomy by offering relevant information to enable alternatives that align with their values. Furthermore, knowing more about the extent of parental knowledge and attitude towards genetic testing will help to highlight the importance of population education and genetic counseling for parents of children with hearing loss. This educational policy is ultimately expected to positively impact the awareness of hearing loss in the target population.

MATERIALS AND METHODS

This cross-sectional study was conducted in several centers in Jordan.

Participant Selection

Samples were collected randomly from different Jordanian governorates and included 309 Jordanian parents. Parents of deaf and hard-of-hearing children were selected after confirming hearing loss in their children through comprehensive audiological evaluations at King Abdullah University Hospital. Conventional audiological tests were used to assess the hearing functionality of target children. The tests included an otoscopic examination, pure tone audiometry, speech tests, immittance measurements, auditory brainstem response, and otoacoustic emissions. The respondents were required to fill out KAP version designed to test the hypotheses for the present study.

Subjects were included in the study if they had at least one child with normal or impaired hearing, and a certified otolaryngologist confirmed the hearing status of children. The exclusion criteria involved subjects who were parents of children with disabilities other than hearing impairment and those currently parenting for less than four weeks; in the opinion of the research team, a diagnosis of hearing loss might take additional time post-birth. Responses were collected through face-to-face interviews led by an experienced audiologist. The questionnaire commenced with an introductory paragraph explaining the aims and significance of the study was provided, accompanied by an applied ethical policy ensuring avoidance of personal questions or unclear phrasing.

Material

The questionnaire was developed using the questionnaire produced by previous literature [32] as a reference to investigate the level of knowledge and attitude regarding genetic hearing loss and genetic testing among parents with and without deaf and hard-of-hearing children in Jordan. The questionnaire covered demographics, familiarity with hereditary hearing loss and testing, and degree of enthusiasm in exploring the testing results. Additional questions were asked in case parents whose children who previously undergone genetic testing about their reasons for had choosing genetic testing services, and their perspectives on the benefits and consequences of the testing. Parents whose children had not been tested were queried about their awareness of genetic testing and any recommendations from healthcare providers. For those who declined testing, further details about their decision were investigated. The questionnaire comprised two sections: the first comprised questions about demographic information, while the second

Table 1. Sociodemographic characteristics of 309 participants

Variables	Cateegory	Normal hearing (n=204)	Hearing loss (n=105)
Age of a participating parent in years: Mean (SD)		29.5 (±5.30)	28.1 (±5.10)
Age of a child in years: Mean (SD)		6.5 (±4.97)	6.3 (±5.80)
Gender	Male	109 (53.43%)	56 (53.30%)
	Female	95 (46.57%)	49 (46.70%)
Educational level of mother	High school	69 (33.82%)	40 (38.10%)
	Diploma	36 (17.65%)	18 (17.14%)
	Bachelor	88 (43.14%)	43 (40.95%)
	Master	9 (4.41%)	2 (1.90%)
	PhD	2 (0.98%)	2 (1.90%)
Educational level of father	High school	74 (36.27%)	59 (56.19%)
	Diploma	36 (17.65%)	16 (15.24%)
	Bachelor	72 (35.29%)	25 (23.81%)
	Master	11 (5.39%)	2 (1.90%)
	PhD	11 (5.39%)	3 (2.86%)
Profession of mother	Non-worker	144 (70.59%)	64 (60.95%)
	Health-care provider	18 (8.82%)	10 (9.52%)
	Teacher	25 (12.25%)	10 (9.52%)
	Engineer	7 (3.43%)	6 (5.71%)
	Manager	4 (1.97%)	7 (6.67%)
	Fieldworker	1 (0.49%)	2 (1.90%)
	Military	1 (0.49%)	0 (0.00%)
	Retired	4 (1.97%)	6 (5.71%)
Profession of father	Non-worker	9 (4.41%)	16 (15.24%)
	Health-care provider	12 (5.82%)	7 (6.67%)
	Teacher	33 (16.18%)	8 (7.62%)
	Engineer	13 (6.37%)	7 (6.67%)
	Manager	36 (17.65%)	10 (9.52%)
	Fieldworker	33 (16.18%)	21 (20.00%)
	Military	32 (15.69%)	9 (8.57%)
	Retired	36 (17.65%)	27 (25.71%)
Annual salary for child's family (USD)	Lower than $8,500	132 (64.71%)	67(63.81%)
	$8,501-12,000	36 (17.65%)	32 (30.48%)
	$12,001-14,000	23 (11.27%)	6 (5.71%)
	Higher than $14,000	13 (6.37%)	1 (0.95%)
Child's residence	Urban	96 (47.06%)	50 (47.60%)
	Rural	108 (52.94%)	55 (52.40%)

contained 28 questions addressing knowledge of genetic hearing loss consequences, inheritance patterns, risk factors of recurrence, and attitudes toward PND. All items were originally written in English and then translated into Arabic by a professional translator. Response options included yes/no, multiple choice, and short essay formats.

Statistical Analysis

Statistical analyses were performed using statistical package for the social sciences (SPSS) software, version 16 (IBM, IL, USA). Descriptive procedures were applied to the collected data to classify patients based on several variables, including age, gender, family residence, annual salary, and educational level of parents. Additionally, linear regression was employed to determine the discriminants between the parents of children with hearing loss and those with intact hearing to compare average knowledge scores between these two groups. A p-value<0.05 was considered significantly different in all tests.

RESULTS

Demographic Information

A total of 105 parents (74 mothers and 31 fathers; mean of age: 28.1 years) of children with hearing loss (mean age: 6.5 years) and 204 demographically matched control parents (161 mothers and 43 fathers; mean age: 29.5 years) of normal hearing children (mean age: 6.5 years) were included in the study (**Table 1**).

Based on responses from parents of hearing loss children, the hearing loss duration ranged from one month to 16 years (mean=4.4±4.1 years). All the parents of children with intact hearing also had normal hearing, while among families of children with hearing loss, 70 (66.67%) had both parents without hearing loss, 16 (15.24%) had one parent with hearing loss, and 19 (18.09%) had both parents with hearing impairments. Among the parents of deaf and hard-of-hearing children, 59 of 105 (56.19%) parents reported receiving genetic counseling on hearing loss. Contrarily, the remaining 46 (43.81%) parents claimed they were unaware of the issue.

Awareness & Attitude of Parents with Normal Hearing Children About Genetic Basis of Hearing Loss

Most parents with children having normal hearing had good knowledge about the genetic basis of hearing loss regarding considering genetic transmission as one of the causes of hearing issues (97, 47.55%), the possible comorbidities of other defects with genetic hearing impairment (125, 61.27%), acknowledging that the phenotype of hearing impairment might not be expressed immediately after birth (96, 47.06%), and realizing that genetic hearing loss

Table 2. Knowledge of 204 parents with normal-hearing children & 105 parents with deaf & hard-of-hearing children about genetics of hearing (numbers & percentages of correct answers on each item have been listed for both groups & results suggested that parental knowledge about hereditary hearing loss was similar regardless of whether their child had hearing loss or not)

Statement	Normal hearing	Hearing loss	Statistics
One of the causes of hearing loss is the genetic transmission.	97 (47.55%)	10 (9.52%)*	F=29.740, p<0.00
Hearing loss is the most common developmental disorder among infants.	38 (18.62%)*	10 (9.52%)*	F=4.410, p=0.04
If the father and mother do not suffer from hearing loss, then it is not necessary for their child not to have hearing loss.	127 (62.25%)	59 (56.19%)	F=1.060, p=0.30
Genetic hearing loss can be associated with other health problems.	125 (61.27%)	49 (46.67%)	F=6.090, p=0.02
All genetic hearing impairments are caused by genes equally inherited from father & mother.	65 (31.86%)*	36 (34.29%)*	F=4.410, p=0.04
Genetic hearing loss leads to language acquisition problems.	174 (85.29%)	91 (86.67%)	F=1.110, p=0.75
Genetic hearing loss leads to future problems in the child's educational achievement.	160 (78.43%)	72 (68.57%)	F=3.620, p=0.06
Genetic hearing loss leads to psychological and social problems for the child.	176 (86.27%)	78 (74.29%)	F=6.920, p=0.01
The child's hearing loss could be transmitted if both the father and mother carry genes of hearing loss without showing symptoms of hearing loss.	105 (51.47%)	50 (47.62%)	F=8.430, p=0.01
Hearing loss may be transmitted if the mother only carries a gene that causes hearing loss and does not have symptoms of hearing loss.	64 (31.37%)*	17 (16.19%)*	F=1.720, p=0.20
Male and female children have equal chances of acquiring hereditary hearing impairment.	61 (29.90%)*	24 (22.86%)*	F=6.920, p=0.02
All cases of hereditary hearing impairment show symptoms immediately after birth.	96 (47.06%)	43 (40.95%)	F=3.620, p=0.06
Genetic hearing loss can be largely avoided through genetic testing of the mother and father before pregnancy of an at-risk fetus.	101 (49.51%)	57 (54.29%)	F=0.630, p=0.43
There is no cure for hereditary hearing impairment.	89 (43.63%)	46 (43.81%)	F=0.001, p=0.98
Genetic hearing loss appears in all infected cases in the same pattern, type, and severity.	129 (63.24%)	53 (50.48%)	F=4.700, p=0.03
The more hearing loss is detected early, the less it affects the child.	174 (85.29%)	94 (89.52%)	F=1.070, p=0.30
There is a chance of having a second child with hearing loss if the first child was born impacted with hearing loss.	94 (46.08%)	53 (50.48%)	F=0.540, p=0.47
Genetic testing to detect the possibility of hearing loss is a painful procedure.	82 (40.2%)	53 (50.48%)	F=2.990, p=0.09
Genetic testing is important to determine the causes of hearing loss and the possibility of transmission among members of the same family.	165 (80.88%)	75 (71.43%)	F=3.600, p=0.06

Note. *Indicates incorrect answers by majority

did not appear uniformly in all affected cases with the same pattern, type, and severity (129, 63.24%).

A total of 165 of 204 respondents (80.88%) reported an enthusiastic attitude towards genetic screening for hearing loss and realized the need of identifying the underlying causes of hearing loss and the likelihood of auditory genetic deviation among same family members.

Most parents in this group were unconcerned about losing their confidentiality and that of their families (128 of 204, 62.75%) or linking their family with social stigma (119 of 204, 58.33%) because of genetic screening for hearing impairment. Out of 204 parents, 82 (40.2%) thought that genetic screening to detect the potential of developing hearing loss was not a painful procedure.

Most parents with children having normal hearing responded appropriately to certain aspects of genetic transmission, including "if the father and mother do not suffer from hearing loss, then it is not necessary for their child not to have hearing loss" and "the child's hearing loss could be transmitted if both the father and mother are carrying genes of hearing loss and without showing symptoms of hearing loss," while they failed to correctly answer other aspects, like the increased tendency for males to have genetic hearing loss compared to females (61, 29.90%), not all genetic deviations associated with hearing loss are inherited equally from both parents (65,31.86%).

In the case of an X-linked inheritance, most parents with normal hearing children answered mistakenly on the statement that a male child may inherit hearing loss only if the mother carries a gene that causes hearing loss, even without displaying symptoms of hearing loss (64, 31.37%). Additionally, many parents were unaware that hearing loss had a highest incidence among other developmental disorders in infants (38, 18.62%; **Table 2**).

Awareness & Attitude of Parents with Deaf & Hard-of-Hearing Children About Genetic Basis of Hearing Loss

Most parents with deaf and hard-of-hearing children understood common facts about genetic hearing loss, including possibility of their children having coexisting deficits besides genetic hearing conditions (49, 46.67%), the symptoms of hearing loss might appear after birth (43, 40. 95%), and the fact that forms and degrees of genetic hearing loss varied among patients (53, 50.48%). More than half of the participants indicated the benefits of genetic screening for hearing loss as an assessment tool to highlight the mechanism and familial risk of hearing loss (57, 54.29%). Also, 53 of 105 (50.48%) participants realized that genetic sequencing was not an unpleasant procedure for patients to reveal hearing disorders.

A large proportion of parents with hard-of-hearing children correctly defined details regarding genetic transmission paradigms involving "if the father and mother do not suffer from hearing loss, then it is not necessary for their child to not have hearing loss" and "the child's hearing loss could be transmitted if both the father and mother are carrying genes of hearing loss and without showing symptoms of hearing loss." However, fewer participants provided correct responses to questions that boys had a higher risk of developing hereditary hearing loss than girls (24, 22.86%), and all genetic variations related to hearing loss were unevenly received from parents (65,31.86%). Boys could have hearing loss if the mother were carrying a mutation in a gene that could transfer to the fetus without the mother expressing symptoms of hearing loss (17, 16.19%). Furthermore, a small percentage of participants knew that hearing defects are considered the most common

Table 3. Summary of detailed information about attitudes toward hearing genetics & genetic technology collected from 105 parents of children with hearing loss

Statement	Percentage (%)
Previous experience with genetic testing for their hard-of-hearing child	59/105 (56.19%)
Reasons for not using genetic testing	
No one offered test	17/46 (36.96%)
No one recommended test	13/46 (28.26%)
Lack of knowledge about genetic testing	8/46 (17.39%)
Doubts that hearing loss has a genetic basis	8/46 (17.39%)
Advantage of genetic testing	
Knowing percentage of having more deaf children in future	40/59 (67.80%)
Determine etiology of hearing loss	10/59 (16.95%)
Choosing an appropriate medical & audiological intervention	9/59 (15.25%)
Conducting genetic analysis on siblings of child with hearing impairment	88/105 (83.81%)
Rationale for agreeing to conduct genetic testing on siblings	
Specifying percentages of having hearing issues in siblings	55/88 (54.50%)
Helping siblings make choices about having kids	33/88 (37.50%)
Rationale for performing genetic testing on parents	
Determining risk of recurring childbearing kids with hearing loss	82/88 (93.18%)
Selecting appropriate treatment for their deaf & hard-of-hearing children	6/88 (6.82%)
Rationale for not performing genetic testing on parents	
Parents do not suffer from hearing difficulties	15/17 (88.24%)
No genetic causes of hearing loss in the family	2/17 (11.76%)
Interest in prenatal diagnosis for future babies	61/105 (58.10%)
Reason for being interested in prenatal diagnosis	
Preparing to have a child with hearing loss	59/61 (96.72%)
Other	2/61 (3.28%)
Rationale for not being interested in prenatal diagnosis	
Test is worthless	41/46 (89.13%)
No knowledge about this test	4/46 (8.70%)
Other	1/46 (2.17%)
Number of parents correctly estimating recurrent risk for normal hearing parents of a child with non-syndromic deafness	26/105 (24.76%)
Number of parents correctly estimating risk that an individual with non-syndromic deafness will have a deaf child	28/105 (26.67%)

developmental disorders in infants (Korver et al., 2017), and that genetic mutations are one of the hearing loss factors (10,9.52%; **Table 2**).

Knowledge about the genetic basis of hearing loss in both groups, parents with normal hearing children and those with hard-of-hearing children, were insignificantly different. The average knowledge scores were comparable, with parents of intact hearing children scoring 9.53/19±2.56 points and parents of children with hearing impairment scoring 10.08/19 ± 3.17 points ($F[1, 307]=-2.17$, $p=0.14$) with an R^2 of 0.007, indicated by linear regression analysis.

Regarding attitudes toward genetic technology, 75 of 105 (71.43%) parents of deaf children had a positive attitude, 69 of 105 (65.71%) parents believed that genetic test results for deafness did not compromise the privacy of a tested individual or the entire family, and 63 of 105 (60.00%) respondents stated that the genetic outcomes would not cause a social stigma associated with the involved family.

The same 105 parents of children with hearing loss were asked to complete a second questionnaire regarding their attitude towards genetic mapping to highlight abnormal sequences associated with auditory problems and their previous experience, if any, with genetic tests. Only 59 of 105 (56.19%) parents revealed that their hard-of-hearing children had undergone genetic tests, while 46 (43.81%) indicated they had not been exposed to this kind of evaluation before. Furthermore, these 46 respondents listed varied reasons for not trying genetic testing, including 17 (36.96%) parents listing that no one had offered the test to them, 13 (28.26%) parents complained that no one had recommended the test to them, 8 (17.39%) parents did not know the benefits of genetic testing, and 8 (17.39%) parents believed that the hearing loss of their children did not have a genetic basis. Among the 46 parents who did not receive genetic testing for their children, 38 expressed the interest in examining the genetic material of their children; the remaining parents showed no interest in genetically assessing their children for auditory damage.

The advantage of screening the child for a mutation that might cause hearing loss was evaluated by further questioning parents whose children had previously undergone genetic testing. The majority (40 of 59, 67.80%) thought that the estimation of the percentage of patients with future hereditary hearing loss incidence in the family was the most crucial advantage.

Among the 105 parents of children with hearing impairment, 88 (83.81%) expressed their willingness to undergo genetic testing themselves for hearing loss as parents of affected children, while 17 (16.19%) declined. A large portion (82 of 88, 93.18%) of participants who responded positively to genetic testing, their reasons were linked to assessing the risk of future children having hearing loss. Conversely, many (15 of 17, 88.24%) of the respondents who declined suggested that they had never experienced hearing difficulties.

Approximately half of respondents (61 of 105, 58.10%) were interested in prenatal genetic screening of hearing functions in fetuses during pregnancy because they wanted to be prepared to have a deaf child. The other half were not enthusiastic about completing this procedure since the majority (41 of 46, 89.13%) believed the examination was unnecessary and worthless (**Table 3**).

Among the 105 parents with hard-of-hearing children, 26 parents (24.76%) correctly estimated the recurrent risk for normal-hearing parents of a child with non-syndromic deafness, and 28 parents (26.67%) appropriately estimated the risk that an individual with non-syndromic deafness will have a deaf child. Previous research has stated that the real recurrent risk for intact hearing parents of a child with non-syndromic deafness is 10-18% [33], and the possibility that a person with non-syndromic hearing loss will have a child with the same impairment is approximately 5% [34]. In the current era of widespread and accessible genetic testing, it is important to affirm, as stated in [34] that "gene localization and more accurate recurrence information will require improved means of diagnosis."

DISCUSSION

This study addressed the knowledge and attitude of parents with intact and hard-of-hearing children toward the genetic basis of hearing impairment and genetic testing. A total of 309 parents completed a questionnaire to assess various aspects of this topic, identifying areas that require targeted education to equip parents with the skills necessary for raising a child with hearing loss, understanding the etiologic diagnosis of hearing loss of their children, and realizing the risks of having other children with hearing defects.

This research is considered one of the few scientific studies that examined the variations in parental knowledge between parents of children with and without hearing loss. Both groups shared the same level of knowledge. However, the subject group was assumed to have higher knowledge than the control group since they had experience dealing with deaf and hard-of-hearing children and had must been educated by professionals. The results suggested that the awareness programs for families raising children with hearing loss might not be effective. Deaf and hard-of-hearing children who are identified through early hearing detection and intervention have improved results in speech, language, intellectual, and social development [35]. Strengthening the parental awareness about hearing disorders, manners, developmental milestones, and psychosocial restraints of their children is fundamental to ongoing, timely diagnosis and well-chosen intervention [36, 37]. Professionals should offer family-centered programs, allowing parents full and immediate access to comprehensive information, family support, and the latest evaluation and treatment technologies. Indeed, the successful accomplishment of any intervention plan needs both the involvement and dedication of specialized experts and the knowledgeable participation of the parents [38].

The present study compared the knowledge and attitude related to the genetic basis of hearing loss and testing between parents of children with and without hearing loss. Other studies have only described the attitudes of parents of children with hearing impairment towards genetic testing, including the study [32], which involved 96 normal-hearing parents with one or more deaf children. This study had results similar to the current research, with most participants reporting a positive attitude toward PND. The parents in both studies demonstrated limited knowledge about genetics, specifically in estimating the recurrence of hereditary hearing loss and misunderstanding the inheritance models.

The results of the current study showed that many parents, from both groups with normal-hearing and impaired-hearing children, had positive attitudes concerning genetic testing for deafness. These findings are consistent with the previous study [39] on 17 of 19 deaf or hard-of-hearing participants, revealing their support of genetic testing for hearing loss. While parents of deaf children in our study expressed similar advantages of PND as deaf or hard-of-hearing respondents in the study [39]–highlighting its value in preparing parents for a child with hearing loss and facilitating suitable intervention–the latter study identified additional benefits. These included timely and accurate diagnosis, preparing parents for special needs of the child while language acquisition and schooling, and contributing to research and progression of investigations regarding the factors and potential treatments for hearing loss. The higher emphasis on using PND in the study [39] than in the present study could be attributed to the fact that deaf and hard-of-hearing individuals were more concerned about hearing loss than parents of deaf and hard-of-hearing children who did not have hearing loss.

Conversely, it was found that 15% of 337 deaf college students have negative feelings toward genetic technology compared to 22% reporting positive emotions, and 40% were unsure of their attitudes [40]. These findings contradicted the findings of the present study, where 54.29% of participants supported the genetic field of hearing. However, the majority of respondents in the current study and the study by Stern and colleagues viewed neonatal genetic screening as a helpful procedure with audiological benefits. Additionally, among the 87 deaf representatives attending an international conference on the "deaf nation" held at the University of Central Lancashire in 1997, who were asked to complete questionnaires considering the implications of genetic testing and PND for deafness, 25% agreed that genetic testing results in more negative outcomes than positive ones. Only 16% of responders encouraged the application of PND services [41]. These conclusions contradict the findings of the present study, which could be explained by variations in the hearing status of participants and their response tendencies to the survey questions included in these studies. While it was studied the attitude toward genetic testing for hearing loss in deaf individuals [42], most participants in the current study were parents with normal hearing. The significance of this study lies in highlighting key considerations for genetic counselors and other professionals, specifically those discussing the suitability of genetic testing for PND. This technology proves useful in reducing the ambiguity about having a child with abnormal hearing status. Previous literature has suggested that genetic knowledge and testing empower the deaf society by equipping them with information beneficial to determine the future of their family members [43].

Through this study, it has been reported that parents have limited knowledge about genetic testing. This contradicts their good awareness of other topics related to hearing conditions, including otitis media. The study [44] showed that 425 parents demonstrated acceptable knowledge (77%) and good care-seeking practices (70%) when dealing with incidences of otitis media in their children. Differences in parental knowledge levels of hereditary and middle ear-affected hearing loss have been attributed to the fact that otitis media is more prevalent among the pediatric population [45]. Contrary, another KAP study on 28 pediatric otolaryngologists has found that these physicians have good knowledge about genetic hearing loss

and testing of deaf and hard-of-hearing patients; however, information regarding the chances of having recurrent incidences of genetic hearing loss in families already having a child with hearing defects seemed imprecise [46]. It seems that the lack of focus on awareness of hereditary hearing loss and poor communication between caregivers and parents contributed to insufficient parental information regarding hereditary hearing loss.

The critical application of comparing parental knowledge between those with hard-of-hearing and normal-hearing children revealed a notable similarity between the two groups, both displaying incomplete knowledge. These results highlight significant flaws in early hearing detection and intervention programs, explicitly involving educating parents of deaf and hard-of-hearing children about the genetic basis of hearing and genetic technology using the genetic test to assess the risk of recurrence/occurrence of hearing loss for a specific couple, studying the partner to allow the couple to choose their reproductive options, such as PND. More actions must be taken to educate the Jordanian population about the severe health and hearing effects of consanguineous marriage. Notably, Jordan population and family health survey indicated a decline in consanguinity rates, with 35% of total marriages being between close relatives in 2012, a decrease from the reported 57% in 1990 [47]. Raising genetic counseling and avoiding consanguineous marriages will eventually reach fewer cases of hereditary hearing loss [48]. The findings of this study should be interpreted considering some limitations. Most of the selected sample comprised of parents and children from low-income families. Though the selection was randomized, poverty is the standard economic status in Jordan. The results obtained might be affected by the financial hardships of the participants and are likely to be generalized at only some social levels.

CONCLUSIONS

This study revealed that parental attitudes and awareness about the genetic basis and assessment of hearing loss remained consistent, regardless of whether they had a child with hearing loss or not. Thus, medical professionals should pay attention to increasing parental knowledge, especially those with deaf and hard-of-hearing children, about genetic services and procedures to use as ways to reduce the incidence of hereditary hearing loss. Moreover, genetic counseling can enhance understanding of test results, providing the potential to alter estimates of recurrent risk among family members. Future studies should evaluate active hearing detection and intervention programs, ensuring they effectively educate parents about hearing genetics and emphasize the importance of genetic testing to define the auditory capabilities of their newborns.

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