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## Abstract

**Background**: Hearing impairment and its consequences in children are often worsened by late identification in Pakistan. Deep-rooted cultural beliefs make some parents reluctant to seek clinical treatment, making adaptable solutions that traverse levels of socio-ecological model necessary.

**Aims**: To determine the impact of hearing impairment on children's participation in social activities, and the financial burden on their parents.

**Methods**: This cross-sectional study included 377 parents of children with hearing impairment. The sample was recruited from special education schools and hospitals in Islamabad and Lahore, Pakistan, from November 2015 to April 2016. A 15-item structured questionnaire was used for data collection. SPSS version 21 was used for statistical analysis.

**Results**: Among children with hearing impairment, 47.5% faced moderate challenges in joining social activities, and 26.0% faced severe challenges. There was a significant positive correlation between the severity of hearing impairment, the person who suspected hearing impairment, age of detection of hearing impairment, and time of referral. Children with hearing impairment caused moderate financial strain on 39.0% of parents and mild strain on 26.8%.

**Conclusion**: Hearing impairment can significantly impact children's participation in social activities and cause financial burdens on their parents.

Keywords: hearing impairment, disability, children, parents, caregivers, hearing screening, social life, Pakistan

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## Introduction

The World Health Organization (WHO) defines the inability to hear at a threshold of 20 dB as hearing impairment, and disabling hearing loss as loss of > 35 dB in the better ear (1). Hearing impairment is a major disability globally and is more frequent in developing countries. A study from 1 region of Pakistan reported a prevalence of 7.9% in school children (2). Late identification of hearing impairment among children is prevalent in developing countries, including Pakistan, because of the absence of neonatal hearing screening (3), and 26% of cases of mild hearing loss may even be missed in the presence of neonatal screening (4). Neonatal hearing screening in Pakistan is hindered by financial constraints and a dearth of research and reliable epidemiological data (5). Hearing impairment is an invisible disability, and missed or delayed diagnosis or lack of treatment results in delayed development of speech, language, and communication (5). This has a negative effect on educational progress, leading to unemployment or lower level of employment, isolation, loneliness, as well as social stigmatization. The global economic impact of untreated hearing impairment is around US$980 billion annually (1).

Although hearing impairment has detrimental consequences, deep-rooted cultural beliefs can predispose some parents or caregivers to refuse clinical treatment or rehabilitation (6). Hearing

impairment is 1 of the 4 major disabilities recognized by WHO (7) and early hearing detection and intervention are required for speech and language development in children with this condition. Delays in identification of hearing impairment can result in speech and language, social, emotional, cognitive, educational, and occupational delays. Hence, hearing screening should be conducted by 1 month of age, diagnostic tests by 3 months, and appropriate intervention by 6 months. Transient evoked otoacoustic emissions and auditory brain response are commonly used for hearing screening (8), and brainstem evoked response audiometry and auditory steady state response are reserved for routine clinical testing (9).

Hearing is sometimes called the social sense because it has a fundamental role in interacting and relating with people and the social environment (10). Therefore, adaptable solutions are required for individuals with hearing impairment to improve hearing-related health and wellbeing (10). The extent of hearing impairment from moderate to profound has been highlighted in previous studies in which children were prone to make pragmatically inappropriate responses because they lacked the ability to comprehend environmentally available auditory cues and were victims of extreme literalness (11).

Diseases such as cancer, epilepsy, polio, hepatitis, AIDS, and drug abuse have been extensively studied and have received community support, accompanied by educational efforts, to improve knowledge and attitudes (6). However, there has been a lack of similar efforts towards the study of hearing impairment (10). There is a strong link between development of speech and language skills and activities such as those involving music in children with hearing impairment (12). There has also been an emphasis on the role of psychological models and need for cross-cultural research in addressing hearing impairment (6).

This study was conducted to determine the impact of suspicion, identification, and diagnosis of hearing impairment on the challenges faced by children with hearing impairment when participating in community activities (festive or religious), and the financial burden on their parents.

## Methods

In this cross-sectional descriptive study, we used convenience sampling to recruit 377 parents of children with hearing impairment. The sample included parents of male and female children aged 4–15 years. Parents of children with any other disability were excluded. We recruited parents of children at special education schools and hospitals, including Special Children’s School, Bahria College, Al-Nafees Medical Hospital, and National Special Education Centre for Hearing Impaired Children in Islamabad; and Sheikh Zaid Hospital and Pearl Centre in Lahore, from 1 November 2015 to 30 April 2016. Data were collected using 10 items of a structured

15-item questionnaire developed by Mumtaz et al. (13) Ethical approval for the study was given by the Institutional Research Board of ISRA University (approval number 1402-PhD-011, dated 2 October 2015). Five hundred copies of the questionnaire were distributed to speech language pathologists and audiologists in the study settings, and 377 copies that were complete and met the selection criteria were included in the study.

SPSS version 21 was used for statistical analysis. Descriptive statistics, frequency and percentage of demographic and relevant questionnaire items were calculated. Pearson correlation was used to determine the linear relation between variables including severity, suspicion, identification, and diagnosis of hearing impairment in children. A -1 score represented total negative correlation, 0 no correlation, and +1 total positive correlation. The findings were then compared with national and international literature.

## Results

The mean age of the children was 9.57 (4.21) years. Hearing impairment was profound in 207 (54.9%) children, severe in 106 (28.1%), moderate in 38 (10.1%), and mild in 26 (6.9%).

One hundred and thirty-two (35.0%) parents noticed hearing impairment before 6 months of age ( Table 1 ). Hearing impairment was noticed first by parents in most cases (258, 68.4%), followed by grandparents (89, 23.6%). Professional advice was first sought at 19–24 months of age by 127 (33.7%) parents. The first professionals from whom advice was sought were audiologists in 166 (44.0 %) cases. One hundred and sixty children (42.4%) were referred immediately to another professional. Brainstem evoked response audiometry was the most commonly performed investigation (227, 71.8%), followed by auditory steady-state response (59, 18.7%). Late detection of hearing impairment at age 19–24 months was reported in 173 (45.9%) cases. Moderate challenges were reported for 179 (47.5%) children in joining community activities because of hearing impairment, and severe challenges for 98 (26.0%) children. One hundred and forty-eight (39.0%) children caused moderate financial strain on their parents.

Pearson’s correlation matrix showed that challenges in participating in community activities had a positive correlation with severity of hearing impairment (r = 0.19, P

## Discussion

This study shows that parents in Pakistan were late in noticing hearing impairment in their children, with only 35% reporting it before 6 months of age, 14.3% at 13–18 months, and the remainder even later. In contrast, in a 2017 study from the Khuzestan implant facility, Islamic

Republic of Iran, age of suspicion of hearing impairment among 72 children was 9.05 (10.55) months for boys and 10.02 (10.46) months for girls, and in an older study in 2007, it was 12.6 (8.9) months (14,15). An Indian study in 2014 reported the age of suspicion as 16.5 months (16). A South African study in 2016 and an Indian study in 2010 reported an even higher median age of suspicion of 18 months (17,18). With no neonatal hearing screening in Pakistan, suspicion of hearing impairment before 6 months of age in this study is encouraging.

Hearing impairment is an imperceptible disability that is hidden and escapes early intervention, causing noticeable impediment in speech and language development (13,19). Parents, especially mothers, suspect hearing impairment when they realize that their child is not reacting to typical environmental sounds (18). Even children with negative results in neonatal hearing screening have been diagnosed with hearing impairment later in life because of parental apprehension and screening at school (20). In this study, hearing impairment was initially observed by parents (68.4%), followed by grandparents (23.6%) and teachers (6.1%). Professional advice was first sought at 19–24 months of age in 127 (33.7%) cases and

Interaction between speech and language pathologists and multidisciplinary teams creates a pool of clinical assessments for informal detection of hearing impairment as speech and language pathologists appraise a vast range of communication impairments (21). Research in rehabilitation sciences is difficult in a developing country like Pakistan with a fragile healthcare system (22). It is a continuous process for rehabilitation professionals to cope with emerging research trends to cater to the increasing demands at individual as well as community level (23).

In this study, hearing impairment was noticed fairly in time that is, before 6 months of age in 35% of cases and at 13–18 months in another 14.3%. The first professionals from whom assistance was sought were audiologists in 44% of cases followed by paediatricians in 27.1%. However, there was late detection of hearing impairment at 19–24 months in 45.9% of cases and at

Socializing is a core component of human activity, and educating children with hearing impairment should also focus on this vital aspect of life. Hence, timely suspicion of hearing impairment, with prompt diagnosis and early intervention, positively affects socialization, including active involvement in festivities and religious activities. A 2002 review reported that children with hearing impairment are socially immature compared with children with normal hearing (25). Children with hearing impairment tend to interact more with other children that have hearing impairment rather than those with normal hearing. A South African study in 2011 revealed that children with hearing impairment who were engrossed in community and extracurricular activities had constructive social interactions (26).

In this study, 47.5% of children with hearing impairment experienced moderate challenges participating in community activities and 26% experienced severe challenges. Severity of hearing impairment, the person who suspected hearing impairment, age of detection, and when children were referred to another professional for further investigation, were all positively correlated with challenges to participating in community activities. At a global level, onset of hearing loss is projected to be the second major contributor to years lived with disability by 2050 (27).

In this study, 39% of children with hearing impairment caused moderate financial strain on their parents, and 26.8% caused mild strain. Severity of hearing impairment, first professional from whom advice was sought, when children were referred to another professional, and challenges joining community activities were positively correlated with financial strain on parents. Age of suspicion of hearing impairment, age of detection of hearing impairment, and when professional advice was sought were negatively correlated with financial strain on parents.

Professional failures can result in delayed diagnosis and fitting of amplification devices, in spite of suspecting hearing loss in the first 3 years of life (16). Lack of knowledge regarding the critical age of speech and language development and lack of rehabilitation facilities contribute to the delay in identification and rehabilitation of hearing impairment (18). Therefore, it is essential to improve awareness among mothers, as primary caregivers in Asian communities, of the importance of timely identification and intervention for hearing impairment (28).

Parents can be made to believe that their child does not have hearing impairment if the child has been subjected to a perfunctory testing regime that does not conform with internationally accepted norms of detection by neonatal hearing screening. For example, at age 2 days, some paediatricians resort to manual testing of children’s hearing by clapping or clicking their fingers. This can yield a false and misleading result, even for parents who suspect hearing impairment. Such children are deprived of the appropriate neonatal hearing screening, which invariably causes delay in rehabilitation and management of hearing impairment (5). Instead of the stepwise involvement of various professionals, the hearing impairment goes unnoticed. Subsequently, after the parents’ suspicion is heightened, the child is brought to the clinic or hospital and subjected to the requisite screening and hearing impairment testing. This sequence of events is common in the present healthcare system in Pakistan and emphasizes the lack of standardized neonatal hearing screening that needs to be addressed as a priority.

One limitation of our study was that the participants were not from all the provinces; therefore, the results cannot be generalized to the rest of Pakistan.

## Conclusion

Suspicion and identification of hearing impairment had a significant impact on children's participation in community activities, and caused financial burden for their parents. The challenges faced while participating in community activities were positively correlated with severity of hearing impairment, the person who suspected hearing impairment, age of detection of hearing impairment, and when the child was referred to another professional. Financial burden on parents and caregivers was positively correlated with severity of hearing impairment, first professional from whom advice was sought, when the child was referred to another professional, and participation in community activities. Financial burden was negatively correlated with age of suspicion of hearing impairment, age of detection of hearing impairment, and when professional advice was sought.

**Funding**: None

**Competing interests**: None declared.

## La déficience auditive et son impact sur les enfants et les parents au Pakistan

## Résumé

**Contexte** : La déficience auditive et ses conséquences chez les enfants sont souvent aggravées par une identification tardive au Pakistan. Les croyances culturelles profondément ancrées suscitent chez certains parents une réticence à rechercher un traitement clinique, d'où la nécessité de trouver des solutions adaptables qui prennent en compte les différents niveaux du modèle socio-écologique.

**Objectifs** : Déterminer l'impact de la déficience auditive sur la participation des enfants aux activités sociales et le fardeau financier qui pèse sur leurs parents.

**Méthodes** : La présente étude transversale incluait 377 parents d'enfants qui souffrent de déficience auditive. L'échantillon a été recruté dans des écoles d'éducation spécialisée et des hôpitaux à Islamabad et à Lahore (Pakistan) de novembre 2015 à avril 2016. Un questionnaire structuré comprenant 15 items a été employé pour la collecte de données. La version 21 du logiciel SPSS a été utilisée pour l'analyse statistique.

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**Résultats** : Parmi les enfants atteints de déficience auditive, 47,5 % ont rencontré des problèmes modérés concernant la participation aux activités sociales et 26,0 % ont été confrontés à des problèmes graves. Il y avait une corrélation positive significative avec la gravité de la déficience auditive, la personne qui a suspecté la déficience auditive, l'âge lors de la détection de cette dernière et la date de l'orientation médicale. Les enfants atteints de déficience auditive étaient une source de pression financière modérée pour 39,0 % des parents et faible pour 26,8 %.

**Conclusion** : La déficience auditive peut avoir un impact significatif sur la participation des enfants aux activités sociales et entraîner un fardeau financier pour leurs parents.

# ضعف السمع وأثره على الأطفال والآبا ء في باكستان

ناظيا ممتاز، غلام صقولين، محمد بابور

## الخلاصة

: يتفاقم ضعف السمع وما يترتب عليه من عواقب وخيمة يعاني منها الأطفال فيالخلفية
باكستان في كثير من الأحيان بسبب اكتشافه المتأخر . فالمعتقدات الثقافية الراسخة تدفع
بعض الآباء إلى الإحجام عن التماس العلاج السريري، الأمر الذي يستلزم إيجاد حلول يمكن
تطويعها بحيث تتجاوز كل مستويات النموذج الاجتماعي - الإيكولوجي السائد .

: هدفت هذه الدراسة الى تحديد أثر الاشتباه في الإصابة بضعف السمع واكتشافهاالأهداف
وتشخيصه على مشاركة الأطفال في الأنشطة المجتمعية، والعبء المالي الواقع على الآباء .

: شملت هذه الدراسة المقطعية 377 من آباء الأطفال الذين يعانون من ضعف السمع ,طرق البحث
واختيرت العينة من مدارس ومستشفيات التعليم الخاص في إسلام أباد ولاهور، باكستان، في
الفترة من نوفمبر / تشرين الثاني 2015 إلى أبريل / نيسان 2016. واستُخدم استبيان منظَّم
شمل 15 بندًا لجمع البيانات . واسْتُخدم كذلك الإصدار 21 من برمجية SPSS لإجراء
التحليل الإحصائي .

: من بين الأطفال الذين يعانون من ضعف السمع، واجه 47.5% مشكلات متوسطة الشدةالنتائ ج
فيما يتعلق بالانضمام إلى الأنشطة المجتمعية، بينما واجه 26.0% مشكلات جسيمة .

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وتبيَّنَ أيضًا وجود علاقة ارتباطية إيجابية مهمة بين مدى وخامة ضعف السمع، والشخص
المشتبه في الإصابة به، وسن الكشف عنه، وتوقيت الإحالة . ويتحمَّل 39.0% من الآباء
عبئًا ماليًّا متوسط الشدة جرَّاء إصابة أطفالهم بضعف السمع، بينما يتحمَّل 26.8%
منهم عبئًا ماليًّا خفيفًا .

: يترتَّب على الاشتباه في الإصابة بضعف السمع واكتشافه أثرٌ ملحوظ فيالاستنتاجات
التصدي للمشكلات التي يواجهها الأطفال أثناء انخراطهم في الأنشطة المجتمعية والعبء
المالي الواقع على آبائهم .

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