A High Risk Register for Hearing Loss in Children : A Feasibility Study on an Indian Population *

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The present study was an exploratory effort at developing a High Risk Register relevant to an Indian population. As different from other such efforts carried out elsewhere this investigation adopted an ex-*post-facto* approach aimed at arriving at a high risk register based on risk histories presented by the mothers of a group of deaf children as compared to histories presented by the mothers of a randomly selected group of non-deaf children. Thus, the study circumvented the need for not only screening of thousands of children at birth for high risk factors, but also, the need for follow-up evaluation of those classified as at risk.

The study was conducted in two parts. In Part I, a questionnaire incorporating all the risk factors suggested as possible risk indicators in Indian conditions was developed and was pretested on a small group of mothers. After due modifications, it was used to collect risk information on 369 randomly selected children. Data were collected by this investigator, a small group of trained volunteers and through a written questionnaire filled by mothers themselves. A small group of mothers were subjected to cross-questioning to answer the validity of their initial answers. Opinions of 10 teacher-mothers and volunteers were also considered. Results indicated that the questionnaire was feasible in the Indian context and the data collected through 3 different modes were similar on initial yes–no response screening on 21 main questions. Except on two questions the data samples did not differ much in terms of initial responses. In terms of efficacy, the questionnaire was found to be deficient, in that, it classified too many non-deaf children as at risk.

In Part II of the study, data on 83 confirmed deaf children were collected, and along with the randomly selected data collected in Part I of the study, were subjected to further and deeper analysis to rule out false risk answers. In addition, data were also subjected to further randomization by representing only one child from each mother in the sample. The total and the randomised samples were then subjected to cross-analysis to check the similarities and differences. Statistical computations were carried out on a computer.

Based on the results o the comparative analysis of deaf and non-deaf children

* Master's Dissertation, University of Mysore, 1981.

a list of discriminating questions was selected and were tried in various combinations to check their sensitivity and specificity. Finally a list of five questions was selected to make up a High Risk Register. The questions tackled the following factors :

1. Family History of hearing loss.
2. Consanguinous parentage, primarily involving uncle–niece marriages.
3. History of rashes and fever during pregnancy, irrespective of the trimester.
4. Report of Rh/blood group incompatibility.
5. Parental concern about their child's hearing.

Results indicated that by using this register at birth or soon after birth, one could classify 53·54% of deaf children along with 21·22% of non-deaf children as at risk. By applying the same register at 1 year of age, one could classify 75·72% of deaf children as at risk without any corresponding increase in the number of non-deaf children classified at risk.

Conclusions

1. It is feasible to collect information needed for high risk classification without relying on medical records.
2. It is feasible to develop a High Risk Register based on history presented by the mother at birth or at/before age 1.
3. This High Risk Register can select a small group of children to be followed up and catch most deaf children.

Implications

1. The data collected could be subjected to further analysis to examine whether one can improve the sensitivity and specificity of the questions and the register developed in the present study so that a still more efficient High Risk Register could be developed.
2. Using this approach, High Risk Registers for other disorders, which are not very apparent at birth or early infancy, like Mental Retardation, could be developed.
3. The register developed in this study can be implemented through maternity hospitals, post-partum care centres, well baby clinics and whoever who comes in contact with children soon after birth like vaccinators, auxiliary nurse-midwives, medical social workers and village level workers.

Limitations

1. This study was only an exploratory study and as such embodies all the hit-and-miss limitations of an exploratory study.
2. Precision of the data collected on deaf children may have been influenced by better education and more exposure to questions asked in this study.
3. The samples studied here may be basically those who actively make use of medical facilities.
4. Limitations of time and resources have reduced the scope of the present study.

Recommendations

1. The efficacy and utility of the register developed in this study can be tested on a larger population, on stratified samples and on captive populations.
2. The utilization of services of auxiliary nursing staff, medical social workers, and village level workers can be investigated.
3. Conditions associated with deafness may vary geographically. Hence, the possibility of developing different High Risk Registers suitable to different parts of the country could be examined.
4. The register developed in this study should be validated on a larger data and/or by adopting the conventional follow-up approach.

Postscript

A preliminary survey on deaf children by this investigator revealed that, while the mean age at first suspicion and the mean age at first medical consultation about the hearing loss were 1·37 years and 1·75 years respectively, the mean age at first diagnosis of hearing loss was 4·09 years. If not for anything, this High Risk Register could be used to close this gap and facilitate early referrals to Speech and Hearing Centres.