A HIGH RISK QUESTION NAIRE FOR HEARING LOSS IN CHILDREN - A FEASIBILITY STUDY ON AN INDIAN POPULATION.

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AN INDEPENDENT PROJECT SUBMITTED IN PART,
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to my father,
who sincerely believed that everything
he said to me was for my good

and

to the children of Bapuji Children's Home
who may or may not get someone
like him to say it to them.

CERTIFICATE

This is to certify that this independent project has been prepared under my supervision and guidance.

GUIDE.

CERTIFICATE

This is to certify that the Independent Project entitled "A HIGH RISK QUESTIONNAIRE FOR HEARING LOSS IN CHILDREN – A FEASIBILITY STUDY ON AN INDIAN POPULATION" is the bonafide work in part fulfillment for III Semester M. Sc., (Speech and Hearing), carrying 50 marks, of the Student with Register No.

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DECLARATION

This Independent Project is the result of my own study undertaken under the guidance of Mr. J. Dayalan Samuel, Lecturer in Audiology, All India Institute of Speech and Hearing, Mysore, and has not been submitted earlier at any University or Institution for any other Diploma or Degree.

Mysore.

Dated

Reg. No. 2

(ASHOK KUMAR)

I am indebted to

to all mothers,

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1.1 LANGUAGE, SPEECH AND HEARING

Language functions as a means of communicating information. Speech, the spoken form of language, is undeniably the most efficient means of communicating any kind of information, Speech is the birth right of every child.

Some have argued that language is learnt as a network of associations between a large number of stimulus and response conditions. Its acquisition follows the lines laid down by the laws of learning – through operant conditioning and reinforcement and generalization (Skinner, 1957). For them, the behavior theorists and structural linguists, it is learnt, like any other behavior (Quigley, 1977).

Opposing the above view point are the nativists or rationalists led by Chomsky (1957) who propound that language develppe as a result of and innate biological propensity. For them, its acquisition, is a maturational process of neurological structures (Lannaberg, 1967), which follows, what are called 'Language Universals' which are common to all human beings and languages (Quiglay. 1977).

Following a more or less middle-of—the-road approach are the cognitive theorists, of who Piaget is an early proponent. They emphasise the interaction between the biological predisposition to communicate information and the environment which provides the input and receives the output. For them, the development of language depends on the general cognitive development of the child. (Quigley, 1977).

Whether it develops as a result of innate capability or whether it is learnt or whether it is acquired along with general cognitive development, the acquisition or development of language is directly related to the kind and extent of sensory input the child receives. For speech, the input is and must be auditory (Schuell, 1974) and there must be plenty of it. Anything that interferes with the input severely geopardizes acquisition itself. The

functional patency and the intactness of the hearing mechanism is therefore a must.

1.2 EFFECT OF HEARING LOSS ON LANGUAGE DEVELOPMENT

Hearing loss can be considered as a generic term covering all degrees of disability. When measured and quantified, hearing loss can be considered as a continuum (Quigley, 1977). Somewhere along this continuum is a point wherein an individual ceases to communicate with the external world primarily through his ears and instead switches over to other sense organs. This point is however, influenced by several factors like the age of onset, general intellectual ability, etc. Specifically when it occurs early, before the development of language, its effect is devastating.

Thus, early hearing impairment has definite effects on language development and the effects seem closely related to the degree of impairment. Even very mild hearing loss are often related to language and educational deficits (Quigely and Thomas, 1968; Goetzinger, 1962; Harrisom, 1964). The language deficit, as a function of degree of hearing loss, is evident in all facets of language-phonological, syntactic and semantic (Quigley, 1977).

At some point however, the hearing impaired child passes from having language problems to having no language at all, unless intensive and specialized educational procedures are employed. This point, around perhaps 80 or 90 dB ISO (Quigley, 1977), which is again affected by various factors like intelligence, age of onset etc., takes the child to a different world – a world of sight only perhaps, where he will be called 'Deaf'. Atleast one in every thousand children born is deaf at birth (Carvell, 1978).

Aristotle was one of the first to suggest that instinct of language and speech did not exist in the deaf. Deaf children have been variously described as language deprived, seriously retarded in

language, and as essentially a linguistic (Scmitt, 1966; Moores, 1970; Dale, 1976), entirely dependent on formal education in acquiring language (Pinter and Patterson, 1916), unable to form association between an incident, a person or thing and its language symbol (Fitzgerald, 1961). Traditionally he is considered as linguistically deficient (Prutting and Skarakis, 1977).

Language deviations in hearing impaired children, and more so, the language development itself, is perhaps more related to the age of onset than the degree of hearing loss. Earlier the onset, more striking is the effect. This is but, logical, since it is in these early ages, perhaps from birth to two years, that conditions most conductive to language development like speech stimulation are optimally operating. Consequently, the longer the speech stimulation is delayed, the less efficient will be the language facility (Tervoort, 1964). Thus a child deafened at age 3 may continue to build on his already acquired language base, as did Helan Keller (a striking example for the fact that she was blind also). A child born deaf and who is afforded most intensive educational efforts beginning at age 3 would have serious problems even to master the basics of language. Consequently, older the child when the hearing loss is detected the greater will be the social, educational and psychological disadvantages (Mencher et al., 1978).

The child with a hearing loss is an exceptional child. He needs our urgent attention. The impact of hearing loss on him, his family and society is devastating, especially when he sufferes it before the acquires the basics of language. It is thus imperative for all of us, especially in the field of human communication, to recognize the importance of early identification of a hearing loss, be it of any degree. The sense or urgency can perhaps be underscored by a quotation by Bernad Z.Friedlander from his 1975 book, the
Exceptional Infant :

> "Systematic early identification of children who are known to suffer developmental disability, or who have a high risk of doing so, is potentially the most powerful means at hard for reducting the impact of exceptionality-on the individual child, on the family, and on the community and society at large".

1.3 IMPERATIVES OF EARLY IDENTIFICATION

First all, it is imperative to define "Early". If we accept the premise that the development of language begins at birth-with the child's first cry, or atleast accept Menyuk's (1977) proposition that babbling period enables the child to make both perceptual and productive categorization of the speech signal which may be crucial for later language development, then "Early" turns out to be very early indeed. Downs (1978) puts it more emphatically "It is important to identify hearing loss by 3 months of age". But, Mencher (1980) goes further: "When we say early identification we mean at birth; when we say early diagnosis, we mean within the first few weeks and when we say early management, we mean as early as possible in life, even beginning within the first month. Infact .... if he is over 3 months of age-he is a geriatric".

The following discussion will enunciate the imperativeness of early identification in more detail with reference to various aspects, problems, findings and contradictions to the concept of early identification.

1.3.1 The concept of 'Critical Period'

The concept of critical period is basically an offshoot of the demonstration of "Imprinting" behavior in birds by and more specifically, the 1963 Hubel and Weisel study on the devastating effects of sensory deprivation on the visual system of Kittens (Davis, 1978). It arose in this particular context-the hearing loss, because of a generally marked and universally acknowledged discrepancy between the verbal linguistic abilities

of the normally hearing child who has spontaneously acquired language and the deaf child who has had to learn it, or to be more precise, who had to be taught to acquire language. There is also a similar discrepancy between the linguistic abilities of pre-lingually hearing impaired child and the post-lingually impaired deaf child (Bench, 1978).

It has been argued that deprivation of auditory experiences during early life has long lasting deleterious effects on the subsequent hearing skills and the development of speech and language (Tervoort, 1964; Lennebar, 1967, Downs, 1976). Northern and Downs (1974) even specified that the first 2 years of life as the "Critical period" for the development of linguistic abilities. Downs (1974) emphasised that "there must be bountiful intake of sensory material in the first 2 years of the child's life if he is to attain his potential function". Menyuk (1977) maintained that there are critical years as demonstrated by the great progress in language development made during the very early years. Lanneberg (1967) referred to the biological timelocked function of the language learning that can never be regained once its time has passed.

The concept of critical period has however, come under severe criticism, notably by Bench (1971; 1978). Bench noted that while all reliable work in this area has been on animals, the human experiments – the "natural experiments" on ghetto children, malnourished children and socially isolated and deprived children like Genis, have serious experimental and procedural flaws that render unequivocal interpretation impossible. High lighting the absolutism of the term and concept 'Critical' he suggested the use of an altered concept of "vulnerable period" which has more heuristic value and better utility (Bench, 1978).

Avoiding the term "Critical" altogether, Koepal and Felsenfeld (1977) in their recent review of data on sensory deprivation noted that "while the normal hearing child (or adult) is continually

Interacting with his environment and receiving an abundance of novel sensory input, the hearing handicapped child is very often left in a state of relative social isolation which in turn has the potential of interrupting his reception of sensory information" defining "Sensory Deprivation " as the "period of time when an organism experiences an absence of sensory stimulation" they noted that a deaf child is said to experience sensory deprivation as a consequence of (1) experiencing less total stimulation than a hearing person, and/or (2) experiencing less variety of stimulation since certain sound intensities and frequencies are unavailable as a source of novelty.

Experiments reviewed by them and also Kyle (1980) reveal that language problem may arise in deafness not because of poor education, but because we have failed to appreciate the importance of auditory deprivation to higher level (cortical) processing. It also suggests that fairly high levels of sensory input appear to be necessary for normal neurological development and any deprivation imposed on the organism seem to result in the organism's attempts to replace that input with another form of sensory input. These findings have particular implication to early identification. Through remediation of impairment of through amplification the severe permanent consequences of deprivation can be prevented. Early detection offers the possibility, perhaps the only possibility for early remediation of such consequences (Koegel and Felsenfeld, 1977.

1.3.2 Effects of Early Intervention

The numerous advantages provided by early intervention like early use of amplification, continued audiological management, training in language and communication skills and parent conselling are well recognized (Bess et al, 1976). It is not only enhances the opportunities to develop adequate speech and language but also benefits the educational and social development (Horton and Sitton, 1970; Seestedt, 1974).

Heber and Garner (1970) compared two groups of babies of mothers with low IQs and found that early stimulation program starting at birth made as such a difference as 30 IQ points by the age of 2 years with the difference increasing till the age of 4 years. The results of Head start program (Edwards, 1968) indicated that programs that began after the age 3 failed to produce permanent educational achievement gains in socially deprived children whose early life was linguistically deficient. So it is quite probable that in Heber and Garner's study even intense intervention after the age of two would not have closed the gap between the two groups (Downs, 1978).

The Lexington study by Greenstain et al., (1976) compared two groups of deaf children with various measures of speech and language skills over a period ending at 40 months of age. One group had been identified and started on program before the age of 16 months and the other whose hearing loss was not detected not training begun till after the age of 16 months. They found that the before-16 months group were significantly superior in speech and language skills than the after-16 months group. More interestingly deaf children of deaf parents proficient in sign language, who presumably had exposure to sign language before the age of 16 months were the highest in both speech and language measures. Thus even early exposure to signing appeared to give children better strategies for learning speech and language (Downs, 1978).

Another study by McConnel and Horton (1970) investigated on whether given the advantage of early intervention deaf children would develop better speech comprehension skills, if so, which types of intervention would be most suitable. They selected 72 subjects b/w 10 and 18 years and grouped them into 4 groups which were dichotomized according to whether parents were deaf or normal hearing. The four groups were children of (1) Deaf parents using manual English, (2) Deaf parents who had used some form of Ameslan (American Sign Language) with their deaf children during infancy

and early childhood, (3) Normal parents who had provided an average oral education for their children. Results on Test of Syntactic manual group scored highest followed by average manual, intensive oral and average oral groups (Quigley, 1977). However, it is not clear what "early childhood" meant, specially with the intensive oral groups. But still it underscores the importance of early intervention.

Green (1976) discussed factors contributing to the pattern of behavior among hearing impaired persons educated in hearing environments and whose personality patterns were like those of normal hearing persons. She noted that early identification, early use of amplification, early intensive training with emphasis on residual hearing, early parental counseling and involvement and early start in hearing rehabilitation as contributing factors.

It has been said that "Education of all children begins at birth". They why should the deaf child's education bedelayed? An early and good start in life is his right (Mencher et al. 1980). The first step in making early education possible is, but naturally, the early identification.

1.3.3 Parental and Family Involvement

The role of parental and family involvement in effective management cannot be overstressed. As seen in many of the studies quoted above (Heber and Garner, 1970; Green, 1976 and Quigley, 1977) parents form the backbone of many a successful program. The following discussion on two recent studies will further emphasise the role of early parental involvement.

Backer (1976) analyzing the personality characteristics of parents of deaf children who detected the handicap early and who did it late, proposed that "in addition to being desirable for the child's development, early detection... also helps the parents to

Adjust more realistically to the hearing loss and its implication for the functioning of the family". She also noted that "early detecting parents who had identified the impairment and adopted to the child training appropriate to the child early will be better equipped to handle future decision and expectation for the child and will provide the child with a more effective model for solving his own problems".

Stedman (1977) on a comprehensive review of early educational programs for high risk children uncovered the following two important findings relavent to the parents : (1) There is evidence that the affect of early intervention programs are significantly strengthened by involvement of the child's parents, and, (2) the family's method of establishing social rules leaves little doubt that family environment (parental language, styles, involvement and concern) has a significant impact on the child's development before he reaches his second birthday. She concluded that "the truth is that right kinds of early intervention will help parents remain in control of the future of their handicapped children".

1.3.4 Economic Gains

Over the past few years considerable attention has been turned to screening children for conditions, which include among others those which affect the ability of a person to learn or earn a living. It is for this latter reason that tests for hearing loss have been consistently included in screening procedures (Gerkin, 1977).

Perhaps the most telling justification for early identification comes from the area of economics (Downs, 1978). Citing a National Association for the Deaf study, Downs (1978) noted that when deafness occurs after the development of language, say at age six or even age three, the earning power of the individual is markedly higher than when it occurs at birth. Thus, there is a direct relationship between the age of occurrence of deafness and the degree of language skills that make an individual occupationally productive. She concluded that

early identification and training would bring the congenially deaf on per with those in whom deafness occur later, bringing about an increased manpower productivity.

Downs (1976) estimated that United States incurred a loss of 1.75 billion dollars per year in man hours lost and in educational and training programs of nearly 3.8 million deaf individuals whose needs varied from special training programs to clinical services. She concluded that "The real essence of the problem probably lies in the immeasurability of the handicap … There is no numbers … no billions of dollars… that can express this loss of fulfillment in life".

The only alleviation to the problems is early identification. Gerber (1974) aptly expressed the need "There is no age which is too young for diagnosis and there is no time too soon for habilitation. Economic cost to you as tax payer of finding and habilitating one deaf infant is substantially less than the cost of not doing so. The humanitarian cost is immeasurable".

1.3.5 **Contrary Views : Is Early Identification really beneficial?**

Implicit in the dissonance to the sense of urgency in early identification are two view points. One highlights the negative aspects of mass screening procedures and the other actually maintains that early identification can be damaging to the hearing impaired child. The former view point as expressed by many, notably Goldstein and Tait (1971) will be discussed a little later (See 1.5.3).

Bench (1978), perhaps the only and the most vocal of those holding the latter view point quotes Williams (1970)'s study on maladjusted children to support his views. Williams studied an original group of 51 deaf children aged 5-14 years (mean 10 years) with severe to profound hearing losses. Excluding children with late acquired deafness, Williams found that early diagnosis of deafness was associated with a much lower incidence of speech than when the diagnosis was delayed until after the age of 2 years.

The results seemed at first improbable which made him to review the data. This time, excluding educationally subnormal and psychotic children, he found that failure of early diagnosis was even more marked. Williams considered three reasons for the results, viz.,

(1) the earlier diagnoised group could have had a high proportion of children with central disorders of speech and language. But, he offered no evidence to support this (Bench, 1978).
(2) Some of the earlier diagnosed may have been fitted with unsuitable hearing aids (Bench however noted that this made no difference since most aids have rather similar frequency responses).
(3) Early diagnosis which is not followed by appropriate rehabilitative and counseling may lead to parental in decision which deprives the child of "affection unhampered by anxiety".

Significantly, however, Bench concluded " … in the light of William's disturbing findings we should be prepared to consider whether early diagnosis with provision of a hearing aid may be harmful without demonstratably adequate counseling and guidance for the deaf child (emphasis added). He called for well designed studies that meet the requirement of this adequacy before concentrating on early diagnosis.

1.3.5 Implications

The above discussion makes it imperative for us, specially audiologists to take up the challenge to identify a child with hearing loss at the earliest possible time. There are two possibilities: One to test and evaluate every child born thoroughly, which by its sheet weight is not possible; or two, to screen all children or atleast a selected population of children whenever and wherever they are accessible soon after birth.

1.4 THE SCREENING MEHTOD

Screening as accepted by World Health Organisation (WHO) is defined as "the presumptive recognition of unrecognized disease of defects by the application of tests, examinations and other procedures which can be applied rapidly" (Roberts, 1977). Screening tests sort out apparently well persons who probably do not have a disease from those who probably do have the disease. They are not intended to be diagnostic. Persons with positive or suspicious findings must be referred to specialists for diagnosis and necessary treatment (Wilson and Lungner, 1968).

1.4.1 Types of screening

There are five types of screening which can be employed (modified from Roberts, 1977) Viz.,

i) Mass Screening : Where an entire population may be screened by mass screening techniques. E,g. newborn screening for Phanyl Keto nuria disease (PKU).

ii) Selective or Prescriptive Screening : Which can be applied to a given group of people who are more suspect than the general population e.g., screening of only Jewish population for Tay Sach's disease.

iii) Multiple Screening : Which extends the number of screening measures used on a given individual from the two or three used in multiple screening to a battery of as many as ten screening tests.

iv) Surveillence : Used to periodically follow an individual or a group and to moniter their present state of well being.

All but multiphasic screening are in use in newborn screening.

1.4.2 Screening Criteria

Public Health experts have fixed certain criteria for a successful screening program (Frakenberg, 1971 and 1973). They are :

i) Occurrence of the condition frequent enough or consequence serious enough to warrant screening.

ii) Ameniability to treatment or prevention that will forestall or change the expected outcome.

iii) Availability of facilities for diagnosis, follow up and treatment, and referral.

iv) Cost of screening reasonably commensurate with benefits to the individual.

v) A screening tool or test that validity differentiates a disease from Don disease.

vi) Acceptable to the public.

Frankenberg (1971) also prescribes the following specific criteria for an efficient screening tool :

i) Sensitivity : accuracy in correctly differentiating an individual with the disease from the general population.

ii) Specificity : accuracy in correctly differentiating the individual without the disease from those having it.

iii) Standardization : The test should be well established as compared with a standard – either another test or a diagnostic test.

iv) Validity : it should measure what it is supposed to measure.

v) Reliability : screening results should be consistent each time the tool is used.

vi) Acceptability : to the patient, the family, society and the tester.

vii) Its cost should be reasonable.

There are also certain factors that one has to consider in a screening program (Roberts, 1977): screener's skills, population to be screened, the cost, the time factor for the screener, the patient, and the family, screening place, where and whom to refer failures or suspects and so on.

Considering all these, hearing, screening, in its present state-of-the-art meets all these criteria at every level-newborn level, pre-school age level and school-age level. It also meets specific goals – goals that are different for each level (Downs, 1978).

1.4.3 Principles of a Hearing Screening Test

For a hearing screening program to be effective, it must evolve from a sound set of basic principles, strive toward adequate goals, and be applicable to the situation it serves (Mencher, 1977). The following set of principles and/or goals are given by Darley (1961) and Mencher (1977).

1) The fundamental concern is the maintenance of an optimum state of health.

2) The ultimate goal is conservation of human resources or the optimum functioning of the individual, acceptance by his pears and maximum use of his skills, regardless of severity of the hearing handicap.

3) Need to be established on the broadest possible base to reach the largest possible number of children.

4) A compromise with the ideal program of hearing evaluation.

5) It is not an and in itself nor does it stand alone. Proper referrals must be made when and where needed.

6) It will not be effective unless high standards are established, implemented and maintained. It cannot be expected to give 100% identification. False positives and false negatives are part of the picture and are to be expected… Without them the procedure is not screening.

7) A longitudinal approach to hearing screening is needed. The ideal is to conduct a reliable test as early in life as possible and to provide follow up screenings.

8) Ongoing hearing screening programs not only identify disorders but also awaken awareness and interest on the part of the citizens in the prevention and treatment of hearing losses.

9) They can alert communities as to future needs, how to utilize existing resources, the personal services and facilities needed.

10) Money spent for the prevention of hearing loss or early identification and treatment of a problem is money and time saved.

11) Description and implementation of an ideal screening program is not an end to the process, extensive research must continue to investigate "why", "how often", and "in whom" hearing impairment occurs and what can be done about it.

12) Hearing screening programs are not the single province of otology, paediatrics, public health nursing or audiology. While one of these disciplines must coordinate at any given site under any given circumstances, the process must be a joint effort of sister professions with appropriate referral and ultimate management predicted on the etiology, prognosis and types of treatment required.

It is tall list of what-to-do's and what-also-to-do's. But it emphasizes the immensity of the problem of early identification.

1.5 SCREENING NEWBORNS FOR HEARING LOSS

1.5.1 Epidemiology of Hearing Loss

While the true incidence of severe hearing impairments is about one in 1,000 births, it is Likely that some measurable loss occurs in 1 infant in every 200 born. Moreover, many children develop hearing loss in early childhood due to disease or to degenerative processes. Thus the true incidence of hearing loss is probably higher than most of us would have anticipated (Carrel, 1977).

Since the 1931 census we have had no dependable incidence figures in India. However, the National Sample survey of India in their 16^{th} round undertook a small survey and noted that there are 124 deaf persons per 100,000 people (Advani, 1967). This means that there are nearly, 7,50,000 deaf persons in India at present. Perhaps, they actually number more than a million. We can also infer from a gross estimation, that every year nearly 25,000 deaf children are born in India.

1.5.2 Early Mass Screening Studies

In 1964 Downs and Sterritt described a hearing screening method based on observing behavioral changes in the newborn in response to a 90 or 100 dB signal (whine noise and/or narrow band noise). In 1965, Downs noted “experience in observing auditory behavior of over 5000 newborn infants leads us to believe that it is feasible to screen for peripheral hearing deficits at birth. In 1969, Downs and Hemenway reported the results of their screening program involving 17,000 newborns. They found that they could identify 1 deaf child in every 1000 newborns.

Though their techniques were sound in principle, their specific testing procedures were not as sensitive as intended (Gerber, 1971). As a result those who did not understand the preliminary nature of the project instituted their own newborn screening programs. Data published subsequently showed that they could detect anywhere from one deaf infant in 1000 to none in 14,000 in all, out of 61,000 babies of incidence of 1 in 2800 was reported (Downs, 1971).

These screening procedures did not prove to be very accurate. There were too many misses and false hits. Also, the low morbidity of hearing loss, very high false positive rate (usually in the order of 12 to 20%) made the cost of screening too high for general use (Davins, 1978). Some of the later projects also had limited successes. Boardley and Hardy (1972) screened 1182 newborns and found that his program misses 98% of the true positives. Shapiro (1974) screened another 4000 newborns and could not find any baby with a confirmed hearing loss (he was unable to follow up most of his hearing test failures). Nikam and Dharmaraj (1971) screened 941 infants and found that their test failed 31.2% of them. They too faced the problem of follow up.

1.5.3 Critics of Mass Screening

Before presenting the critical review of the newborn screening its positive aspects first need mentioning. Goldstein and Tait (1971) list the following advantages :

1) Routine screening in a hospital is desirable because it is the only situation or time when all babies (except those born outside the hospital facilities) are available for testing.

2) It provides an opportunity to discover the few deaf infants who might have escaped detection at birth solely on the basis of suspicion.

3) It may provide information regarding adequacy of hearing at birth in children who may later lose their hearing.

4) It may provide information regarding adequacy of hearing at birth in children who may later lose their hearing.

5) It can help alert the physician to the presence of a more general or more pervasive of auditory responsivity.

6) It could, if carefully controlled, provide valuable information about normal development of auditory responsivity.

7) Provide an important stimulus to the physican, and particularly, pediatrician to become more conscious of, and, knowledgeable in auditory disorders in children.

8) The cost of screening can counterbalance cost of training one deaf child (Downs, 1967).

Criticisms against newborn screening can be better appreciated if we first understand what criteria are used in judging the efficacy of such a program. Redell and Calvert (1969) list four important criteria.

i) It should be valid in identifying a high proportion of those with significant hearing loss.

ii) It should be efficient in screening out those with no significant hearing loss.

iii) It should be expensive in cost and staff time, and

iv) It should be applicable to a wide variety of prestimulatory conditions.

The criticisms against newborn screening have come mainly from Goldstein and Tait (1971), Eisenberg (1971), Ling (1976) and also Downs and Sterritt (1967). However, the most comprehensive of all is the review by Goldstein and Tait (1971) who discussed them under four headings.

A. **Magnitude of the problem** : They argue that the magnitude of the problem is not at all that bleak. Most deaf children are seen before the age of 2 and that it is improper to blame the parents and physicians for it since the onset may be delayed one. They also point out that such delayed onset cases are most likely missed by a newborn screen. They also feel that 90 to 100 dB level of test signal may be more and that unilateral hearing loss cases are not detected though they may have listening problems. They also point out the dangers of misdiagnosis and subsequent mismanagement of the child which may further compound the difficulty.

B. **Effectiveness of Screening Procedures** : They point to the fact that Downs and Hemenway could detect only 4 deaf out of 10,000 and the high false positive rate (150 initially suspected). They feel that rapid testing often resorted to allows no room for unclothing the baby besides reducing its reliability.

C. **Effectiveness of Follow up procedures** : They feel that clear answers to various questions concerning follow up procedures are not apparent and that they maintain that routine neonatal screening as proposed can lead to parental and professional confusion and to mismanagement.

D. **Limitations of Emotional Appeal :** They question the validity of various arguments and appeal for encouraging neonatal screening. They argue that concern may lead to unnatural treatment

of the deaf child and that parental interest and involvement cannot be taken for granted. Arguing about economic aspects, they feel that one year gained by early identification can be useless (unless that one year gained makes a qualitatively important difference to the child) unless it eliminates atleast two years of special education at a later date and that evidence to support this is not available. They also point out that cost of screening is not really negligible as claimed.

Arguing that comparison to PKU is not justificable since it is a reversible process whereas deafness is not, they point out that no follow up studies have been done to confirm the expectations and benefits claimed. Finally, they quota Downs herself, who felt that original enthusiasm about the effectiveness of the screening had not been justified (Downs, 1970).

Eisenberg (1971), however, points out that newborn is not a suitable subject for volunteers or other untrained personal because the newborn hearing is a function of CNS maturity. She points the inbuilt danger of felacy in pass-or-fail procedure. She also points out that such a inflexible test can say nothing about the integrity of the 8^{th} nerve or any other system. She emphasizes the lack of basic research as its glaring drawback.

Thus in the face of proliferating newborn screening programs, the poor showing, and wening consensus on the usefulness of the screening itself, a need for joint control and co-ordination of screening procedures was realized. The result was the appointment of a National Joint Committee on newborn hearing screening whose main objective was to control and guide the research in this field. This perhaps changed the whole outlook of newborn hearing screening.

1.6 THE PRESENT STATE-OF-THE-ART

1.6.1 Recommended Screening Procedures

The Joint Committee reviewed the results of various programs and sought to halt all the mass screening programs. Following a

Conference on newborn hearing screening held in San Francisco in 1971, it putforth a set of recommendations. In affect, it recommended selective screening of those babies who may have a greater risk of developing a hearing handicap.

The recommended program attacks the problem of identification from three aspects : (1) The application of a high risk register of all those babies at risk of having or developing a hearing loss at birth or any time thereafter, (2) Application of behavioral screening method or test, if perfected, as a supplement to the high risk register, and (3) Follow up screening of all those infants in the high risk register.

In the present state-of-the-art, the high risk register is very well established, well supported by research data, and recognized as being affective in identifying approximately 65 to 70% of those born deaf (Mencher, 1976, Northern and Downs, 1974). In addition, a protocol for behavioral screening has also been evolved. Behavioral screening recommended is either an Arousal Test (Mencher, 1974) or a semi-objective mechanical procedure like the Crib-o-gram (Simmons and Russ, 1974; Simmons, 1976). However, both these methods are recommended only as a supplement to the high risk register. When children failing a behavioral test is added, the sensitivity of HRR increases to nearly 80% (Mencher, 1977).

1.6.2 **Hearing Screening as a Health Screening Program**

Hearing screening program has proved to be one of the most acceptable procedures in a multitude of health detection programs. For all periods of life, hearing screening techniques have been standardized that give higher yields and show greater validity then most health related identification programs (Downs, 1978). The comparison of the yields of various newborns screening programs in Table illustrates the relative status of hearing screening.

TABLE

Yield in Screening Results.

(Modified from Downs, 1978).

Disease screened	Yield	Approximate incidence
Phenyl Ketenuria (PKU)	1 in 50,000 births	1 in 15,000 births
Combined Immnodeficiency	25 in 3 million "	25 in 3 million "
Maple Syrup Urine Disease	1 in 300,000 "	1 in 300,000 "
Neonatal hypothyraoidism	1 in 6000 " "	1 in 6000 " "
Neonatal hearing screening (high risk register)	1 in 750 births	1 in 750 births "

Furthermore, hearing screening emerges with highest ratings, when it comes to criteria for acceptable meeting of goals. Once the problem is identified it is more productive than screening for PKU in which case early intervention may not completely alleviate the retardation. In fact, if the child is falsely identified as having PKU and treated, serious problems can result. Only in Maple Syrup disease and in hearing problems are the results certainly advantageous and the treatment non-harmful if properly applied (Downs, 1978).

1.7 THE HIGH RISK REGISTER

The concept of high risk register was introduced to newborn hearing screening by a pediatrician, Dr. Janet Hardy. The concept utilizes history and /or evidence of physical abnormality to anticipate the likelihood for a hearing loss to occur or develop in any given child. Its basic assumption is that deafness has a suggestive history or is accompanied by other demonstratable abnormalities. Thus any child who has a suggestive history by his physical appearance suggests an abnormality, is at a risk. He is a High Risk Infant.

In Hardy's concept a HRR is an idea of registering every baby who is at risk, and carrying out systematic follow up every few months. Thus, it is a list of infants at risk. For the purposes of screening the concept assumes that "one can identify a small group of children whose history or physical condition identifies them as possessing a high chance of having the handicap searched for (Downs, 1978).

In the course of time, however, HRR has assumed another meaning (Devis, 1978). The second meaning is the list of conditions that places the infant at risk. In case of hearing loss, there are a large number of factors that have been associated with the handicap. However, some through studies have shown that the greatest number of hearing impaired children fall into only five or six categories of risk (The National Joint Committee has endorsed only these conditions for an effective HRR (Gerber and Menchar, 1978). Presently the HRR consists of

A. History of childhood hereditary impairment.
B. Rubella or other non-bacterial intrauterine fetal infections (Cytomegalovirus infection, herpes infection).
C. Defects of ear, nose, throat: malformed, low set or absent pinnes cleft lip of palate (including submucous cleft) any residual abnormality of the otorhinolaryngeal system.
D. Birthweight less than 1500 grams.
E. Bilirubin level greater than 20 mg./100 ml. serum.
F. Significant Asphyxia associated with Acidosis.

The High Risk Register should not be exhaustive, if it is to be effective. Longer the list Higher will be the follow up population and consequently less efficient it will be. Though a longer list can identify a higher number of deaf children it will enhance the cost and workload for the subsequent follow up work.

According to public health specialists a HRR, to be effective, must have a prevalence of the condition 14 times greater then that found in the general population (Richards and Roberts, 1967). Some

of the programs (See Chapter-2) have found a prevalence of one in 40 as compared with one in 700 in the general population, easily 14 times greater. Thus the yield makes it a statistically acceptable approach (Downs, 1978).

Generally the implementation of a HRR requires some one to collect information required for high risk classification from various sources like hospital records, oral or written interview of the mother, physical observation of the child, etc. Such risk information is then classified and those children categorized as at risk are followed up after a behavioral test or without it. In various places it has been conducted through trained volunteers and/or through public agencies and/or through private or community agencies (Downs, 1978).

1.8 **OBJECTIVES OF THIS PROJECT**

Functionally, information required for high risk categorization comes from three sources : History, Medical records and physical observation or examination of the child either by an investigator or a physician. Historic information is collected from the mother by a querry, mostly about family history and rubella exposure. Rest of the information is gathered from the hospital records. Thus in most newborn screening programs conducted elsewhere (See Chapter-2) medical records form the chief source of risk information.

Conditions in our country are very different. Only 5 to 10% of deliveries in India are medically supervised, mostly in big hospitals confined to cities and townships. Even in these hospitals there barely exists any system of maintaining detailed case records on every birth. In many primary health centres babies are not even weighed. Laboratory facilities for even routine blood investigations are scarce. Clearly, we cannot depend on medical records for obtaining risk information in India.

Thus we are left with only one source – History, as given by the mother. History is potentially a very important source. Most Physicians in India agree that history forms a very important source of information for a functional diagnosis (Shetty, 1980). Moreover, most physical abnormalities found at birth associated with deafness are quite evident even to a laymen. Thus the mother can very well report these abnormalities. As far other conditions like maternal infections, asphysia and conditions resulting in the accumulation of bilirubin at birth make themselves evident through their own symptoms and signs. Hence, it is quite probable that the mother can relate these signs and symptoms reliably, as she does to a Physician.

Thus it appears that the mother could be the only source of dependable if not accurate information. But, the validity of relying solely on the mother as the source of risk information is open for investigation. This study is only a beginning of such an investigation.

First, since we have to rely on the mothers report as to what she had seen or suffered, or on how much she knows and remembers, we have to devise ways and means of eliciting the required information from her. Hence, this project aims at constructing and validating a simple questionnaire which can be administered to the mother either as an interview schedule or as a written questionnaire. Specifically, this project aims at testing the feasibility of the questionnaire itself. The following are the specific objectives of this Project.

1.8.1 **Specific Objectives**

1) To compile a list of high risk factors considered to be more applicable to conditions prevalent in India.

2) To construct a questionnaire based on the above, which can be used to elicit risk information from the mothers.

3) To investigate the possibilities and problems encountered in the data collection through oral and written questionnaire.

4) To investigate whether one can use volunteers to collect risk information.

5) To see if there are any significant difference between risk information obtained through Investigator interview, volunteer interview and written Questionnaire.

6) To see if there are any significant differences between risk information obtained between Investigator and volunteer samples, investigator interview and written questionnaire samples and volunteer interview and written questionnaire samples.

7) To test the validity of the questionnaire. More specifically,

   i) to know if the mothers can understand the questions and their concepts.
   ii) to see if the questions elicit desired responses.
   iii) to see if the questions are acceptable or if they carry any social overtones.

8) To see if the questionnaire needs modification.

1.8.2 **Null Hypotheses**

Three null hypotheses were framed. Viz.,

1) There is no significant difference, in terms of risk-no risk responses obtained between all three samples of data and between Investigator Interview and volunteer interview samples, and between Investigator Interview and written questionnaire samples, and between Volunteer Interview and written questionnaire samples of data.

2) There is no significant difference, in terms of risk-no risk responses obtained through each of the chosen questions between all three samples.

3) There is no significant difference, in terms of risk-no risk responses obtained through each of the chosen questions, between Investigator and volunteer interview samples, between Investigator interview and written questionnaire samples and between Volunteer interview and written Questionnaire samples.

1.10 INTRODUCTION TO METHODOLOGY ADOPTED

A list of High Risk factors were compiled from literature, authorities active in the field and local medical and allied specialists. A review of the High Risk Programs and factors appears in Chapter-2 and 3 respectively.

Based on these factors a preliminary questionnaire was developed and pretested on 10 mothers. Taking the results of the pretest into consideration the project questionnaire was developed, to be used as an Interview Schedule. A written questionnaire was also developed based on the schedule, which was so designed as to enable a high school enrolled or passed mother to answer it. A data recording sheet designed for speedy recording of responses was also developed. A review of and the discussion on the questionnaire development in Chapter-4.

Mothers attending the local Medical College Hospital for women and children and a Municipal Primary Health Center were interviewed by the investigator. Data was also collected through the written questionnaire given to the mothers there. A group of trained volunteers also collected the data from around the localities they lived in. Thus they formed 3 groups of data.

The validity of the questionnaire was tested by Cross checking the answers of 20 mothers (within the Investigator interview group) to know if they understood the questions, concepts and of there were any changed responses as a result of education. A small group of teacher-mothers and volunteers were querried about the social acceptability of the questions.

The data collected and the responses obtained were subjected to statistical analysis to test the null hypotheses. Chapter-5 describe the Methodology while Chapter-6 discusses the Results. Summary and Conclusions follow in Chapter-7.

CHAPTER-2

REVIEW OF HIGH RISK PROGRAMS

2.1 The Toronto Conference, 1964 : The Beginnings of HR concept.

2.2 Early projects.

- 2.2.1 The Haifa Study.
- 2.2.2 The Jerusalem Study.
- 2.2.3 The Nebraska Neonatala Project.
- 2.2.4 The Elke – Purple project.
- 2.2.5 The Newzeland projects.
- 2.2.6 Their outcome and shortcomings.

2.3 The National Joint Committee (NJC) on Early Identification.

2.4 The Nova Scotia Conference, 1974.

2.5 Later Projects.

- 2.5.1 The University of Colorado Screening Project.
- 2.5.2 The Halifax project.
- 2.5.3 The Utah High Risk Program.

2.6 The Saskatoon Conference, 1978.

2.7 Current Projects Underway.

- 2.7.1 The Utah statewide. Infant HR Hg. Program.
- 2.7.2 The Colorado HRR-BER program.

2.8 Proposed Projects

- 2.8.1 The Taxes proposal.
- 2.8.2 The Massachusettes plan.
- 2.8.3 The Santa Barbara plan.

2.9 HRR as an Adjunct Behavioral screening and Research Projects.

2.10 The outcome and shortcomings.

2.11 The outlook.

2.1 THE TORONTO CONFERENCE, 1964 : THE BEGINNINGS OF HIGH RISK CONCEPT

It was during the Toronto Conference on the "Identification and Management of the Young Deaf Child" that the concept of "picking up children at risk" of hearing impairment and to test them soon after birth was introduced. During the discussions, Dr. Fabritus of Norway mentioned of a new birth registration form which was about to be introduced in his country that could make possible such a procedure.

During the same conference Dr. Janet Hardy, a pediatrician pointed out that most of the cases of impaired hearing are found in particular groups of children who can be identified in advance on the basis of family background, the mother's pregnancy, conditions of delivery and events of immediate post natal period. The High Risk concept was well received and subsequently the panel recommended in effect, that

> "A high risk register should be instituted listing those babies with a substantially higher risk than those in the general population and they should be followed closely and tested frequently during the first two years".

It was also pointed out that success of such a program will depend on the education of the physician, public health personal and above all, the parents. Active involvement of pediatricians and obstratians, among other specialists was sought (Davis, 1964).

However, there has been a few efforts to mass screen children for hearing loss before. The John Hopkin's Collaborative screening project screened nearly 4000 babies, but the results were disappointing. (Hardy, 1974). Meanwhile, the 1964 rubella epidemic in the United States gave a spurt to many mass screening programs through-out that country. Unfortunately, many of these studies overlooked the Toronto Conference recommendations and ultimately were found passing some hard of hearing children (false negatives) and failing a significant number of normal children (false positives), (Gerber, 1971).

This trend continued despite the findings of many studies. Downs (1968) recommended that only high risk babies should be screened. Eisenberg, Coursin and Rupp (1966) and Feld et al (1967) had noted that differential responses can be observed if the newborns could be categorized on the basis of risk. The fact that most of such programs were unco-ordinated made the matter more murky.

Finally, as a result of proliferation of such programs the American Speech and Hearing Association invited the American Academy of Opthologists and Otolaryngologists and the American, Academy of Pediatrics to form a National Joint Committee (hereonwards abbreviated as NJC) on Infant Hearing Screening [1] in 1969. The Committee formed in 1970 and chaired by Marion Downs, was critical of testing programs at that time and sought to halt such unco-ordinated projects. It formulated some guidelines after a through review of available data.

Subsequently in 1971 San Francisco Conference on newborn Hearing Screening the NJC recommended a screening protocol which actually bifureated early identification into two distinct but not necessarily independent areas: The use of High Risk Register (hereonwards abbreviated as HRR) and Behavioral auditory screening of the newborns (Mencher, 1974). Consequently many high risk registers were devised for the purpose of predicting those infants who have auditory and/or other neurosensory deficits (Gerber, 1977).

2.2 **THE EARLY PROJECTS**

Around the same time of forming of NJC the Maternal and Child Health Services division of United States Public Service department funded two longitudinal research projects in Israel. Another project, the Nebraska Neonatal Project, founded by the National Foundation (March of the Dimes) began in 1970. These early projects later were to contribute much to the refinement of the HR concept.

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[1] In 1976, the American Nursing Association Joined the end eavour.

2.2.1 **The Haifa Study**

Between 1965 and 1967 this study screened nearly 10,000 babies with a very broad HRR consisting of 25 high risk factors. It included such factors as first cousin matings, family history of deafness, imminent abortion, prematurity and Jaundice. On extensive follow up they could identify 13 deaf children but, only 9 fall into the high risk register. Deafness was 2 to 3 more times common in the high risk population than in the general population (Altmann, 1969). This however, was such below Down's (1968) estimation.

2.2.2 **The Jerusalem Study**

This longitudinal study screened 17,731 newborns between 1967 and 1970 with a broad HRR consisting of nearly 16 items. It included many items used in the Haifa study. All children were also screened with the Apriton Test of Downs and Sterritt (1967). Those included in the HRR and as well as those filing the Apriton Test were again tested at 5-7 months by Stycar test, a modified form of Ewing Test. Both these tests were administered by trained nurses in the newborn nursery or the Baby Clinics.

Children failing the Stycar test twice within a month were later evaluated thoroughly at an Audiology Centre. Rest were screened again at 18-24 months using communication and verbal skill tests by trained nurses. A fourth and a last screening test assessing hearing communication ability in children was administered at around 3 years of age. Those failing were thoroughly evaluated in both the instances.

As on 1974 this study turned up 23 profoundly or partially deaf children. Feinmesser and Tell (1974) concluded that a broad HRR which covered about 20% of entire newborn population did not prove to be economical and practical. A much restricted register recommended by the NJC (See 2.3 below) with an addition of two items viz, Apnea and Cyanosis [1] (Apgar score 1-4) and neonatal

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[1] for clarification please refer Chapter-3 on High Risk Factors.

severe infection would have had identified 15 of them. That could have reduced the follow up population to only 7% saving much time, money and efforts (Mencher, 1974).

2.2.3 **The Nebraska Neonatal Project**

This was a computerized longitudinal study which between 1970 and 1974 screened over 10,000 babies. Children were followed through physician's reports, auditory examination and/or mail or telephone contact. Initial contact involved recording of a multitude of prenatal and birth data from hospital charts and personal interview with the mother. Children were followed at 1, 3, 6, 12, 18 and 24 months and information related to developmental stages, language level, disease incidence, hearing loss and other health related data were obtained. It turned up 9 children and 5 of them would have been placed on the HRR recommended by the NJC (Mencher, 1974).

2.2.4 **The New Zealand Study**

Started with the assistance of National Audiology Centre, Auckland in 1972, this program known as the National Women's Hospital Program screened 17,250 children between 1972 and 1976. It employed a hearing test and a 9 month at-risk screening program. All children were tested within 1-2 days after birth or before being discharged, by two technicians with no specific training in audiometry. The criteria of risk are not clear (Greville and Keith, 1978) but, they presumably constitute a broad list.

Those who failed twice to respond to a warble tone at 90dB and 100 dB also those at risk were followed up at 9 months. Of the 29 failed, only 3 were deaf. 73% were thus over referrals. Among 10 deaf children born in that hospital during that period and who were followed up retrospectively, only one had been placed on the HRR though 8 of them should have been. Among the 1400 high risk infants 1000 were followed up and only two were found to be deaf (Greville and Keith, 1978). This is a poor performance in view of the reported efficacy of HRR.

2.2.5 The Elks-Purple Cross Project

The Canadian Benevolent and Protective Order of Elks and their auxillary, the order of Royal Purple, both non-profit service organizations have implemented a project called a Deaf Detection and Development Program for early identification of hearing impairment at Halifax, Canada. Children were examined in three age groups : 48 hours to 1 week, 3 months to 1 year and 9 months to 1 year. A HRR was maintained and older children were seen in public health facilities or in co-operating audiologic facilities (Alexander, Coulling and Coulling, 1974).

With neonates they employed both the HRR (items are not known) and a pure tone screen. Similar procedure were employed with older children but the screening was done at 60 dB rather than at 90 dB. By the end of 1974, 10,000 newborns had been screened of whom 600 were not cleared (High Risk?). This figure seems to be consistent with those reported elsewhere for the size of follow up population. Among those children referred to public health agencies, 15 of 383 were not cleared (Hearing impaired?). More details are wanted.

2.2.6 The outcome and shortcomings of early attempts

Mencher (1974) retrospectively analysed the available data from the two Israeli and the Nebraska study and pointed out that out of 37,000 babies screened 40 deaf or hard of hearing children had been identified (an incidence of 1 in 925). Most of these studies involved a high proportion of follow up population. With the application of the restricted high risk register recommended by the NJC 27 of them could have been included in the follow up population of only 7 to 10% of the population. This could have saved a lot of time and money. Thus it appears that the crucial shortcoming of the early studies is the length (nay, the breadth) of the HRR.

As regards the New Zeeland Project, neither the mass screening nor the 9 month at-risk program was worthwhile (Greville and Keith, 1978). The problem with this study seems to be the criteria rather than the concept of High Risk itself. The elimination of the category "Mild Prematurity" and the application of a more stringent criteria could have drastically reduced the follow up population to manageable limits.

Moreover, the New Zeeland study seems unusually badly directed and uncontrolled with too many procedural and administrative lapses. The risk classification and follow up procedures are highly vague. However, as Greville and Keith (1978) have pointed out, the HRR was indeed very helpful at the follow up test at 9 months since no deaf child passed the Ewing test at 9 months.

2.3 THE NATIONAL JOINT COMMITTEE RECOMMENDATIONS

In the prevailing confusion about the size and scope of the HRR, Mrs. Merion Downs, the Chairman of the committee, carefully analysed the available data and very cleverly came up with a simple and a very efficient 5 point HRR. She gave a mnemonic devise which she called the A.B. C. D.S of Newborn Nursery (Downs, 1972), which is given below.

Fig. Down's Mnemonic Device

A. Affected family (congenital sensorineural hg. loss in first cousins or closer).
B. Serum Billirubin level of 20 mg or more.
C. Congenital rubella (regardless of trimester).
D. Any observable Defects of E.N.T. (any first arch syndrome).
S. Small at birth (1500 gms or less).

Downs also pointed out that this restricted list would increase the sensitivity of the screening nearly tenfold. In view of the accumulating evidence from various projects, the NJC in 1973 further recommended the application of HRR and endorsed, with a few modifications, the Down's manifest as its criteria for high risk classification.(See appendix-1).

These recommendations clearly reflect the growing awareness of the need for a compromise between the effectiveness of the HRR and the cost of realizing that effectiveness in terms of the size of follow-up population and testing time. It also recognized the importance of frequent follow up checks, especially in those children in whom hearing loss need not necessarily be present at birth but may develop any time there after.

2.4 THE NOVA SCOTIA CONFERENCE (1974)

At about the same time the NJC was providing structure for the direction of research programs, the US Government, the Elks Purple Cross and other Government and private foundations were founding planned programs necessary to further research and to develop and refine early identification techniques. Since these programs were conducted in many parts of the world communication between them was essential.

In order to bring all those engaged actively in such programs together and to arrive as a consensus, a Conference was convened at Nova Scotia, Halifax, Canada with the assistance of Elks-Purple cross foundation. It brought together representative from 6 nations who met for 4 days during September, 1974. During the deliberations in public and in closed door meetings the conference reviewed the accumulated data involving more than 150,000 babies. The end result was a set of recommendations, which are now familiar as the recommendations of the Nova Scotia Conference (See Appendix-2).

In effect, the conference confirmed the effectiveness of the HRR and recommended that it be universally implemented and urged the World Health Organization, National and Local Governments and Health Agencies to adopt this system, if necessary by legal mandate. While re-affirming the role of follow up checks, it also recommended the use of suitable behavioral screening tests as a supplement to HRR. It also noted that those fall in the HRR often suffer from other communication disorders which can further the usefulness of the High Risk Concept.

The Nova Scotia recommendations were to later become the basis for many well directed and controlled screening programs which have proved successful both in terms of yield and their potential values in various research efforts. These have been reflected in many of the later screening programs.

2.5 LATER PROJECTS

2.5.1 The University of Colorado Screening Project

Supported by a National Foundation Grant this program starting from 1972 began to apply a HRR using a core of trained volunteers. About 50 volunteers, most of whom had been involved in several years of testing of newborns and observation of responses joined the program. The program followed a procedure which had three parts, viz.,

1. Maternal Interview with questions concentrating on family history of hearing loss and rubella infection or exposure during pregnancy. A specific questionnaire was used.

2. Review of hospital charts to collect data on birth weight, hyperbilirubinemia, neonatal infections, ENT anomalies, etc.

3. Continued screening of infants using the Vicon Apriton Test. The criteria for a pass was arousal or startle response.

Information on every newborn was collected and a risk category was assigned. Parents and physicians were informed when a child fell into HR group and follow up appointments were made. The following constituted the criteria for High Risk classification :

1. Positive family history of hearing loss (before the age of 5 years) in parents and/or siblings.

2. Maternal rubella or rubella exposure.

3. Congential anomaly of the head or neck (cleft palate, microtia grossly abnormal pinnae, cleft lip).

4. Neonatal Meningits.

5. Birth weight of less than 1500 gms.

6. Unconjugated Bilirubin level of over 20 mgm or an exchange transfusion.

As on 1977, the results showed (Gerkin, 1977) that ogit of a total number of 10,727 births, 1,144 were classified as high risk (1 in 9 or 10.7%) and 17 were identified of having loss (1 in 67 or 1.5%) 4 subjects suspected hearing loss were lost to follow up. Significantly all the confirmed cases were classified as high risk and though 6 of them passed the Apriton test they were identified on basis of HRR. On an average, they were suspected at 4.4 months and confirmed at 9 months. The mean suspected and confirmation age were 3.6 months and 6.5 months if those who did not turn up at advised time were excluded. Garkin (1977) sums the five year experience with the following statements :

i) "Volunteers can do the required work in the nurseries. But, one needs some one to assume the primary responsibility and to coordinate the work".

ii) No attempt has been made to contact those not at risk and therefore little is known about missed deaf children in that population. Only one not-at-risk child has been referred back with a hg. loss. The incidence of confirmed hg. loss of all types significant for language development if 1:600 HR sensitivity is 1:80.

iii) The follow up response has been poor with only 30% keeping appointments, even after the repeat tests were made free of cost. This is probably because of the type of the population the hospital serves. Another private hospital in Denver with a similar program has been averaging a 98% return for repeat tests.

iv) The ideal time to screen infants for hearing loss is probably at the age of 6 months, at well Baby clinics.

v) Latters and public education pamphlets have considerable educational value.

2.5.2 The Halifax Project

A mass infant screening program was initiated in the Grace Maternity hospital, Halifax, Nova Scotia in Canada in 1977. The program (See Fig.3) incorporated the recommendations of the Nova

Schematic Diagram of New Born Hearing Screening And Deafness Detection Program

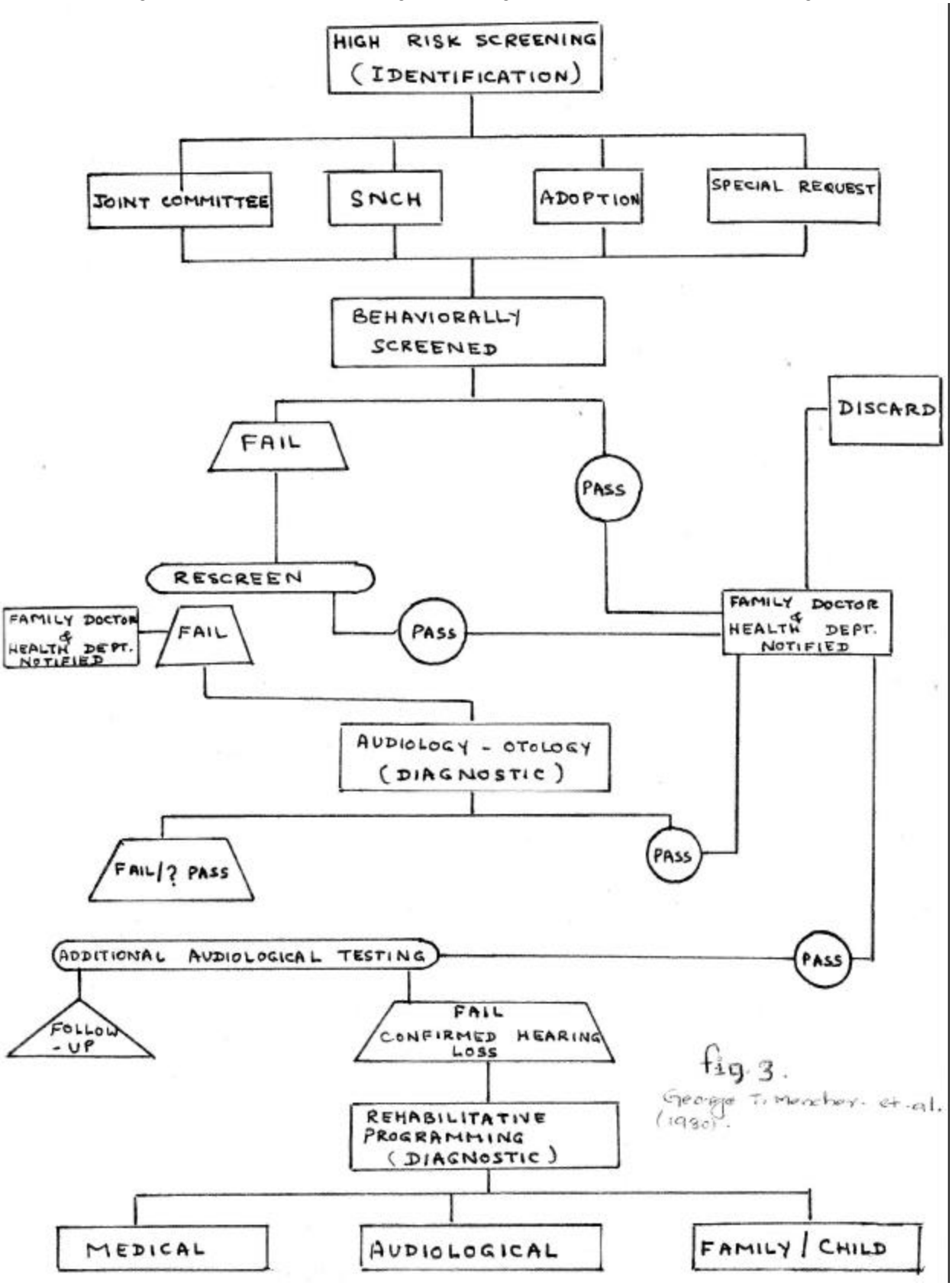

fig. 3.
George T. Meacher. et. al. (1980).

Scotia Conference and utilized the HRR proposed by the NJC and a behavioral test. All children listed on the HRR as well as any child whose parent requested a hearing screening evaluation were behaviorally screened. Children up for adoption and some children falling under specific investigation categories were also behaviorally screened as part of on going research.

Every mother admitted to the hospital received a packet of material containing, among other things, a letter from Nova Scotia Hearing and Speech Clinic which informed her about the aims and procedures of the program. She was asked to fill in a simple questionnaire and to provide additional information regarding the family and the baby. The questionnaires were collected, answers verified and medical record checked for birth weight, first arch syndromes and bilirubin count by a part time staff person.

All children considered for behavioral screening were tested according to a set protocol. No child below 1 day in age was tested. Any child failing this test was retested within 24 hours. Failure on the second test meant immediate and automatic referral for a full audiological and otologic evaluation and follow up. This examination was considered a part of routine hospital care, very much like the investigatory X ray and was covered by the initial blanket permission signed by the parent. To avoid unnecessary trauma to the families the parents were not even involved in the program until after the full audiological test. Counselling and follow up appointments were deferred till then.

The family doctor was then posted with the details of results and placement on the HRR and was requested to provide specific follow up on HR children. The visiting nurse from Nova Scotia public health department was also provided with all information and they in turn, provided additional screening at home and assisted in follow up as and when needed.

The accumulated results of the program are not yet available. However, according to the yearly report (Mencher et al, 1980) in 1979 the centre screened 4910 babies of whom 669 were high risk. (The HRR was essentially the same as NJC has recommended with asphyxia included on the recommendation of the Saskatoon Conference; 2.6 below). They constituted 13.6% of the newborn population. In addition 373 babies in the Intensive Care Unit (ICU), 119 children up for adoption and 325 babies meeting other special research needs were tested with the Arousal test (Mencher, 1974). The testing was done as outlined by the Nova Scotia protocol. Eventually 110 infants were referred for detailed evaluation. 70 of them were cleared after the initial visit. Of the remaining 31, 8 were definite failure while 23 were still questionnaires. Subsequently 15 of the 23 have been cleared and 8 were still pending.

Among the 8 definite failures, 3 had confirmed sensorineural loss and 5 conductive hearing loss. However, it was not sure if any of these conductive hearing loss cases had a sensorineural component as well. As Mencher et al, (1980) noted "it is quite possible that any or all seven of them may develop a sensorineural hearing loss later on, something which has been reported to occur with children exposed to rubella and other viral infections. However, it should be noted that all 3 of the confirmed hearing loss cases were on the HRR, one being a case of severe Asphyxia and the other two being low birth weight babies".

As part of the ongoing research, the centre also screened all children admitted to ICU at another hospital using a Crib-O-gram. However, no HRR was considered. It picked up 4 deaf children among 158 tested and 28 failed initially. When the loss was confirmed all the 4 were less than 3 months old. Interestingly, all the 4 could have been placed on the HRR. That means that all the 7 deaf babies identified in Halifax last year were on the HRR (Mencher et al, 1980).

2.5.3 The Utah High Risk Program

This project actually began in 1967 as a Maternal and Child Health demonstration project (Mahoney and Eichweld. 1979). From that time until 1972, a mass screening program was conducted in 7 hospitals. In 1972, in response to NJC recommendations a pilot project involving a questionnaire was introduced. The Utah high risk program in 1974 became a priority project (Mahoney, 1977). Its major objective was to recruit all the State's hospitals into the program. It was coordinated by a paid full time audiologist. By 1977, 36 of the 37 hospitals in the state were participating in the program covering an annual birth rate of 37,000 babies.

It followed a model which facilitated data collection with minimum hospital and/or professional participation and at a time when it was easily obtainable on the majority of the target population. The goal was to screen all the babies born in Utah hospitals which comprised of 98.9% of the total number of births in that state. (Mahoney and Eichweld, 1979).

The 7 item questionnaire incorporated the following factors : hereditary deafness, rubella exposure, birth weight, ENT defects, Rh factor requiring blood transfusion, severe neonatal illness and parental concern. It had been a product of many revisions over a period of 5 years. Since the respondent was the mother it was so designed as to make it easily understood by all. Specially upon the advice of the pediatricians it omitted "other non-bacterial intrauterine infections "changed "bilirubin level" to "Rh factor requiring blood transfusion" and "1500 gms" to "3½ lbs". Thus in addition to the 5 recommended HR items it included a question on neonatal severe illness and one on parental concern. The program protocol consisted of 8 basic steps (Mahoney and Eichweld, 1979) viz., (See Fig.4).

1. HRQ's were sent to the hospitals from the Speech Pathology and Audiology section of the state division of health.

2. For convenience, the questionnaire were distributed to mothers for completion along with the birth certificate. Also included a convering letter explaining the program and an information leaflet that outlined the normal auditory development.

3. The questionnaires were accumulated and returned to the section at regular intervals, by the hospital staff.

4. The returned questionnaire were immediately dichotomized into HR or not HR. A positive response to one or more items constituted a HR determination, as did failure to complete any item.

5. When the HR child was between 6 and 8 months of age, the mother was sent a follow up questionnaire that included the original questions plus two additional questions regarding her child's auditory behavior: "When your child is in light sleep in a quiet room does he move and begin to wake up when there is a sudden noise?" and "Does your child turn towards an interesting sound or when his name is called?".

6. When auditory behavior reported by the mother was found questionnaire or when parental concern did exist, either an audiological evaluation was arranged or educational literature was mailed to parents followed by another telephone inquiry after continued parental observation.

7. Parents who desired an audiological evaluation were asked to bring their children to one of the 3 regional clinics that had sound isolation test environment. When found necessary the initial screening was accomplished at one of the state-wide intenerant clinics. In both cases hearing and middle ear assessment was accomplished by certified audiologists. Periodic follow up procedures were performed as advised by the NJC. Brain Stem Evoked Response evaluation was also arranged for the difficult to test.

8. Hearing aid evaluation, medical consultations and family physician contact was initiated with infants found to be hearing impaired. Referrals for habilitation was made preferably before or by the time the baby was one year old. The Parent Infant Program (PIP) of the Utah School for the deaf usually became involved at this time. Parent advisors visited home on a regular basis and trained parents in hearing aid management and in methods to develop language skills in their children.

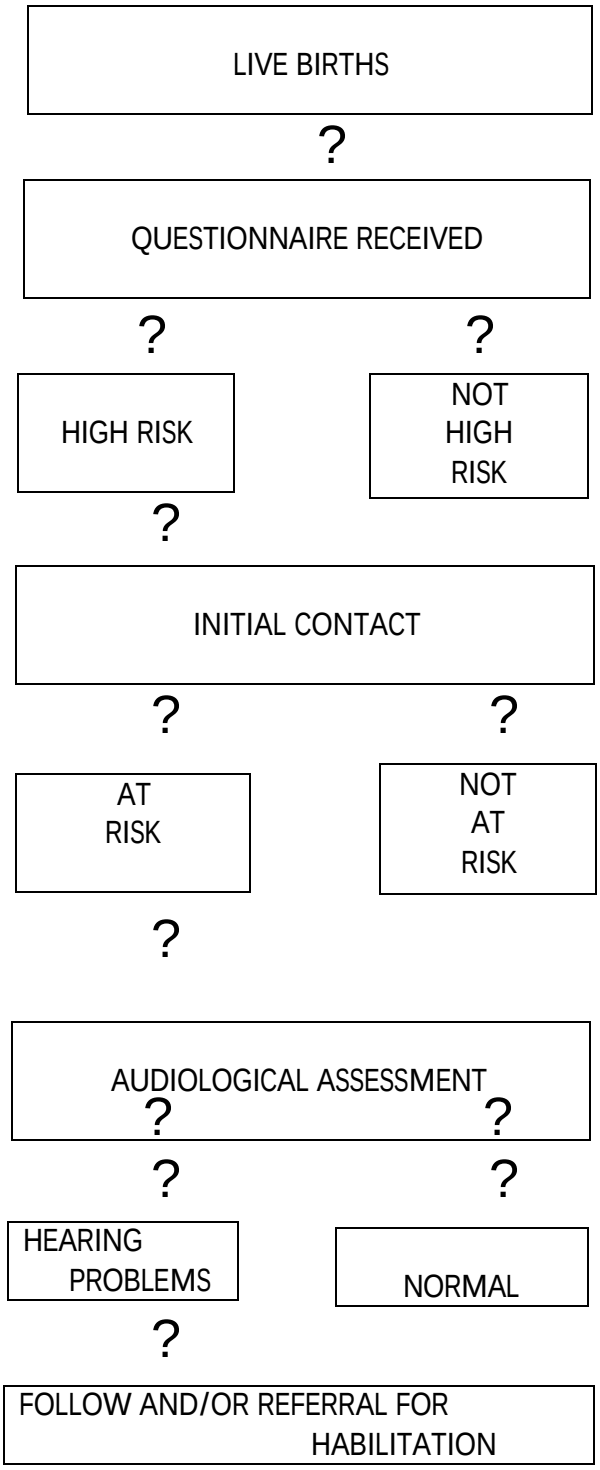

Fig.4: Flow chart of The Utah High Risk Program. ref. Thomas. M. Mahoney, 1977, Summary report of Utah Division of Health. May, 1977.

As reported (Mahoney and Eichwald, 1979) the results show that of the 50,700 birth a b/w January 1, 1976 and Dec.30, 1976, 26,352 (52%) completed questionnaires were received. 4,591 (17.4%) were classified as high risk on the first inspection; i.e., one or more of the 7 items were marked positive or left blank. Of these 181 (3.9% of the HR) remained at risk after the follow up contact and 54 infants (29.4% of those at risk) were found to be hearing impaired by audiological evaluation. There were in all 711 false positive questionnaire consisting of inaccurate responses that mistakenly identified the baby as HR. Typically such responses involved a presbycusic relative in the family history category.

It should be noted that those finally considered "at risk" were those babies whose parents were concerned about the auditory behavior as reported by them at 6 or 8 months of life on the follow up questionnaire. Thus the program relied heavily on not only the accuracy of the parents response to questions but also on their ability to assess their baby's early auditory behavior. In trying to improve sophistication they were also mailed a leaflet highlighting early auditory landmarks including the development of localizing ability, along with the follow up questionnaire as early as 4 months. However, it was found that despite the educational efforts parents become better reported only with the advancing age of the infant (Mahoney and Eichweld, 1979). The program now follows the risk child between 6 and 8 months with the goal of identification and fitting for amplification by one year of baby's age.

Mahoney (1977) makes another interesting observation which concerns these infants admitted to intensive care units (ICU). These were initially lost the high risk registry. This could not be helped because, in their own words "it appeared insensible, at best, to request parents to complete a questionnaire when their child is facing a life threatening situation". However, some of those babies whose mothers voluntarily participated in the Children and Youth Diagnostic Clinics (C & Y clinics) at about 6 to 8 months

were assigned to the program. This group has been considered to be excessively at risk since man of such children have presented severe to profound sensorineural hearing loss. Efforts have also been made to contact the parents of remaining children (who went through ICU's).

The initial questionnaire return rate was around 52%. This pointed to the programs most serious of the problems – maintaining the hospital staff's interest and cooperation. This was complicated further by frequent staff changes which adversely affected the continuity of the questionnaire delivery and retrieval. The limited hospital stay of most mothers was also a contributor. The return rate, however, did not improve even after a vigorous effort towards increased hospital participation. Mahoney and Eichwald (1979) hence concluded that "this relatively poor return rate seemed to be the best one can expect for a preventive non-mandatory health programs".

2.6 THE SASKATOON CONFERENCE (1978)

This was the third major conference to be held in Canada and sponsored by the Elks-Purple Cross Foundation. While the Toronto Conference recognized the high risk concept and the Nova Scotia Conference endorsed it and recommended a condensed high risk register to advantage, this conference recognized the fact that the high risk register was now a proven guide for early identification and a great help in research concerning the general problem of identification and evaluation of hearing impaired children.

As a desired consequence of Nova Scotia Conference, many Audiology and Otology centers all over the world were receiving an increasing number of newborns and young infants under 6 months of age and were required to differentially determine if there is a hearing loss. As a result, the key focus of this Conference was on the accurate testing and diagnosis of hearing loss in newborns.

In his key note address, Dr. Hallowell Davis noted the prove value of the HRR and proposed an extension of the 5 point register to include Apnea and Cyanosis at birth i.e., Apgar Score of 4 or less and severe sepsis in the perinatal period (the inclusion of these items had been suggested by Feinmesser and Tell, 1975). He noted that alerting the medical and allied professionals and parents about the high risk factors was the best tool for earliest identification (Davis, 1978).

During the three day deliberations, this issue, among other issues was discussed in detail by the Conferees who labored and brought forth a series of 14 resolutions. In effect, these resolutions (1) Provided specific reference to utilization of parents as an active participant in the identification and management programs, (2) provided detailed methodologies for screening newborns for hearing loss, (3) took note of the need for medical and speciality schools to included information on hearing loss and its identification, diagnosis and treatment and (4) accepted and recommended the use of Brain stem Evoked Response audiometry as a clinical/diagnostic tool in the audiological battery (Gerber and Mencher, 1978).

Specifically the Conference recommended the inclusion of a category to the High Risk Register – "Significant Asphyxia associated with Acidosis" (See Apendix-3). It also recommended that "A comprehensive evaluation of a child's hearing should be performed as soon as possible after a child is considered to be at risk and suggested a protocol". Significantly it also resolved that "in cases of parental concern, that child, be of any age should be immediately referred for audiological evaluation ". All these developments were to significantly contribute the concept of high risk registry.

2.7 PROJECTS CURRENTLY UNDERWAY

Two projects are currently underway which demand discussion on the virtue of their value. Though not much data is available on them they have been discussed below as comprehensively as possible with the available literature and personal communication as the source.

2.7.1 The Utah Statewide Infant High Risk Hearing Program

This pilot program was instituted in 1978 after much search for an alternative to hospital material and staff as the source of high risk data. This utilized the Birth Certificate (BC) as a means of obtaining information about high risk hearing factors. Birth certificate in Utah is a mandatory legal document and thus it assures 100% screening rate. Working with the Utah Committee on vital statistics with the approval of Utah Advisory Committee on Health Statistics and National Centre of Health Statistics the birth certificate was revised to include an item on history of hereditary childhood hearing impairment. The birth certificate as it was covered only the remaining 4 items recommended by NJC. Thus, the revised Birth Certificate governs all the five recommended high risk either directly or indirectly.

The Utah Live Birth Certificate has 2 sections, designed for health and medical use – one to be completed by the parents and the other by the physician supervising the birth. (Mahoney, 1980). It contains the following items pertaining to HRR : complications of pregnancy, current illness or condition affecting pregnancy, Apgar score, birth weight, and congenital malformations. Since all items are computerized it was relatively easy to generate a computer program for the project. The speech pathology and audiology section receives a monthly read out from the state bureau of vital statistics containing the names and addresses of all infants with one or more high risk factors and an item analysis of each risk category. The program has established a set protocol. (See Fig.5).

When the high risk infant is 6 to 8 months of age, a questionnaire is mailed to the parents, which contains two questions concerning normal auditory development viz. (i) “when your child is in a light sleep in a quiet room, does he move and begin to wake up when there is a sudden noise?” and (ii) “Does your child turn

PROGRAM FLOW CHART

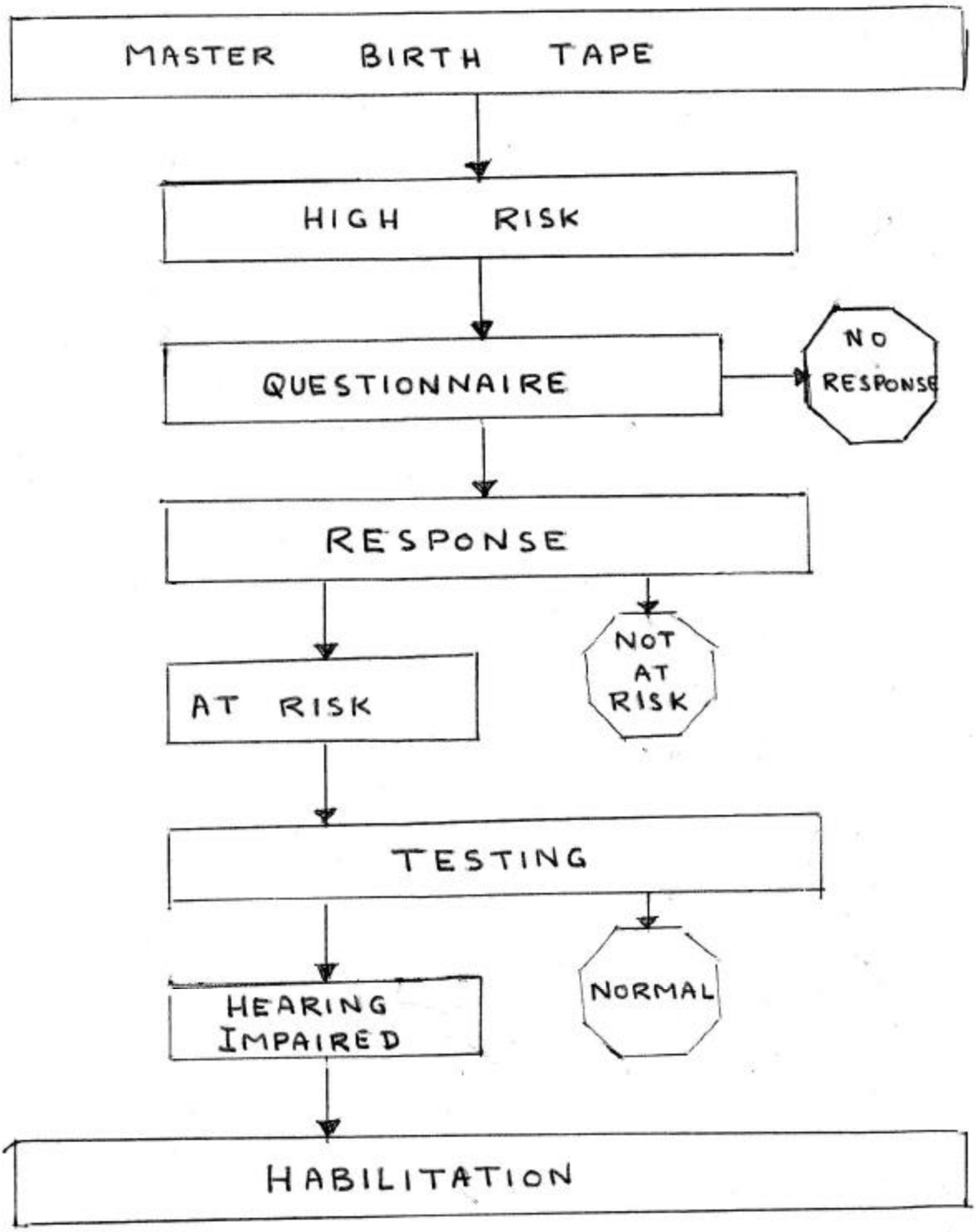

Fig.5: Flow chart of Utah State wide Infant High Risk Hearing Program.
Thomas .M. Mahoney.et. al., (1978).

Towards an interesting sound, or when his name is called?". A third question allows the parents to express their concern regarding their child's hearing. Along with the questionnaire an information leaflet on normal auditory development is also mailed.

If the questionnaire is not returned no further action is taken. From the returned questionnaire at-risk determination is made on the basis of auditory or parental concern. The remaining procedure is the same as in the hospital program described earlier (See 2.5.3).

Initial data analysis has indicated that of a total population of 21,109 infants born in the first 6 months of 1978, 5647 infants (26.9%) were considered high risk by the present criteria. Item analysis revealed that 13.2% of population answered positively to "complications of pregnancy ". A sample analysis of 500 HR birth certificates was run and it was found that more than 98% of medical conditions listed under complication of pregnancy were not pertinent to hearing risk according to the NJC criteria. It was then realized that the permanent inclusion of this item would weaken the sensitivity of the birth certificate. The question is now eliminated as a high risk item. The revised data projected a high risk population of 13.7% which is closed to the 7% population sensitivity reported by Northern and Downs (1974), (Mahoney and Eichwald, 1979).

It is now proposed that, if proven successful, the BC should permanently replace the hospital questionnaire which should improve both initial screening rate and program efficacy. It could then realize the promise of screening nearly 100% of the state's newborn population so ardently recommended by the NJC.

2.7.2 The Colorado Infant Hearing Assessment Program (IHAP)

This program was initiated in the University of Colorado Medical Centre in November, 1979. It is essentially a High Risk screening program which employees, apart from the high risk register,

both a behavioral screen and a Brain Stem Evoked Response (BSER) screen (See Fig.5) it is carried out by a group of volunteers from the local chapter of Telephone Pioneers of America, a volunteer organization of the Bell Industries. They work in coordination with and under the supervision of hospital staff (Gerkin, 1980). The program has two parts : Normal Nursery risk screening and Intensive Care Nursery Screening. Both these follow well defined program protocols. (See Figure.6).

In the Normal Nursery program, volunteers screen the hospital records for risk information and babies are classified into a control group and a high risk group. The high risk group undergoes BSER screening as well as a auditory behavioral screen. Both the control and the high risk group are followed up.

In the program involving intensive care nursery, a maternal questionnaire is employed, as part of a trial program. This questionnaire reportedly differs somewhat from that employed in the original program (Gerkin, 1980). The questionnaire screen is conducted by a Primary Nurse who administers the questionnaire to mothers and also screens hospital records for risk factors. ICU babies are divided into 3 groups: Study group; Non study high risk group and No risk group. The study group undergoes BSER screen as part of newborn service whereas the non study high risk group undergoes both the BSER screen and a behavioral screen. Both groups a followed up at special baby clinics and Audiology centers at 40^{th} gestational week and again at 4 month post birth. The no risk group which serves as the control group is also followed up at the hospital and/or through mail.

No data has been published so far because the study is still a trial program. From the available material obtained through personal contact it has not been possible to exactly deduce what the aims of the study are, but, presumably it is aimed at evaluating the feasibility of employing BSER test with and without high risk classification. Further details are awaited.

NEWBORN SCREENING PROCEDURE

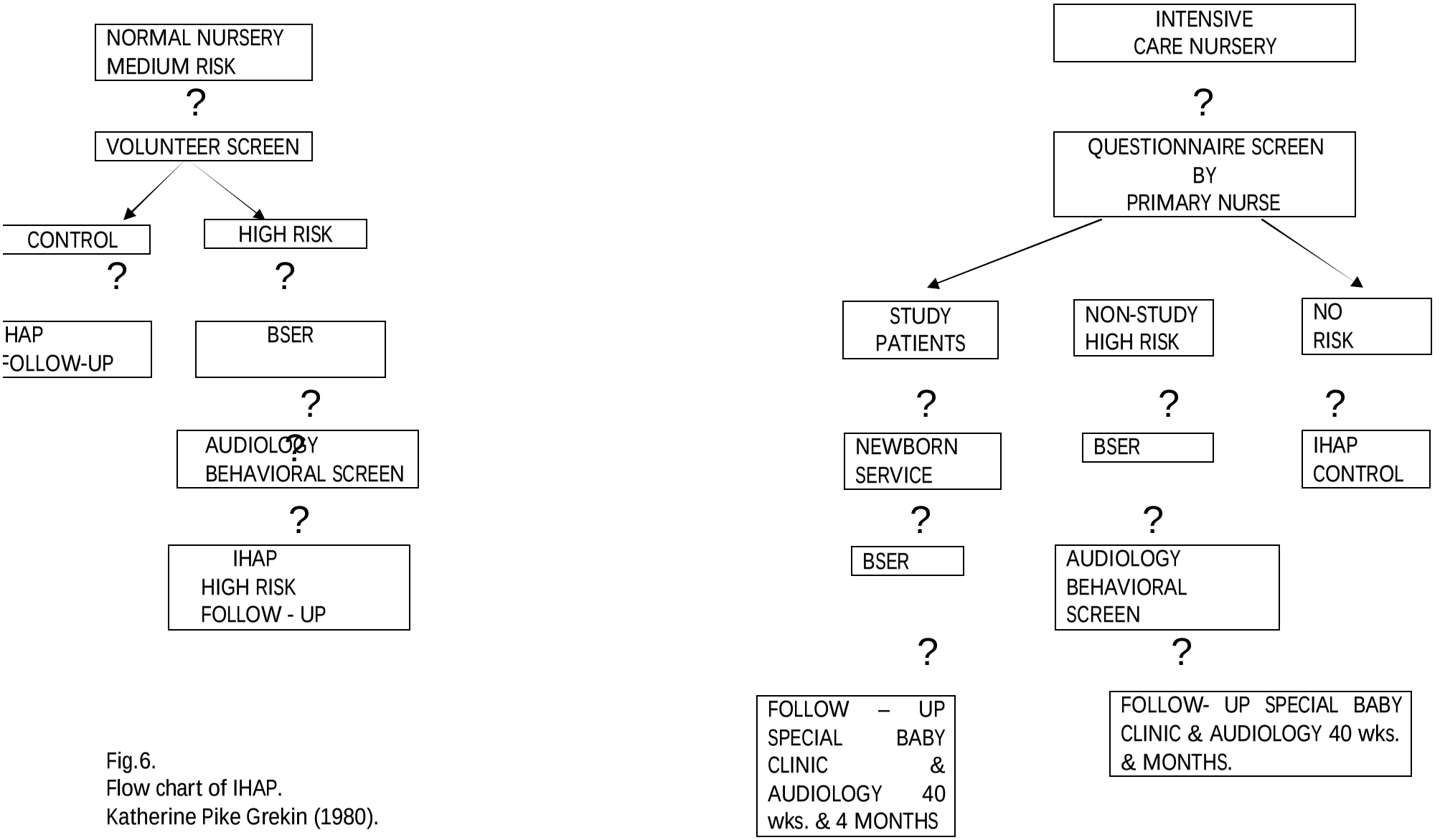

Fig.6.
Flow chart of IHAP.
Katherine Pike Grekin (1980).

2.8 PROPOSED PROJECTS

Following are the reported success of many HR programs, similer programs had been proposed in various places. Some have been implemented, some waiting to be implemented for lack of funds or personnel, and some have remained as proposals.

2.8.1 The Texas Proposal

In 1974 during the Nova Scotia Conference Glorig and Curtis read out a paper on the proposed Texas Project. It is not known if it has been implemented but the proposal was a far reaching one.

It involved a HRQ to be completed by the hospital staff, preferably by the delivering physician on every newborn in Texas within 7 days after the birth. It was recommended that the HRQ should be considered as part of baby's birth record. The HRQ incorporated 5 items recommended by NJC. If the answers to any one or more of questions was positive the baby was the undergo in depth hearing evaluation at 4 months and again at 11-18 months of age.

The proposal recognized the fact that hospital staff cannot be expected to maintain a continually effective program. Hence, it proposed that the HRR should be made mandatory for all hospitals. The Director of Education of the Deaf was required to maintain a register of all at-risk babies. The proposal also justified the use of HRR on the grounds that the HRR can identify other potential cases of learning difficulties and thus its pay-off would increase. Consequently, it noted that other learning disabilities can be simultaneously detected earlier at little extra expenditure.

2.8.2 The Massachusettes Plan

The Commonwealth of Massachusettes passed a law in 1971 that specified certain high risk conditions that merit further examination. (Gerber, 1977). viz.,

1. **Before Birth**

   a) family history of deafness as indicated by any one or more deaf or hard of hearing children in the family.

   b) maternal thyroid disease.

   c) maternal German measles in the first three months of pregnancy.

   d) maternal influenze or chicken pox in the first 3 months of pregnancy, and

2. **Newborn difficulty** :

   a) Mycin group of drugs.

   b) multiple abnormalities from whatever cause.

This differe from the NJC list in many ways. Prinicipally, the inclusion of maternal thyroid disease is not justifiable because of its statistical insignificance. Serum Bilirubin and Birth weight have been left out. The inclusion of all mycin group of drugs seems unwarranted (Gerber, 1977).

It main difficulty however is not the conditions but, the implementation. No where does the law require that infants be examined, either physically or by the study of records. It instead states that "the parent or the legal guardian be provided with literature which describe the conditions. They would then consult their physician and if a HR determination is made the child should be referred to one of the four centers where diagnostic work may be done, at no extra cost to the family". It is curious t know what one of the 4 centers designed is a department of Orthopedics. Since the law has been passed there has been no report that it was worked or it works. This, at best, in the words of Gerber (1977) "serves as a model for one to emulate".

2.8.3 The Santa Barbara Plan

The Santa Barbara unit of speech and hearing sciences had been involved in a pilot screening program till 1978. The mother was required to complete a questionnaire before the child is born with

the help of a obstetrics nurse. It was then completed after birth by nurses in delivery room and nursery. The questionnaires were then verified by volunteer graduate students. The primary café physician or a pediatrician was then posted with details and was entrusted the follow up work. After an initial family contact the infant was screened for an arousel. A second failure in this entailed the child to a detailed behavioral and electro physiologic tests. Since the project is a sort of demonstration one, no data has been published (Gerber, 1977).

Meanwhile, a Conference of Infant auditory assessment was convened in Santa Barbara in February, 1979. Its overall objective was to assist the maternal and infant health section in formulating guidelines for auditory screening along the lines of those existing for visual, neurological and pulmonary disorders. The conferees concurred with the consensus arrived at all the precious conferences that there is no universal auditory screening test what is both cost effective and diagnostically effective. Hence, they reaffirmed the validity of the HRR and recommended that a high risk registry be set up in the state of California. They agreed that all infants should be risk rated as follows :

1. All with a family history of childhood hearing impairment.
2. All with cranio-facial anomaly
3. All who have confirmed disease by TORCH (i.e., Toxoplasmosis, rubella, cytomegalovirus and Herpes), and
4. All sick enough to have been in a teritary ICU and some of those discharged from a secondary intensive care nursery.

The conferees also proposed that “all high risk infants, as defined above are to be sent for definitive diagnosis to centres specifically certified for that purpose. Since the families of such infants also need ancillary services like public health nursing, social services, nutritional and health education support, etc., these services (hearing evaluation) should be built within the care program”.

To insure a definitive diagnosis, they recommended, "initial contact is to be established by two months post discharge or at 3 months post discharge or at 2 months adjusted post natal age. Definitive statement on hearing sensitivity should come by 5 months after the date of definitive diagnosis. It is an unacceptable practice to defer a definitive beyond this time arrival, considering both lost benefits to the hearing impaired infant and the state-of-the-art in establishing a diagnosis by this time. The procedure should include evoked potential screening or complete ERA or total auditory evaluation" (Gerber, 1979).

The conference also considered the possibility that an automated behavioral test might be employed in all tertiary ICUs and perhaps in secondary care nurseries. In that case, all infants who fail in that test should be referred to the centers for the definitive diagnosis as just defined. The conferees also recommended that 12 geographically distributed centres should be established in the state of California to serve all the high risk infants as defined above. (Gerber, 1979).

2.9 HRR AS AN ADJUNCT TO BEHAVIORAL SCREENING AND RESEARCH

The HRR has come to be recognized as a very useful tool in selecting the test population in behavioral screening and machineaided diagnostic procedures like BER procedures. Mencher (1977) used it as an adjunct to validate Crib-O-gram and found it a valid method of differentiating infants with severe impairment from normal children. He also noted an abnormally high percentage of mental retardation, cerebral palsy, childhood aphasia and other associated speech and language problems in the group with normal hearing but which is high risk and has failed on the Apriton behavioral screen (Mencher, 1978).

Galambos (1978) suggested a protocol on "how to test almost every neonate with peripheral hearing loss". It proposes, in effect, selection of candidates from (1) ICUs (except those previously

tested and cleared), (2) a HRR which should be maintained in every newborn nursery, (3) those who fail behavioral test, and (4) those suspected for any other reason. He concludes that "only rarely will a hearing impaired one is diagnosed as normal".

Mindel (1978) found middle evoked potential testing particularly useful in conjunction with a High Risk Register. He reported of a project in Santa Barbara where HR questionnaire is employed in two of the local hospitals to determine the cases at-risk to be tested by a behavioral screening method and if they fail in that test are scheduled for electro encephalic audiometry.

High risk registry has also served as an adjunct to the study of early vocal behavior of deaf infants. One pilot study in Memphis, has indicated the possibility of deaf infants being identified through cry-spectrographic prints (Beasley, 1980). Further details are wanted.

2.10 THE UTILITY AND SHORTCOMINGS OF HIGH RISK REGISTRY.

In general, employment of the HRR has proved to be failly productive. Reports of its success have been shown by Mencher (1976), Stevert (1974), Rossi and Guidoti (1976), Mahoney (1977 and 1979) among others. Only Mayer and wolfe (1975) have had limited success as did Greville and Keith (1978).

Downs (1976) reported of finding 1 deaf child in 57 listed in her HRR. Mencher (1974) applied the 5 NJC items retrospectively to data from a number of sources and found that the 5 item register would have correctly detected about 66% of true positive cases. In general, it is observed that the 5 item list includes about 6 to 8% of the newborn population, and 2 to 4% of the high-risk population will prove to have a hearing loss and of these perhaps half will be severely impaired cases (Gerber, 1977).

The HRR has succeeded when behavioral methods fail. Mencher (1974) found that it leads to much higher correct detection in the newborn nursery than does the use of various screening methods. One can recall that in the Jerusalem study 17 hearing impaired passed the 3 stage behavioral screen. Findings of the New Zealand study further stresses the role of HRR when correctly applied. No hearing impaired child in the HRR passed the 9th month behavioral screen.

Gerber (1972) and Mencher (1974) found that those who are at risk and those who fail to respond to intense acoustic stimuli frequently have neurosensory deficits, other than deafness like mental retardation, cerebral palsy, childhood aphasis, an interesting side benefit of the HRR. Those at risk and who are not deaf form a very intriguing group who merit intensive study and follow-up.

However, the implementation of high risk registry is not without its own problems. The most often sited areas of difficulty are :

i) continued professional contact with each hospital has proved to be time consuming and cumbersome procedure.

ii) Hospital staff changes adversely affect continuity of the program, especially, questionnaire delivery and retrieval.

iii) Heavy work load of most drawbacks is a major draw back.

iv) Since most of the programs are non-voluntary, preventive health programs, certain amount of complacency on the part of the hospital staff has to be taken for granted.

v) An equal amount of, if not greater than, complacency on the part of the parents in returning the questionnaire is also to be expected.

vi) Limited hospital stay of the mother decreases the population of mothers in terms of opportunity to complete the questionnaire.

vii) Initial non availability of certain groups of children like those in the ICUs, most of whom are initially lost to the high risk registry.

viii) Many columns in the returned questionnaires are either left blank or contain false positive information.

ix) The transient nature of the population in many places makes follow up difficult.

Inspite of these difficulties the high risk registry has proved its feasibility because,

i) It enhances the cost efficiency of the screening procedure by virtually bypassing the need for mass biologic screening. This is very important asset since the incidence of deafness in the general population is low (about 1 in 1000 to 1 in 2000) (Gerkin, 1977).

ii) The population of mothers of newborns is easily available in hospitals, well baby clinics, etc.

iii) 75 to 90% of all children who eventually incur hearing loss could e listed on a high risk register. (Downs. 1969).

iv) High Risk information can be obtained through a simple questionnaire, and where possible it can be obtained relatively easily through legal documents like the birth certificates.

v) It can make possible 100% screening rate, especially when it can be made mandatory without making it cumbersome.

vi) Since HRRs often include those children who would eventually suffer handicaps other than deafness, its value can be immense.

vii) It has proved as a very useful adjunct to research involving detection, diagnosis and management of not only hearing impairment but also other handicapping conditions.

2.11 THE OUTLOOK

Though it is difficult to draw any general conclusions, there appear two possible inferences that can be arrived at-one disappointing and the other promising (Gerber, 1977). First, it appears that even in the United States, most responsible public health agencies have not addressed themselves to the problem keenly. Marion Downs, in her key-note address at the Nova Scotia Conference estimated that less than 1% of the newborn population in USA is

being screened for hearing loss. Three years later, Egan (1977) on a survey found that the progress was too slow with a majority of the states inactive in the area of legislative actively. Among various reasons cited were lack of funds, lost personnel, laws relating to confidentiality of records and the question of cost efficiency. Situations in other countries does not look much different.

On the promising horizon few good things are happening. New York has mandated and funded a HRR for hearing loss and Colorado Nova Scotia and Utah have well developed programs going on. The Utah Project has virtually obtained 100% screening rate. Halifax project has been expended to include province wide population. Sweden has a very efficient mass screening program. Above all, a few promising efforts are being made in some developing countries as well.

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CHAPTER 3. HIGH RISK FACTORS

3.1 Classification systems of Etiology of Hearing Loss

3.2 Pathology of Hearing Loss

3.3 High Risk Factors

3.3.1 Genetic Hearing Loss

3.3.2 Consanguinity

3.3.3 Complications of pregnancy
1. CMV and other transplacental inspections
2. Maternal illness
3. Threatened Abortion
4. Transplacental ototoxicity

3.3.4 Birth Complications
1. Delivery complications
2. Prolonged Labor
3. Birth Isphyxia and Cyanosit

3.3.5 Bilirubin Encephalopathy

3.3.6 Law birth weight
1. Jaundice
2 Rh and Blood Group Incompatibility
3 Blood Transfusion

3.3.7 Congenital oral Facial Anomatier

3.3.8 Neonatal Illnesses

3.3.9 Ototoxic Drug therapy

3.3.10 Parental concern

3.4 List of High Risk Factors considered for this study

3.1 CLASSIFICATION SYSTEMS OF ETIOLOGY OF HEARING LOSS

Deafness or Hearing loss is caused. Like any other biological symptom or sign it may have multiple causes. The caused may be inherited or sporadic (non-inherited), intrinsic (related to factors within the organism such as a malformation) or extrinsic (related to external factors). (Gerber, 1977).

The etiological factors can also be classified chronologically, as Congenital and Delayed onset, with an additional category 'unknown onset'. Another example or reference such classification system follows the order Prenatal, (Antenatal), Perinatal (Neonatal) and Postnatal. These two classification systems are commonly used in medical profession.

Another, simplified classification system classifies h.l. into congenital and adventitious or delayed hearing loss. A hel is congenital when the patient is born with it, which develops in the uterus and may be the result of hereditary or environmental factors. Congenital refers to the time of appearance of the defect and not the mechanism by which the defect is caused. Adventious h.l. is that which develops after birth as a result of hereditary, environmental or treumatic factors (Di Bortolomeo and Gerber, 1977).

According to another system, Prelingual h.l. is that suffered before the development of speech. Hereditary deafness is the result of inherited or genetic factors, dominant or recessive. Familial h.l. is that which affects many in the family but apparently is not hereditary. Di Bortolmeo and Gerber(1977) present a classification system based on whether h.l. appears at birth (congenital) – as a result of either heredity (genetic) or environmental and traumatic influences (acquired) or in delayed h.l., which occurs as early as prelingual years (postnatal and infancy) or later in life,

and may reflect either a genetic defect or in environmental insult which is responsible for such a handicap.

As can be inferred from the above text both the classification systems and the terminologies can be confusing. Hence the read or this report would do well to be aware of the differences in these terms and systems.

3.2 CAUSES OF HEARING LOSS :

Whether acquired or congenital, h.l., as entity, occurs as a result of a pathology. The pathology may be the result of hereditary (or genetic) determined factors or adverse environmental (acquired) factors like bacteria, virus, toxemia or treumatic agents. (Gerber 1977).

Congenital deafness occurs as a result of a pathology during prenatal development, which can be due to a failure cochlear or conductive structures to develop as a result of inherited factors or toxic affects of certain maternal illnesses or drugs during the first 3 weeks of pregnancy. Later during the pregnancy endcorine insufficiency and other biochemical factors may also influence the development of the organ of corti, middle ear and the external ear. These changes may occur any time during the development of the cochlear vestibular apparatus.

The path of acquired h.l. may also be due to infections or drugs or infections. Many areas of the brain, the first organ to differentiate during the embryonic life are succeptible to perinatal damage. They include basal genglie, rhinencaphalon, dantete and auditory nuclei and vestibular systems (Singh, 1979). Ototoxic drugs primarily cause defeneration of HCs, organ or corti and peripheral cochlear naorons. Viremee has been associated with inflammatory and degebrative changes limited primarily to the endolyphatic system.

Congenital melformatine which are frequently seen with deafness may present as abnormalities of inner, middle or outer ear. Since embryonic development of inner ear is different from that of middle or ext. ear the h.l. may occur as s-n, conductive or mixed. Delayed deafness (as in rubella) relates to the degenerative changes of the sense organ after its complete development and may be progressive.

After birth, hereditary or environmental factors may cause degenerative changes affecting scale media, organ or corti and nerve elements including the spinal ganglie and the basal nuclei. In h.l. with late onset genstic factors play a much less role where as environmental factors assume major significance (Di Borotolomeo and Gerber, 1977).

3.3 HIGH RISK FACTORS

HRFs are these factors that exist which may cause an increased likelihood of the development of a disorder or disorder or disability or those that exist which may indicate an increased likelihood of its presence. Behrman (1975) classified HRFs into two categories viz (i) Causal, for e.g. a virus or a teretogenic drug and (ii) Associative, which merely indicate or alert the clinician of a risk, for e.g. congenite anomalies.

HRFs described in this chapter can be either causal or associative or both (a rubella virus in the salive of a baby can indicate both). They include those factors which have been are being employed as HRFs in various screening programs elsewhere and also those which have been considered for this study.

3.3.1. GENETIC HEARING LOSS :

The ability to hear is a genetic trait (Catlin 1978) and so could be the loss of that ability (the cause can be

some environmental factor also). These traits are carried by genes-those complex factors present in the chromosomes which carry an hereditarily transmissible character. Like other traits h.l. is transmitted either by the ordinary paired chromosomes (autosomal) or by the sex chromosomes (X-linked). Inherited deafness can take many forms, including those which are not congenital. About 50% of the children who are born deaf are so because of genetic reasons (Gerber, 1977). The pattern of inheritance varies according to the type and extent of gene(s) involvement.

In autosomal dominant inheritances there is atleast one dominant gene (or h.l. in one or the ordinary paired chromosomes. A hg. impaired parent in this instance will have one normal gene and one gene for h.l. Such a parent is hg. impaired himself and will transmit either a gene for h.l. or a gene for normal hg to his child. Hence, typically for each pregnancy, the chances for the child to be deaf are about 50%. Males and females are equally affected and trait is carried vertically from one generation to the next. When no h.l. results in such a child it is said to be due to "leck of penetrance". H.l. in affected persons often very in severity because of the "variable expressivity" of the genes. Some of these dominant disease types are well known, e.g., Wardenbergs syndrome. Some other forms are characterized by the late onset of the trait in the offspring. Frequently these children are born with normal or near normal hg and without a HRR are liable to be lost to screening (Gerber, 1977).

The autosomal recessive gene is subservient to the gene for normal hearing. Parents usually have normal hearing but are carriers (heterozygots) who passes one gene for normal hg and one gene for h.l. If both parents are carriers the probability of having a deaf child is 1 in 4. Parental consanguinity (see e.e.2.) may increase this probability. Although two deaf parents who have the same recessive gene should technically produces only hg. impaired

children, normal hg children are often borne because many different recessive genes can affect the hg.

The autosomal recessive inherited deafness is the most common type atleast 35% as predicted by Konigsmark (1971). In the absence of other information (for e.g. a metabolic disorders) one has to essume a recessive mode of inheritance (Gerber, 1977). Frequently, with the first born hg impaired child where the parents disclaim any knowledge of h.l. in their relations the HRR will fail. This probably explains the difference in detection sensitivity b/w the HRR alone and HRR supplemented by a behavioral screen. On the other hand, if the famility history is known and /or if the deaf sibs already exist the next sibling must be considered as being inordinately at-risk (Gerber, 1977).

In the X-linked inheritance, the mother carries the gene for h.l. on one of her two X chromosomes. Since X-linked traits are often recessive, the matching gene on the other X chromosome usually allows for the expression of normal hearing. Thus a daughter would escape whereas each son has a 50% chance of inheriting the loss. However, each daughter of a carrier mother stands a 50% chance of inheriting the affected chromosome and thus become a carrier. An affected male can transmit the X-linked trait for h.l. to all of his daughters, making them carriers, but, none to his sons because he can contribute only Y chromosomes to them. Rarely, however, females may manifest X-linked disorder in modified forms since they are heterozygotes and one X-linked chromosome may be randomly dominant. This follows the trend of what is known as Lyon's Hypothesis and thus an affected female can result form marriage b/w an effected male and female heterozygote (Gerber, 1977). X-linked inheritance contributes approximately 3 to 4% of all cases of congenital deafness.

Apart from these gene transmission, chromosome abnormalities like trisomy, are known to cause hg impairment. In trisomy, an additional chromosome as found within a pair (human being have 46 chromosomes in 23 pairs). Such conditions are not necessarily hereditary. Recognized syndromes include the Down's syndrome (Trisomy 21), Trisomy 13, and Trisomy 18 (the number refers to the chromosomal pair which is affected). Multiple anomalies, malformed ears and h.l are frequently seen in these children. Among Down's syndrome children, an incidence of 10-50% sensori neural hg loss is reported. Since they are also very succeptible to upper respiratory tract infections the incidence of conductive hearing loss (3-20%) and mixed hg loss (10-20%) are also reported to be high (Catlin, 1978).

The risk for any parents having a deaf child, it is calculated, is 1 in 1000 or 1 in 2000. If one or both parents are deaf, due to reasons other than hereditary then also the risk is the same. However, if both parents are deaf due to hereditary cause –say of recessive transmission then the risk is 100% when both the parents autosomal recessive deafness is related to the same gene. However, in actuality the risk may be as low as 1 in 200 because it is believed that a number of different genes determine autosomal recessive deafness (Cerrel. 1977).

The incidence of hereditary deafness varies from 11 to 60% in various reports. (Gerber 1977). puts the figure at around 50% of all congenitally deaf. The variation is probably due to the relative distribution of transmission factors, including dominant, receissive, X-linked multifactor genetic properties, mutations and gross chromosomal abnormal abnormalities. These factors can express themselves in varied forms in conjunction with other anomalies. More then 90 types of hereditrary deafness syndromes have been described by Konigsmark and Gorlin (1976).

Thus, it is very essential to determine the family history correctly. Due to its high incidence it is perhaps the most crucial factor in a HRR. Thus while verifying it, it is important for the person giving information to understand the question. It is not just important to ask "did any body have it?" but more so to ask "Who had it?" (Gerber 1977).

3.3.2. Consanguinity.

Human beings are all remotely related. In fact, it can be mathematically shown that most people are remote cousins. Marriage b/w two closely related persons or consanguineous meetings, though a taboo in many places has been an accepted system in certain communities and regions. It is commonly practiced among muslims and in South India. Incidence figures in South India and in certain communities i.e., estimated to be very high, though no definite figures are available, as against only 0.5% of all marriages in the Western countries (Whittinghall, 1965).

Inbreeding often allows two recessive genes, which are comparatively rare in the general population to come together and express themselves. In the case of first cousin marriages (see fig), the chances are that if one parent is the carrier of an allele, the other also is, because the first cousins have two grandparents in common and therefore have that gene in question in common. Thus such marriages provides far more opportunities for rare recessive genes to appear than the general population (Ford, 1967). However, dominant and common recessive phenotypes are not increased among the offspring of consanguineous mating (Whittinghall, 1965).

Genetic steps
Between relatives

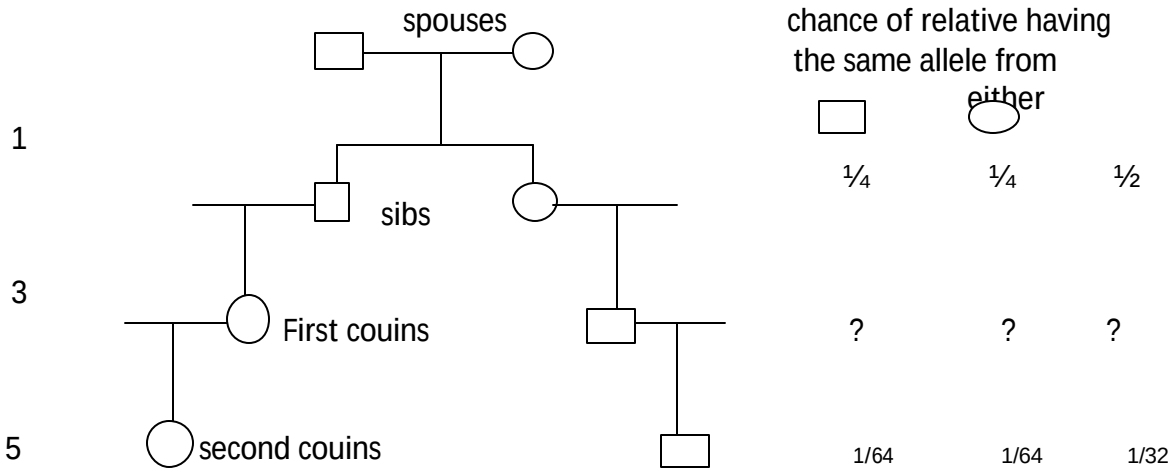

Fig.1: Definitions and degrees of resemblance of cousing (From Whitting hall, 1965).The relationship b/w one parent and one offspring is defined as one genetic step.

The risk of congenital abnormalities in consanguineous offsprings is about thice that expected in the non-conganguinous offsprings (Novitsky, 1977), Nearly 1/3 of all cases of Tay Soch's form of emourotic idiocy in Jewish population results from consanguineous marriages. Ichthyosis congenite, a rare skin disorder is more common in children born of consanguineous marriages by about 50%. Many albinos have parents who are cousins or who are in some other consanguineous unison (See fig.2.).

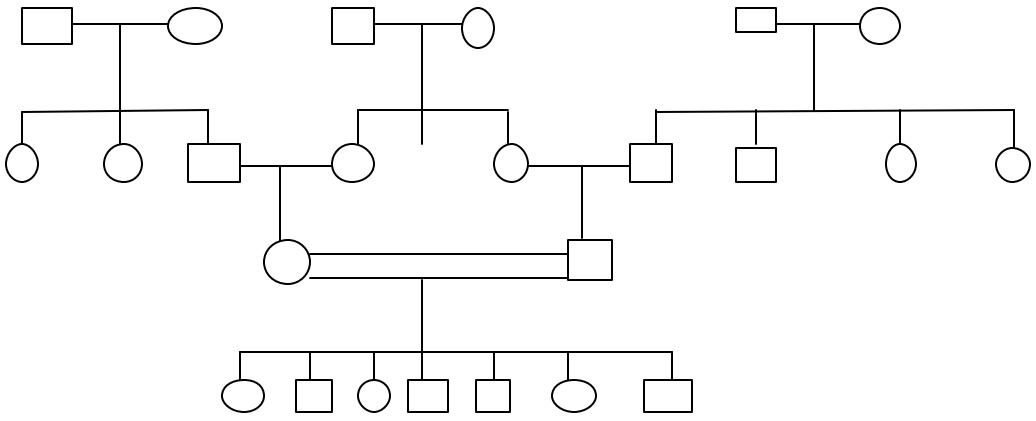

Fig.2 : A pedigree showing the inheritance of albinism in first cousins.

A pedigree showing the inheritance of albinism. In this case the two parents of albinos are first cousins (From Novitsky, 1977).

Deafness as a phenotypes of humans should be considered with caution because of its multiple etilogical factors. In a recent study of all deaf children born in Belgium Antwerp, it was found that nearly 45 of a total of 111 were of recessively transmitted types. The proportion of first cousin marriages among their parents was to high to go with a recessive gene frequency (Whittinghall, 1965). Most traits are recessive and are therefore are most likely to appear in consanguineous offsprings. If non relatives have a 1½% chance of their child having an abnormality consanguineous parents would have a 3% chance of their child being affected. It has been estimated that prohibition of such marriages, as is done in some countries in the west would bring about an eventual reduction of 2.5% of mental defects in the population as a whole, a small yet, a worthwhile reduction (Whinchaster, 1966).

Shah Nawaz (1974) – Survayed the whole population of a village in Karnataka in south india. Gargeshwari is a small village with about 4000 inhabitants who are predominantly maclims. It also has a minority Hindu community, in which system of consanguineous marriage is not commonly observed.

In the Muslim community however, it is a rule more then just a custom. It is laid that the whole Muslim Population of Gargeshwari evolved out of two families. Almost everyone in that village is a first cousin to everybody.

Shah Nawaz found a greater incidence of speech and Hearing problems in this community. The incidence figures were supported to be much higher than both the general incidence

And incidence figures among communities and in regions observing this system of marriage (Ratna 1980).

3.3.3. Complications of Pregnancy.

Maternal well being during the period of pregnancy is very essential for the normal development of the fetus. Majority of the pregnancies pass of unaventually yet, 10 to 20% of pregnancies can be classified as High Risk on the basis of their medical history and over half of all parinatal mortality and mortality is associated with these with these pregnancies (Behrman, 1975). Certain events during pregnancy may increase the likelihood of a host sequel as like abortions, still births, premature births, low birth weight babies etc., Deafness is also one such sequel.

The relationship between deafness and demographic factors like lower socio economic status, maternal age and malnutrition etc., have not been studied in detail. However it is known that the incidence of premature births is highest among women of lower SES (Singh, 1979). Down's syndrome characterizes one of the striking effect of maternal age of 35 – 40 years group. Hydrocephaly and premature births are also more common in such mothers. Very young mothers also show an increased risk of toxemia of pregnancy. Furthermore, CNS malformations are more requent in babies born to women at their beginning or end of their reproductive life (Lansford 1977).

The past pregnancy factors like multiple births, too many children, abortions, still-births have also not been analyzed. The incidence of cerebral palsy children in mothers with history of previous stillbirths is reported to be twice that expected in the community. (1979). Women with one affected child thus seem to run a considerably higher risk of producing another with the same or different affection (s).

Maternal illnesses during pregnancy like diabetes mellitus, hypertension, toxoplasmosis, toxemia of pregnancy and maternal medications like streptomycin and other aminoglycoside salts, quinine salts etc., have been associated with hearing loss. But, the most documented complication seems to be the viral infections like rubella.

3.3.3.1.Rubella, CMV and other Transplacental Infections :

Viruses are nasty little creatures that live long (Gerber, 1977). They are potentially destructive, capable of producing particularly devastating effects on the fetus by crossing the placental barrier while apparently appearing inoccuous or even inapparent in the mother. Rubella and CMV have been well documented as major culprits.

Rubella, popularly called German Measles was first recognized as a disease entity in 1752 by de Berger. But its devastating sequel as became known only after the Australian epidemic in 1939-41 (Lindsay 1961). Its potential to cause congenital deafness become fully known at the time of 1963-64 epidemic in the United States. The John Hopkin's University study has shown that nearly half of those born to rubella exposed mothers had severe hearing impairments. Other common sequel as were cataract, cardiac defects (deafness, cataract and congenital heart defect make up what is known as 'rubella tried'), mental retardation etc., (Bordlex at el, 1967). Rubella birth has a long life and hence can be isolated even after birth.

A susceptible mother usually acquires rubella infection by airborne spread. Infection is not apparent for about a week during which time patients are infectious because they carry the virus in their thro at and urine. Most patients are unware of the infection. During this time the virus is carried in the blood stream, may infect the

placement and in about one case in three also infect the fetus. After about a week of subclinical in action the mother may exhibit clinical symptoms which may be so mild as to go unrecognized. Lymph gland inflammation, mild respiratory problem and rash follow in that order. Characteristically the rash begins in the face and fades rapidly. The rush may be discrete or confluent almost resembling that of scarlet fever. It typically lasts for three days. Fever, headache, joint swelling and malaise may follow. In severe cases encephalitis may be a serious complication. Unfortunately other viral infections also resemble rubella (Bergstrom, 1977).

The incidence of rubella sequelse is directly related to the time of onset. In the first month 50% are affected, in the second, 22%; and 6 to 10% in third, fourth and fifth months (Pumper and Yamashiroya, 1975). The fetus which is infected very early, if it survies the term, is at birth, small for questional age because his body shows fewer cells than it should. The clinical picture of the baby is typical : he is has so called “blue-berry muffin”, is micrecephalic, has kidney, heart, muscle, bone and CNS malformations, has cataracts, is deaf and is retarded mentally and physically. Since the virus persists for long, his CNS, eyes and ears may progressively get affected. The child infected in the 2^{nd} and the 3^{rd} trimester may also be deaf or may develop deafness later. Most affected children show only sensori-neural h.l. and few conductive or mixed (Bergstrom 1977).

Cytomegalovirus infection is another viral disease which manifests very much like rubella (Gerber 1979). It is ten times more common than rubella (Bergstrom, 1974). The infection is asymptomatic in the mother and hence is hard to diagnose. The organism may cross the placenta after the viremia of mother, or the infant may be infected by ascending

infection from the cervix or intra uterine infusion. Though it is said to be the most common cause of perinatal infection, virtually all affected neonate are asymptomatic they appear perfectly normal.

The most common sequel is mental retardation. Hydrocephaly, ancephalitix, cerebral calcification, seizures, hemolytic anemia, blindness and chorioretinitis are some the reported sequelse. It is the most common viral cause of mental retardation (Gerber 1979). Focal involvement of eye, ear, kidneys and CNS may occur and some studies have showed a fairly high incidence of sensori-neural hearing loss (Bergstrom, 1977). It may be progressive in nature. In many, thus many infects born with perfectly normal or near normal hg may become progressively deaf. Often its progression is irreversible.

Other infections have also been implicated sporadically. Measles (rubella) virus has been shown to cross the placental barrier and act as an abortificent but is role in causing h.l. is not clear. Congenital syphilis is know to be transmitted from the mother to the fetus after the 4^{th} and 5^{th} month. Though it affects the eyes more than the ears it has been to shown to cause permanent and progressive neurosensory hearing loss (Bergstorm 1977). Paparella and Capps (1973) report that usually one ear is affected first and then the other in such infants. Onset of deafness can be sudden, anytime from late childhood to age 20 years.

3.3.3.2. <u>Maternal Illnesses</u> :

In general the fetus is well protected and insulated against adverse physical, chemical and biological insults. <u>Y</u>et, few maternal conditions, some peculiar to the mother may jeopardize the fatal safety (Singh 79). Though they may

not directly enhance the risk of the infant developing a congenital condition like deafness. They may however, lead to conditions which are high risk themselves. Also drugs given to the mothers for their management may also adversely increase the risk.

Toxemia or pregnancy is a disorder in which the mother present with high blood pressure, edema (swelling) or pertain in urine. In most severe cases eclampsia which results in convulsions and coma may result. Babies of such mothers are much risk (Lansford, 1977). Similarly, babies born to diabeteric mothers due to their large size are often delivered preterm or be cessarian section, and are susceptivel to trauma, bruises, birth asphyxia and run a greater risk of hyaline membrane disease a serious condition. Incidences of congenital malformations in diabetic mothers is almost double the general incidence (Singh 1979).

Malaria, which is quite virulent in India, can indirectly indicate a risk. Chloroquine phosphate, an antimalarial and antiameobal drug is an abortifacent in large doses. In lesser doses it may simulate an imminent abortion and may endeger the fetus safety. Its ability to cross the placental barrier has been recorded (Lindsay, 1974) and there are reports of its potential ototoxic effects on the fetus (Hart and Naunton, quoted by Lindsay, 1974). Toxoplasmosis, a parasitic infection is also known to cause fetal damage. (Lansford, 1977).

3.3.3.3. <u>Threatened Abortion</u> :

The first three months of fetal life within the uterus is very crucial for fetal safety and its normal development. Any illness or problem during the first trimester of pregnancy can effect fetal development adversely.

If it fails to abort the child. Bleeding during the first three months, known as antepertum Hemorrhage of the I trimester indicates a risk to the child (Kamala 1980).

3.3.3.4.Transplacemental Ototoxicity :

The developing fetus is immature both structurally and functionally. When a pregnant woman is administered a drug there is an unwanted and unavoidable exposure of her unborn child to the same agent. A drug which is apparently safe and well tolerated by the mother may be harmful and damaging the fetus.

The drug reaches the fetus through the placements and to a lesser extent Via the amniotic fluid. The permeability of the placenta increases as the pregnancy advances but the vulnerability of the fetus decreases as the maturity proceeds. Thus the first trimester is the most vulnerable period as it is characterized by organogenesis and any alteration in the fetal environment during this period may lead to developmental defects (Singh, 1979).

Nearly 1/3 of the pregnencies involving quinine drug therapy are known to end in abortion. Certain other drugs are known for their teratogenic action (tendency to produce physical defects in the fetus is called the teratogenic action). Streptomycin which is used to combat tubercular infections and certain other drugs of the aminoglycoside group (see section 3.3.9), chloroquine of the quinine group (Mckiwe 1966) have been frequently implicated though not proved conclusively. Combination of certain drugs like Kanamycin and certain diuretics has been shown to be more potentially ototoxic then either drug alone. However, it is not yet known what makes certain fetuses more susceptible than others. The relative susceptibility of the fetuses seem to be related to the effectiveness of hemolabyringhine barrier which is

presumed to be related to genetic factors (Hawkins, 1977).

3.3.4. Birth Complications :

Every birth is unique. It is a big even for every child, when it has to leave its well protected environment and established his ability to thrive outside the uterus. Though it is big chance, most children do it uneventfully, without much difficulty. However, some face problems. Some have difficulty coming out, some do it hastily or reluctantly. Some have difficulty after coming out and few unfortunate ones do not survive the stress and strain. It is estimated that nearly 6 to 10% of all deliveries in India are eventfully someway or the other (Savitha Rani et al., 1979). 13 to 14% of congenital deafness causes have been attributed to traumatic births (Carrel, 1977).

3.3.4.1 Delivery complications :

The normal presentation for a baby during birth is the head down with the occiput anterior (head first). Abnormal presentations which often which often cause difficult deliveries are breech (in which one or both first come first or the rear is first), transverse lie (cross ways) or chin, shoulder or for head first.

Forceps are commonly used in difficult deliveries which is an HR indicator in itself. Forceps deliveries are commonly associated with temporary facial palsy. Similarly, almost all indications for cesserian section are high risk indicators themselves, any cause for delay in labor, fetal distress, severe toxemia, severe high blood pressure, diuretics, history of repeated still births with no specific cause found, Rh incompatibility, cervical carcinorme of mother etc., (Lansford, 1977).

Precipitated delivery, difficult forceps, and vaccum

extraction in a large baby and other abnormal presentations may be associated with intracranial hemorrhage (Singh, 1979). Severe deafness has been known to occur in cases of breach presentation born with the cord wound twice around the neck" and producing severe asphyxia or hypoxia (Lindsay 1973). Deafness has been attributed to nuclear lesion as a result of asphyxia in such cases. Any birth injury thus suffered, as a primary etiology of hg. loss in children is cited o be ranging from 0.3% (Shimzu, 1976) to 2.5% (Schein and Delk, 1974).

3.3.4.2 Prolonged Labor :

Labor that lasts longer than 24 hours in classified as prolonged labor. Most common causes are Fetopelvic disproportion, malpresentation, malpostitioning and inefficient uttering action. Certain accessory factors like premature rupture of membrane, excessive analgesia or anesthesia also precipitate prolonged labor (Oxhore and Foole, 1975).

Any type of prolonged labor is bed for the child. Longer the labor, higher the morbidity and mortality. The fetus in exposure to the risk of asphyxia from the long labor itself as cerebral damage caused by prenure against the fetal head, injury as a result of forceps rotation and extractions or infection as a result of premature repture of amniotic bag. However, some feel that prolonged labor has little effect on his subsequent development while other claims to have found more intellectually deficient children in the population. Though mode in methods have decreased the incidence of prolonged labor, nearly 1-7% of deliveries are said o be prolonged. (Oxhorn and Foole 1975).

3.3.4.3 Birth Asphyxia and Cyanosis :

In utero the placenta serves to transfer nutrition and oxygen to the fetus. After the separation from the mother,

The baby must breathe immediately or must be made to breathe because within two minutes of tying the cord the child's arterial oxygen tension reduces drastically resulting in asphyxia (Singh, 1979). One frequent cause of birth asphyxia is the compression of the umbelfical cord b/w the pressing part and the pelvic tissues during the process of labour and delivery. It may also be caused by inadequate maternal blood oxygenizetion, low arterial blood pressure, inadequate relaxation of the uterus to permit placental filling, inadequate attachment of the placenta or placental inadequacy as in toxemia and post maturity (Lansford, 1977).

Birth asphyxia or hypoxia (Apnea or dyspnea) is the leading cause of perinatal death and permanent damage to CNS. Cerebral depression or seizures may occur due to cerebral ede, anoxic brain damage and intra cranial bleeding. Birth asphyxia is the commonest medical emergency among newborns and is one of the leading causes of neoratal mortality in India (Singh, 1979).

If the baby stays in an hypoxic state for long, its heart slows blood pressure falls and then it lapses into terminal apnea. The baby appears pale rather than blue (Singh, 1979) – a condition known as Cyanosis. Prognosis is relatively adverse especially when the heart beats are absent at birth or if the baby gets Apge score of less than 4. They are more prone to develop sequelse of brain damage.

The hypoxic infant has long been known to be at risk for neurosensory deficits including hearing impairment. Reported incidence ranges from 8.9% (Shimzu, 1976) to 10% (Marcus, 1976). Apgar score of less than 4 has been used as a HRF (Feinmesser and Tell, 1974). Significant asphyxia with acidosis (a common sequel) has been recommended as a HRF by the Saskatoon conference (See appendix 2: statement are significant asyphyxia).

Devised by Dr. Virginia Apgar, as a guide to prognosis and better observation and care in delivery room and nursery. The baby is evaluated 1 minute after birth for 5 objective signs viz., heart rate, respiratory effort, muscle tone, response to catheter in nostril (tested after the asophegus is clear) and color. Each sign is given a score of 0.1 or2. A total of 10 indicates that the infant is in best possible condition. Thomas McGay and Mark Smith (1975) in Nelsons Textbook of Pediatrics, X Edn, Longon.

3.3.5 Low Birth Weight.

The weight of the newborn is dependent upon the quantity of subscutaneous fat which is accumulated mostly during the last trimester of pregnancy (Achar, 1969). Average birth weight for an Indian baby is b/w 6 to 6½ lb (depending upon the SES of the mother) as compared to 7½ to 9½ lb for European and American newborns. Usually, babies with a bw of less than 2500 gms irrespective of the period of gestation are classified as 1 bw. (WHO, 1962: Singh, 1979). These include both the pre term (babies born before 37 weeks from the first day of the last menstrual period-usually called premature babies) and also term small for dates (children born full term but weighing below 10^{th} percentile for questional age or those who fall below – 2 SD) (Behrman, 1975).

About 30 to 40% of babies born in India are LBW as opposed to 6 to 7% in the Western contries. (Singh 1979). Their higher incidence in our country is hribuited to a higher number of babies with less than normal intra-uterine growth rather than pre term babies. Rampant malnutrition, climatic and racial factors and SE factors have been indentified as possible possible contributors (Achar. 1969). Babies weighing less than 2000 gm who are

more culnerable to disease and distress account for nearly 10% of total all babies born in India (Singh, 1969).

Similarly 8 to 10% of newborns are born pre term in India as compared to 5 to 7% in West (Singh, 1979). These infants are anatomically and functionally immature. A host of causes have been identified but it is difficult to pin-point any one factor for a particular child. These children are more pre-disposed to infection, toxicity, asphyxia, distress reaction etc., prematurity with or without other factors carries a higher risk for CNS problems (Catlin, 1977). The incidence of Congenital anomalies is twice as much as in term babies (Singh, 1979). Prematurity and low birth weight are usually seen together, particularly in infants weighting 1500 g or less and are associated with greater mortality and morbidity incidence. (Lansford 1977).

There is a higher incidence of both neurological and mental handicaps in low babies. Babies mainourished during the later part of their gestation retain potential for normal physical and mental growth. But those who are small for data due to intre uterine infection or certain genetic and/or chromosome disorders which affect their early embryonic development show a high incidence of congenital anomalies. Many of them suffer permanent mental and physical growth retardation. The incidence of congenital anomalies in small for dates is10 to 20 times higher than in normal population (Singh, 1979).

These infants may also be more succeptible to maternal rubella (Lubchanko, 1972). Funaki (1978) report a higher incidence of H.L. in 1bw babies than in premature babies and conclude that physical under development of the hearing organ

may be crucial factor. Similarly, Clarke and Conry (1978) implicate 1bw syndrome but also found that their bilirubin level (see 3.1.6) and Incubator times are significat predicators of sensorineural h.l. Lubchenko et al., (1972) suggest that a combination of gestational age, birth weight and pattern of uttering growth is needed in selecting infants to be followed in order to distinguish b/w normally grown infant of short gestation and the infant with intrauterine growth retardation.

Bothe Nova Scotia and Saskatoon conferences have recommended a birth weight of 1500 gm or less as a HRF. However, Feinmesser and Tell (1976) found that of the 26 deaf infants they found, one would not have been classified as LBW with the 1500 gm criterion but would have been included if the criterior were to be 2000 gm. Hence, they recommended raising of the 1bw criterom. Moreover, many hospitals use 4lb (1800 gm) as their criterior for better care. Many large scale samples of congenital deafness show that 8 to 10% of children who are deaf would be classified as HR in the criterior were to be 2000 gm, who may or may not be classified on any other HRF. However, the National Joint Committee has recently reaffirmed 1500 gm as the criterion opining that redefinition would lead to an unduly large follow up population (Gerber 1977).

Many 1bw and premature babies spend quite some time during their early life in incubators (Isolattes). Thus the time they spend in them could be an indirect H.R. Indicator. Oxygen therapy, incubator time as a indicator of immaturity level and hence CNS damage, and even incubator noise (Cruz and de Izinery, 1976) are being analyzed as HRFs. Their combined effects on the hearing of the newborns is open to question and research.

3.3.6. Bilirubin Toxicity

Bilirubin is a product of red blood call break down. Its high concentration in the blood is toxic to the newborn brain. There are two kinds of bilirubin products. One is byproduct of hemoglobin break down called indirect-reacting or unconjugated bilirubin. The other is the by product of this itsel, after the unconjugated bilirubin has been converted in the liver cells into conjugated on direct-reacting bilirubin. The unconjugated bilirubin is neurotoxic in infants at high concentrations and under certain conditions. Accumulation of this bilirubin in any organ leaves it distinctly yellow stained. This condition is called Jaundice or Icterus.

Jaundice is the commanest abnormal clinical finding during the first week of life. Clinical jaundice manifests at a serum bilirubin (concentration of the bilirubin in the blood serum) level of 4 mg% (ie., every 100 ml of serum contains a bilirubin concentration of 4 mg). Yellow coloration is first evident in the eyes, on the skin of the face, assolabial folds and nose tip. As the extent of bilirubin accumulation in the skin increases trunk, abdomen, actremeties, palms and soles become yellow in the order. Yellow staining of the trunk indicates a level of 10-15 Mg% and when soles and palms are distinctly yellow stained the accumulation is said to be more than 15 Mg% (Singh, 1979). Some, however, maintain that the extent of coloration is in no way related to the level of bilirubin concentration (Behrman, 1975).

Many conditions lead to Jaundice. The most common causes of jaundice, in their order of frequency of occurance in India (Singh, 1979). Physiologic jaundice (functional immaturity of the liver), prematurity, blood group incompatibility b/w the mother and the fetus (both Rh and Abo group

incompatibility), G-6-PD iso-immuno enzyme deficiency, Pre and Post natal infections, subcutaneous bruising and caphalhalmatoma, drugs (such as vitamin K) and breast-milk jaundice.

Bilirubin accumulation in the order of 15 mg% or more is considered potentially neurotoxic depending upon the state of the infant (in premature and 1bw babies, a lesser level is indicated). Only few conditions, however, can result in such a high level of bilirubin accumulation like the Hemolytic Disease of the Newborn (HDN) due to Rh or blood group incompatibility. Incidentally, ABO incompatibility, though less severe in its affect than the latter in India. This has been ascribed to the low incidence of Rh negative women in India-only 2 to 7% as against 15% in white races (Achar, 1969). Rarely infections such as toxoplasmosis, CMV, syphilis, rubella etc., or other conditions result in such high serum bilirubin accumulation (Behrman, 1975).

The day of onset of jaundice gives an important clue to the possible etiology and differential diagnosis of the conditions (Singh, 1979; Behrman, 1975, Achar, 1969). Onset on the first day is always suggestive of a serious disesase process like HDN which is more likely to cause bilirubin toxicity or encephalopathy. It if appears on the second or the third day it is usually physiologic jaundice but may also ba due to hyperbilirubinemia. Jaundice appearing after the 3rd day and within the first week should suggest septicemia as the most likely cause (Behrman, 1975).

If the serum bilirubin reaches a high level (usually around 20 Mg% in a full term infant) and exchange transfusion is indicated, which replaces about 50% of the baby's blood.

Any child whose bilirubin level has risen high enough to have necessitate an exchange transfusion is at risk of having bilirubin encephalopathy. The most severe type of bilirubin encephalopathy is called Karnictures or Erythroblastosis, Thrombosis. These babies are usually severely retarded, have cerebral palsy and have a hearing deficit (Lansford, 1977).

It was in 1950 that Goodhill pointed out that Rh factor incompatibility produce a certain specific type of deafness called "Cochlear Nuclear Deafness" (Goodhill, 1968). Later on, Dublin, (1974), Altenau (1975) and Chisin et al., (1979) confirmed that high levels of bilirubin accumulations causes damage to cochlear nuclei and thus cause a hg. loss. The incidence of hg. loss among hyperbilirunemic children is high. Stever (1974) found 8 deaf children in a sample of 82 hyperbilirunamic children.

Bothe high serum bilirubin level and exchange transfusion have been used as HR indicators in various studies. The National Joint Committee recommended "20 mg% or any free or indirect serum bilirubin concentration which is judged to be potentially toxic". This leaves two quantitative questions "Who judges it?" and "what is the level that leads to such a judgement?" Unanswered (Gerber, 1977). Keeping the established pediatric examination in view Garber 1977) opines". Perhaps we should return to Goodhil criterior of12 mg/100 ml in the full term infant and 15 mg/100ml in the 1bw infant". However, the Saskatoon Conference has re-endorsed its earlier recommendations (Mencher, 1978).

3.3.7. <u>Congenital Oral Facial Anomalies</u>.

Most oral facial anomalies are sufficiently bizzare to be immediately obvious at birth. It does not require a specialist or a questionnaire to determine if an infant is born with one ear completely closed off. /oral facial anomalies

Frequently incorporate hearing impairment among their stigmata (Gerber, 1977) Stool (1975) observed that any child with an unusual appearance should be assumed to have a hearing impairment until it can be demonstrated otherwise. Sometimes it is limited to conductive apparatus, as in Treacher Collins Syndrome or to cochlea, as in Wardenberg syndrome and sometimes to both, as in Hurler's syndrome. Other congenital defects are often seen accompanying deafness (Gerber, 1977).

Fraser (1964) found in his sample, 2½% had a cranial facial syndrome, 7? had goiters, 3% had retinitis pigmentose and another 2¼ had pigment abnormalities. Brown (1967) reported that Pendred's syndrome is the most common syndrome which included deafness and various anzyme defects are also associated with deafness. Fraser (quoted by Brown, 1967) found that Usher & s syndrome characterized by progressive blindness associated with retinitis pigmentose with congenital severe deafness is the second most commonly occurring, identifiable syndrome. Similarly cardiac defects (e.g., Jarvell and Lange Nelson syndromes), skeletal anomalies (e.g. Apert's), pigmentary abnormalities like partial albinism) are associated with deafness.

Congenital oral facial anomalies with deafness account for nearly 20% of those who are born deaf. This emphasizes the special need for careful examination of the child at birth. NJC in its 1973 statement (see appendix) has called particular attention to "residual anomalies of the otrhinolaryngeal system".

3.3.8. Neonatal Infections

Children, especially infants in the first year of life are particularly cusceptible to infections. They account for nearly 20 to 30% of pediatric medical admissions in India (Achar, 1969).

Portuatal infections account for a large percentage of postnatally acquired deafness (Catlin, 1977). The NCDP (National Council for Deafness Project) study conducted by the National Association of the Deaf (NAD) in 1971 quoted meningitis 9.17% scrlet fever, measles and partusise combined (13.11%) and a third category other illness (13.2%) and trauma (5.1%) as most common etiologies for the postnatal onset before 19 years of age (Catlin 1977).

Meningitis may be asceptic or exudative (suppurative). The latter type is most frequently associated with hearing loss. However, its diagnosis in neonates is missed because of its a typical clinical picture (Singh, 1979). As consequences, 25 to 30% show multiple handicaps, 9.8% having more than one handicapping condition beside hearing loss (Catlin, 1977). Aphasia, mental retardation, emotional disturbances and cerebral palsy are also seen. Hearing loss may also occur due to ototoxic drugs frequently used in their management. The cause of deafness has been said to be due to extension of infection from the meninges. Convulsions are common and occur early (Achar, 1969).

Encephalitis or brain fever is not uncommon in India. In fact, it has sporadically reached epidemic proportions in many parts. The convusions occur in sever infections. The cause for hearing loss in encephalitis is said to be toxic neuritis involving the eighth nerve (Lindsay, 1974). Because of its frequent epidemic outbursts its relation to hearing loss has to be investigated further.

3.3.9. Ototoxic Drugs.

Ototoxicity denotes the tendency for any chemotherapeutic agent to cause functional impairment and cellular degeneration of the chchlear and vestibular and organs (Hawkins, 1977). Many well established and well known drugs frequently used to combat life threatening infections are

known to ototocic. Drugs of the Deoxystreptamine Aminoglycoside group such a streptomycin. Kanamycin, neomycin, gentamycin, chioro uine of quinine group are known for their effects. Certain Saticylates like acatylralicylic acid (Gignoux et al. 1966, Jarvis 1966) and divietess like ethacrymic acid (Venkateshwaren 1971) and prusmide (leoyd Mostin and Lord 1971).

The mode of action of there ototoxic drugs has been generally interpreted as a direct tonic action on the sensory cells of the spiral organ. (Hawkins 1973). Their toxicity is related to the high concentration of these drugs in the inner ear fluids, and specifically to the fact that they are retained there for a long time (stupp et al 1973). It has been suggested that there exists a 'blood-ear' (hamato labyrinlline) barrier corresponding to but less effective than the blood braing barrier (Hawkins Jr. 1973). This, possibly explains why unfortunately the ears suffer evade fortunately the brain gets away.

Contrary to popular beliers that these drop are have get only when injected, they are potent even when they are adwousted orally or topically (Ballautyus 1973).

Table – The ototoxic autibiotics (from stap et al 1973).

Streptomycin	Fremycatin	Neomycins
Dihydro streptomycin	Vaccumycin	Gewlaycins
Kanamycins	Palamamycin	
Viomycin	Aminosidine	

However, ototoxicity of the newborn seems an unduly mysterios subjects(Hawkins 1977). Many claim that their potential ototoxiocity is diminished due to relatively high frequency of renal clearance in the newborn. On the other

hand, premature and 1bw infants seem highly susceptible because of their renal inadequacy. Furthermore, many ototoxic agents are also known to be nephrotoxic and thus they may increase the danger of ototoxicity. Nevertheless, ototoxicity is of specialsignificance in India because they are widely used in combating tuberculosis, tubercular meningitis and other infections which have a high prevalence rate (singh 1979).

Streptomycin salts are very effective against tubercular infections like pulmony tuberculosis, meningitis etc., have been in use since 1953. Their otoxic and vestibulotoxic affects were disordered soon after its introduction. 2 to 3 gm of the drug per day given for 30 to 40 days produces vestibular symptoms and larger doses causes denge to cochlear apparatus. Usually it is terminated soon after the onset of vestibular symptoms. Dihydro streptomycin which was sought to replace streptomycin sulphate (which caused debilitating vestibular symptoms) was later discovered to be more ototoic than the sulphate salt. Its delayed action made control difficult and the drug was soon withdrawn from the market. Although its use in infants is uncommon, Hawkins 1967) reported that more than half of children in a study who received streptomycing sulphate had hg. loss Ranta (1958) found that 62% of his sample had hg. loss (usually an abrupt loss located b/w 1 and 8 KHz.) with total deafness in 7% only 18% of the other drugs neomycin which is used to treat certain diarrheal disease is a very potent ototoxic drug. Fortunatally, it is not commonly used with infants. Kanamycin and Gentamycin used very affectively with specific infections however, said to be not ototoxic in early infancy. All said, the triple therby strategy of streptomycin. Isoniezid and pare amino salicylic acid and short duration of therapy has said to have reduced the chance of ill affects of these drugs (Hawkins 1977).

3.3.10 Parental Concern

Mc Area (1970) speaking as a mother of deaf child has this to say : "When he was 7 days old. Our car door was faulty and to close it we had to being it several times. The driver scolded us saying that we would upset the baby, but, Janie lay in his carry-cot staring at the ceiling of the car. No blink, No jark. No response at all. After 6 weeks my husband began to worry and he devided his own tests".

Parents detect about 70% of the cases of hearing impairment in the children. (Wallace, 1973). In fact, often they are the first to detect the impairment. Middel and Vernon (1971) suggest that evidence of hearing impairment is present as early as two weeks after birth. But, the discovery may be slow process related to the nature of the parents personality, parents relationship with the other members of the family, ordinal position of the deaf child and the importance of verbal language to the family and culture (Backar, 1976). Thus, parental concern has cought the attention of many as a important indicator of the risk.

On the other hand, Northern and Downs (1974) and Shah et al., (1978) report 11 and 18 months, respectively as the average age naïve parents suspect deafness in their children. Mahoney and Eichwald (1979) found that parents became better reporters with the advancing age of the infant, regardless of educational efforts they undertook to increase the awareness.

Nevertheless, the Saskatoon conference did recognize the importance of parental concern and urged "In case of parental concern about hearing impartment, it is recommended that a child of any age be immediately referred for audiologic evaluation". The Utah project (Mahoney and Eichwal, 1979)

and Colorado projects (Garkin, 1980) have employed parental concern as high risk indicator in their material questionnaire. In fact, in the Utah project the final at-risk classification is done only if the parents have concern about their child's auditory behavior as reported at 6 to 8 months of life on the follow-up questionnaire. Thus, utilization of parents in the screening of their own children seems a significant step towards the better utilization of the concept of high risk.

3.4 HIGH RISK FACTORS CONSIDERED IN THIS STUDY

The following is the list of HRFs included in the questionnaire.

1. Family History of Hearing Loss
2. Consanguinity
3. Maternal viral Infections
4. Any Pregnancy Complications
5. Threatened Abortion
6. Any Maternal Medication
7. Delivery Complications
8. Birth Asphyxia
9. Cyanosis
10. Smallness at birth
11. Jaundice soon after birth
12. Blood Transfusion soon after birth
13. Any Rh or Blood Group incompatibility
14. Birth deformities of head, ear, nose and throat
15. Any Neonatal Illness
16. Siexures
17. Unconscious episodes
18. Any injections given to the neonate
19. Parental concern about hearing
20. Parents' evaluation of their child's hearing
21. Parents' evaluation of their child's speech & Language.

CHAPTER-4

THE QUESTIONNAIRE

4.1 High Risk Registration Methodologies.

- 4.1.1 Medical Records.
- 4.1.2 Quarry – Interview Method.
- 4.1.3 Legal Documents.

4.2 Options in India

4.3 The Questionnaire Method.

- 4.3.1 Purposes of a Questionnaire.
- 4.3.2 Uses of a Questionnaire.
- 4.3.3 Criteria for and efficient Questionnaire.
- 4.3.4 Types of Questions.
- 4.3.5 Sequencing of Questions.
- 4.3.6 Merits and Limitations of a Questionnaire.

4.4 The Questionnaire

- 4.4.1 The Respondent
- 4.4.2 The Language
- 4.4.3 The Pretest
- 4.4.4 The Data Recording sheet

4.5 The Questions.

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4.1 HIGH RISK REGISTRATION METHODOLOGIES

A HRR can be easily maintained by entering the name and risk information along with other details of those babies suspected to be at risk of developing a hearing loss. Various methods have been employed to collect particulars for risk classification. Functionally the sources of these information can be divided into the following three:

4.1.1 Medical Records

Investigators or volunteers can rummage into case history forms and other medical records and identify conditions relevant to the HRR. This has been successful where detailed records of every birth are maintained. But this cannot serve as the sole source, however exhaustive or efficient the system of medical records may be. Often, the records do not contain all the information needed for HR classification. Interpretation of varied medical terminologies, abbreviations and even handwriting is often problematic. In many places legal complications concerning the confidentiality of medical records arise.

4.1.2 Quarry-Interview Method :

A written questionnaire is administered to mothers at some time after the baby is born. This is usually followed by an interview to cross check the answers. By far, this has been the most employed method because of its ease and effectiveness. Few programmes, like the two Utah programme (see Sec. 2.63 & 2.7.1) have employed the questionnaire alone. Low return rate, high rate of false positive answers and reliance on literacy, coupled with the drawbacks of the questionnaire method itself (see Sec. 4.3.5 below) seemingly reduce the efficacy of this method, when employed without an adjunctant interview. A personal interview, along with its own advantages, also allows for a visual examination of the baby for any congenital malformations.

4.1.3 Legal Documents

In many countries, where most births are conducted in hospitals the birth certificate is a mandatory legal document. They are required to be filled by either the supervising physician or the parent or by both. Birth certificate employed in many places contain certain medical information which may be useful for risk categorization. The Utah state-wide high risk programme (see sec. 2.7.1) has been utilizing this source very effectively. The fact that this system of birth registration often employs computerization data retrieval and classification are made much easier. However, the birth certificates may not contain all the information needed for risk categorization. In much cases, modification or extention of details entered into the birth certificate is necessary which involves legal procedures. If it is successfully exploited, it is the only system that can ensure 100% screening rate.

4.2 OPTIONS IN INDIA

India is a developing country and as such has not been able to afford the king of health care benefits many of the developed countries have been providing. Unlike in countries like Sweden and Denmark where virtually all deliveries are conducted in hospitals, barely 3 to 5% of the deliveries in India are conducted in Hospitals (Savitha Rani et al., 1979). Possibly, another 5 of deliveries may be medically supervised. Except in few, big, well equipped hospitals confined mostly to metropolitan cities, there hardly exists a system of maintaining a detailed case history for every birth. As such, risk information from case history or medical records seems a distant proposition.

Though every live birth has to be legally registered in our country barely 20 to 30% are actually registered! Our birth registers hardly contain any medical information needed for risk categorization. Thus, legal documents like birth certificates are unlikely a choice as potential sources of high risk data.

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1. Manorama year book (1979) Manorama, Kottayam

According to 1975 census only 18.7% of women in India are literate[2], meaning just able to read and write. Most of the literate women live in urban areas. Even if we assume that atleast high school enrollment as the level required to enable the mother to read and answer a detailed questionnaire, only 9.12% of a total of 105.7 million mothers[3] could be administered a written questionnaire. Moreover, unlike in western countries this population of mothers available to fill a questionnaire is not easily accessable. All these, coupled with the inbuilt drawbacks of the written questionnaire itself. (see sec, 4.3.5 below) seemingly make it virtually impossible to employ a written questionnaire as a source of high risk data. However, it may not be so bleak a picture. We can utilize services of Basic Health Workers (BHWs), Auxillary Nurse Midwifes (ANMs) and other social workers to help mothers fill the questionnaire. If this approach proves feasible, it will supplant the additional advantages of scheduled interview method to this method (see below).

Presently a scheduled interview with the mother seems to be most logical choice. Inspite of the projected unsophistication, illiteracy and social conservation she seems to be the only potential source of information relevant to high risk registry. It is quite likely that she will remember most details of events during her pregnancy, of the delivery, the physical appearance of her child at birth and events during early post natal life of her child. In fact, the basic premise of this study is that every mother, if approached in a manner acceptable to her, her family or her community, can be a very useful source of information relevant to a HRR. This would mean that we may have to interview 2500 mothers every year in Mysore District alone, which has a conservative population of 15,000,00 in which 2500 children are born calculated at a rate of 35 per 1000.

2,3. The times of India Directory and year book (1978) The Times of India Press, Bombay.

4.3 THE QUESTIONNAIRE METHOD

Among the data collection methods interviews and Schedules have the distinction of being capable of collecting a great deal of information through fairly straight forward questions. Only in such cases as income, family problems, sexual matters etc., wherein reluctance, unwillingness or just inability of respondents, they may fail to collect the desired amount of information (Karlinger, 1973).

Questionnaire is the term used for almost any king of instrument that has questions or items to which individuals respond. Usually they are of two types, namely Schedules (interviews set on a pre conceived schedule) and Self administered (written questionnaire). Few, however, consider the term 'Questionnaire as more applicable to a self administered (written) questionnaire. (Kerlingar, 1973).

4.3.1 Purposes of a Questionnaire:

The questionnaire serves two purposes it translate research objectives into specific questions with minimum distortion of the response it elicits and secondly, it assists the respondent to communicate the required information (Kerlinger, 1973).

4.3.2 Uses of a Questionnaire : Its uses are many viz., (Kerlinger, 1973)

i) can be used to study relations and to test hypothesis;
ii) can be used as an exploratory device to identify variables, relations, to suggest hypotheses and to guide other phases of research;
iii) can be used as a main instrument of research rather than as more information gathering devices;
iv) can be used to supplement other methods used in a research study follow up unexpected results, validate other methods, and to go deeper into motivations of respondents for responding as they do.

4.3.3 Criteria for an Efficient Questionnaire : Basically they should fulfill two important requirements (Kerlinger, 1973) viz.,

i) It should be reliable: Interviewers must be trained, questions must be pretested and revised to eliminate ambiguities and inadequate wording. It should be shown to be able to gather data in much easer and better way then other methods.

ii) It should be reliable: It should be free from interviewer bias and must be tested for unknown biases. Particular research problem and the nature of information sought must, in the last analysis dictate whether or not these methods will be used.

4.3.4 Types of Questions :

Basically there are two types of questions or schedule items. (Kerlinger, 1973) viz.,

i) Fixed Alternative (Closed) Type : As the term suggest they force the respondent to respond in given alternatives. Usually, a dichotomized YES or NO choice is given. Some add "Undecided" or "Not sure" and even a "Does not know" alternative. They provide for greater uniformity of responses and elicit desired responses to fit previously devised categories and be thus more reliable. But, there is a danger of superficiality and inaccurate alternatives. A respondent may prefer an inappropriate alternative then conceal ignorance. However, when judiciously used with probes and cues and mixed with open-items (see below), they can be very useful.

ii) Open End Type : They are flexible and allow for in depth questioning, can clear up misunderstanding through probing, detect ambiguity, encourage cooperation. Some times they elicit unexpected answers which may be useful. They are very useful in interviews.

A special type of Open-end question is a 'Funnel' question. It starts with a broad question and narrows down progressively to the specific point. Or, it may start with an Open general question and follow up with specific closed questions. This approach avoids distortion of a question by those that preceeds it (Festinger and Katz, 1965).

4.3.5 Sequencing of Questions :

It should make most sense to the respondent. It should follow the logic of the respondent. It should lead him to anticipate the next question. Usually the first question should be very general. From the response it gets one should probably be able to infer the frame of reference of the respondent. The first 2 or 3 questions

must be able to motivate and educate the respondent in the role which is expected of him (Festinger and Katz, 1965).

4.3.6 Merits and Limitations of a Questionnaire :

The questionnaire method has the distinction of being the only method that can collect any kind of information needed in social research with relative ease (Festinger and Katz, 1965). It enjoys many advantages over methods. viz.,

i) it enables us to collect a large amount of data in a relatively short time.

ii) it reduces multiple meaning and ambiguity of responses.

iii) it is economical in that, it does not require instruments.

iv) it provides sharp and constant focus on the problem being tackled.

v) it has greater reliability.

Its major disadvantages is that it takes a long time, energy, money and skill to construct a reliable questionnaire. Problems of language, dialect, time taken to administer are other disadvantages. In addition, it can be disadvantaged by the kind of questions it employees, their arrangement, its social acceptability and various other factors relating to the interviewer or questioner, the respondent, etc.,

4.4 THE QUESTIONNAIRE

A questionnaire was constructed for the purposes of this study taking all the above mentioned factors into consideration (See Appendix). The same set of questions made up both the written questionnaire and the oral questionnaire. Both open and closed type of questions were employed depending upon the amount of information needed from the particular problem being tackled. Funnelling approach

was employed in many questions. The sequencing of questions was so done as to not only set the basis for interviewing and to follow the logic of the respondent, but also, to enable the investigator to arrive at an identification of high risk factor through the process of inclusion and exclusion very much like what a physician does to arrive at a differential diagnosis of a particular kind of disorder.

Questions were divided into 10 main categories depending upon the kind of data being elicited (eg., family, history, consanguinity, pregnancy complications, etc.,). The oral questionnaire had in all 40 questions and 2 requests for description and one request for any additional information the mother volunteers to give. By definition it had only 2 closed type questions whereas the written questionnaire had 23 closed and type and 17 open and type of questions with 3 requests for description and one for any additional information volunteered.

4.4.1 The Respondent

The mother was the respondent in this study. For the purpose of this study, her age and educational level were included in the questionnaire as variables. All those unable to read an write or those who expressed their inability to comprehend the written questionnaire were administered theoral questionnaire. Many educated mother were interviewed likewise. Thus the written questionnaire was administered to those who could read and write Kannada well. In most cases the mother was the sole respondent. In many instances, however, other family members volunteered information or had to be asked for clarifications. A note to that affect was made in the questionnaire.

4.4.2 The Language

The questionnaire was in Kannada and dialect was that spoken in and around Mysore City. Many medical and other specialists were consulted in order to phrase the questions. Most questions were in

simple sentences and considering the heterogeneity of the respondents they were so phrased as to be followed by most of the respondents. The questionnaire phrasing followed the colloquial dialect to make it more informal, even in the written questionnaire. In the oral questionnaire English questions accompanied their Kannada counterparts for the sake of clarification, mainly intended for volunteers.

4.4.3 The Pretest

A pretest was conducted with an initial questionnaire on 10 mothers (both literate and illiterate). Essentially the initial questionnaire contained almost all the questions that eventually made up the final questionnaire. The purposes of the pretest were :

i) to see if the questions were understood by all.

ii) to see if the questions can be put without having to be explained or reworded.

iii) to see if the questions can be better organized.

iv) to see if the responses could be dichotomized into YES and NO, and

v) to prepare a data recording from to facilitate easier and faster recording of responses.

All mothers were interviewed by the investigator. The investigator visited the home of the respondent after getting the consent and interviewed the mother. All questions were put directly to the mother. Every mother was asked if she understood the question or the term (e.g. Jaundice) completely. Questions were repeated or explained or reworded if she did not. All responses were recorded in a blank sheet. The answers were evaluated and it was found that :

i) All questions excepting that on Rh incompatibility and blood transfusion were understood by all. Only 2 of the educated mothers could understand these two also and they both were medical social workers!! None of the uneducated mothers did understand them, because

all of them replied negatively though none of them or none of their children had undergone blood tests, nor did they knew their blood groups.

ii) Excepting the first question "Has any of your relatives had a hearing loss since birth?" None of the questions needed to be rephrased or explained. That question was better understood when it was rephrased as "were there any deaf and dumb children (sick) in your family?".

iii) The questions needed reorganization.

iv) Responses could not be dichotomized into simple YES and NO. Instead, addition of "Not sure" and "Not known" would increase the depth of alternatives without making the responses superficial or ambiguous. It also hastened the system of recording of responses, and

v) A data recording sheet could be devised that made recording of responses easier and quicker.

Hence, a new questionnaire was constructed taking into consideration all the above findings. (See appendix-3). The question on Rh/blood incompatibility could not be simplified further and it appeared that it was the concept itself and not the question that the mothers failed to understand. Hence, the two questions were retained on the advise of pediatricians. The question on family history was rephrased to read "are there any deaf, dumb (sick) child among your relatives?" instead of only 'deaf' but the term 'deaf' was retained on the questionnaire format given to the volunteers who were however, told that the usage of the term 'dumb' made the question better understood. The questionnaire was reorganized to follow a chronological sequence – pregnancy, delivery postnatal events and lastly the child's speech and language development.

The written questionnaire (See Appendix-4) was constructed later on using the same set of questions and the same format. Since it was intended as an alternate method to oral questionnaire, it was not pretested on the assumption that any alteration in the written format would make the comparative analysis difficult.

4.4.4 The Data Recording Sheet

A data recording sheet to record responses and other data of the mother and the child was constructed (See Appendix-5). It allowed for an easy and faster recording of responses. For the closed and type of questions all one had to do was to round off the appropriate answer to that particular question. (If had 4 response items Yes/No/?/NK. A response was taken as ?, or not sure response if the mother expresses doubts about any particular responses, for e.g. "I am not sure if ours is a consanguineous marriage". Similarly a response like "I do not know of the baby cried soon after birth" was taken to be a Nk (or Not known) responses. These latter were included not only to make room for flexible answers but also to allow for speedy recording). For open and questions it allowed sufficient space to record the responses. It also allowed some space for the volunteers to record their own observations. It was cyclostyled on one side of a full-scape paper.

Apart from response blanks, the data sheet had spaces for bio-data of the mother, the family and the child. In addition, it had follow up recommendation choice-to be filled in by the volunteer depending upon his recommendations.

4.5 THE QUESTIONS

The following are the English translations of the original questions in Kannada. They may hence embody all the drawbacks of translation. For the original Kannada questions the reader may refer to appendix . The underlined portions of the questions denote these words or terms or phrases which were stressed for greater emphasis.

Q.1 Has any of your relative had a hearing loss since birth?

1.1 How is he/she related to the child? How old is he/she now?

1.2 Do you know how he/she became deaf?

1.3 Do you know when he/she became deaf?

1.4 How is he/she now? Can he/she speak?

The subquestions were intended to rule out false positive responses like presbycusis or discharge apart from the obvious purpose of analyzing the family history more carefully and perhaps arriving at a pedigree.

Q.2 Have you married any of your relatives?

2.1 Do you consider him your close relative or your distant relative?.

2.2 Please specify the relationship.

The aim was to establish the presence of a consanguineous relationship. 2.1 allowed the mother to define the proximity of relationship herself. The idea was to correlate "close Vs. distant" against the nature of relationship that can be established with response to 2.2.

Q.3.a During your pregnancy did you have a rash with fever?

a.1 When was it : I quarter/II quarter/Last quarter?

a.2 Did it leave any spots?

a.3 Did any body call it chickenpox/measles/3 day or German measles?

3.b During your pregnancy did you have any other illness like malaria, diabetes etc? Give details.

3.c During the first three months was there any bleeding?

3.d During your pregnancy were you given any injections or tablets?

3.e Do you know why?

Q.3.a to a.4 deal with the problem of any maternal viral infection during pregnancy. These questions were constructed on the advise of two pediatricians. The idea was to allow for a differential diagnosis of the diseases by the symptoms elicited

by these questions. Q.4.4 allowed the mother to name the malady herself. This was included to know what really is rubella called in the local parlance. Still it is not known what it is called and it is not even sure if there is a particular term for this highly asymptomatic infection.

Q.3.b is a question concerning any other problem or illness during pregnancy. It also employs two probes or leads which are also risk factors themselves (See section 3.3.3.2). The probes were used to develop a concept of 'significant illness'.

3.c deals with imminent abortion symptoms whereas 3.d and 3.e were intended to elicit information of any maternal medication and to see if the mother knows why she was given those medications.

Q. 4.1 Was the Delivery normal?

4.2 Did the baby cry soon after birth?

4.3 Was the baby blue or tired at birth?

All 3 questions are fairly direct questions concerning the nature of delivery, apeic attacks and evidence of cyanosis. Q.4.3 was some times rephrased to read "was the baby very tired at birth?" which in local Kannada colloquialism also means a cyanosed baby.

Q.5.1 Was the baby very small at birth?

5.2 What was its birth weight?

5.3 At the hospital was the baby kept with you or was it kept in a separate room, in a glass box? Do you know why?

Q.5.1 was phrased negatively to emphasise on the smallness and 5.3 dealt with incubating and to see if the mother knew why the baby was kept in a incubator. 5.1 and 5.2 were also intended to correlate the subjective description of 5.1 to the objective report of its birth weight. There was another presumption behind 5.3. It was presumed that if the baby was kept separately from the mother, usually it meant some problem. The question funnelled down to "glass box" to establish incubating.

Q.6.1 Did the baby suffer from jaundice soon after birth?

6.2 When did you notice it first : I day/II day/later?

6.3 When did it subside?

6.4 Describe what all part had become yellow.

6.5 Was his palms and soles distinctly yellow stained?

6.6 Was the blood of the baby changed within 2 or 3 days after birth?

6.7 Did any body mention that your and your husband's blood do not match?

6.1 was a lead question which stressed on "soon after birth" thus ruling out non-neonatal jaundice. 6.2 and 6.3 were intended to establish the time of onset and the time of subsiding, both possible etiological indicators (See sec. 3.3.3). 6.4 was meant for a gross estimation of the severity of jaundice and indirectly, the bilirubin accumulation. 6.5 was a direct straight forward question, 'Yes' response to this question was a strong indicator of abnormally high level of bilirubin accumulation in the blood (See sec.3.3.6.1). Volunteers were asked to carefully phrase and if necessary repeat or rephrase or explain questions. 6.2 to 6.5 whenever the answer to 6.1 was positive.

6.6 dealing with blood transfusion was a difficult question in many ways. It was highly ambiguous. Yet, far, this was the nearest expression that would explain the concept of transfusion without letting mother to confuse it with blood taken for laboratory tests or blood given in certain instance like surgery.

6.7 was another difficult question in many ways. The term 'Rh' is relatively unknown even to many educated mothers and "blood mismatch" has few overtones of social unacceptance. The question was eventually so constructed as to emphasise any mismatch, be it blood group or be it Rh factor. Volunteers were however told to specify Rh factor if they felt that the respondent could understand the concept of Rh factor.

Q.7 Did you notice any defects in your baby's head, ears, nose or throat?

7.1 Please describe :

Q.7 was a direct question on congenital oral-facial anomalies stressed on "head …". 7.1 was a simple request for description.

Q.8.1 Has the baby been ill soon after birth?

8.2 Did he have any convulsions?

8.3 Did he lose consciousness? For how long?

8.1 in Kannada stressed "within a few days after birth". 8.2 and 8.3 funnelled down to elicit evidence on brain damage. Volunteers were told to elicit any extra information they could obtain to these question.

Q.9 Did the baby receive any injections?

9.1 For how long?

9.2 Do you know why he was given those questions?

9.3 Had he been given any tablets or capsules? also?

These questions were aimed at any injections given for a protracted period along with or followed by oral tablet therapy. It was deliberately made ambiguous as to the period – it did not specify neonatal period. This was done to rule out hearing loss acquired after infancy period. This was necessary for the purpose of this study.

Q.10.1 Did you have any doubts, any time, about your child's hearing?

10.2 Does he hear as well as other children of his age?

10.3 Does he speak as well as other children of his age?

Q.10.1 was aimed at parental concern. 10.2 and 10.3 were intended to see if the parents can evaluate the status of their child's hearing, speech and language abilities by allowing them to compare their children with other children of the same age. It was presumed that given such a opportunity to compare, parents would become better reporters of their children's abilities.

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CHAPTER-5

METHODOLOGY: DATA COLLECTION AND ANALYSIS

5.1 Data Collection

- 5.1.1 Investigator interview.
- 5.1.2 Written Quarry of mothers.
- 5.1.3 Volunteer Interview.
- 5.1.4 Data on validity check.

5.2 Data Analysis

- 5.2.1 To test Null Hypotheses
- 5.2.2 To test validity.

5.3 Statistics

- 5.3.1 Percentage.
- 5.3.2 Chi. Square Statistic (X^2)

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5.1 DATA COLLECTION

Data collection for the study was carried in three ways : Interview by the investigator; interview by trained volunteers; and written quarry of mothers.

5.1.1 Investigator Interview (II)

The investigator sought the permission of various hospital and nursing home authorities to interview the mothers. Finally two location were selected : the local Medical College hospital for women and children and a Municipal Primary Health Centre. A cross section of the population made use of these two public health facilities.

In the Medical College three locations were made use of for the purpose of interviewing viz.,

i) The post-partum clinic : This also houses the well baby clinic where children are immunized. Bulk of the data was collected from this place.

ii) Pediatric OPD for fresh cases : The investigator made use of this location whenever the PP clinic was closed or was too crowded. Doctors attending were requested to divert a random sample for interviewing.

iii) Pediatric ward : This location was chosen because of 3 reasons : One, mothers were more accessible here, Two, they were more free and were not in a hurry and Three, it suited the investigators free time. Beds were chosen randomly and their present histories were discarded from the purview.

The Municipal hospital cared for mostly delivering mothers and mothers utilizing post-partum care and advise facilities. Though rural and mothers from lower socio-economic categories utilized it more urban mothers who made use of it. This location was selected mostly because the investigator could visit it in his free hours.

In all three locations, mothers were told the purpose of the interview and sought permission from the investigator tried to make the interview appear as past of the hospital procedure in order to gain acceptance and motivation on the part of the mothers.

5.1.2 Written Quarry of mothers (WQ)

Before interviewing mothers were first asked if they were educated and if they were willing to answer a questionnaire in writing. Whoever consented were given the questionnaire and a pen and were asked to fill it there itself. Questionnaire were also given to doctors attending the PP clinic so that they could get it filled in the absence of the interviewer.

5.1.3 Volunteer Interview (IV)

The Investigator solicited whoever volunteered to interview mothers. Initially fifteen, mostly students of Speech and Hearing Science volunteered. They were all quite proficient in history gathering and as such formed an already trained group.

First, they were all told the purpose of the study and the role they were playing in it. The purpose and intent of each question and item in the questionnaire was explained. They were to ask all pertinent questions. They were also trained in how to ask certain questions, what to stress on, which questions to snip, what answers to look for and so on. They were also trained how to record the data using the given data recording sheet. They were also asked to record all additional information forthcoming from the mother.

Volunteers were mostly all girl students and mostly day scholars. They were asked to collect the data from around the places they lived in. They were instructed not to choose any mother or child and to make the sample as random as possible. Since they

were all actively engaged in Speech and Hearing field, their abilities, motivation and other volunteer-related capabilities were assumed to be informally favourable. At the end of the study seven submitted their data comprising of 90 children.

5.1.4 Data on Validity Check

A sample of 20 mothers, unselected, and interviewed consecutively were subjected to cross questioning (after they had been interviewed with the questionnaire). The objectives were to see

i) if they understood the questions and the concepts behind them.

ii) if there were any difference in their responses as a result of changed concept – after they had been made to understand.

Another group of 5 teacher mothers was given the questionnaire schedule to read and was asked to evaluate the questions for social acceptability. Specifically, they were asked if other mothers would find it objectionable to be asked any of the questions.

The volunteers were also subjected to a written questionnaire concerning their views (See Appendix) and their answers were considered for answering the validity of the questionnaire.

5.2 DATA ANALYSIS

5.2.1 To Test Null Hypotheses

It was assumed that each pregnancy and delivery were unique in themselves and that the factors affecting them were also unique. Hence, for the purposes of this study a response concerning to one child has been considered as a unit of data. Thus if a mother had 3 children, all the three were taken as 3 different individual data.

The mothers' bio-data was categorized into urban, Vs. rural, educated vs. not educated. The children's bio-data was analyzed according to hospital vs. home delivery and supervised vs. non-supervised deliveries.

For the purposes of preliminary risk screening Yes and No responses to 21 questions were considered. The questions tackled family history, consanguinity, maternal viral infections, any other maternal illness, threatened abortion, maternal medication, delivery problems, Bioth asphyxia, Apnea, smallness at birth, jaundice, blood transfusion, Rh or blood group incompatibility, birth deformaties, reonatal illness, siezurel, 'unconscious' bouts, injectious, parental concern, and parental evaluation of their childs hearing and speech respectively.

In addition all the responses were analyzed for

i) Total number of questions asked, answered and not answered in each group.
ii) Total number of risk answers and no-risk answers in each group.
iii) Total risk population (risk answers to any or all of the questions).

5.2.2 To test validity

In the validity check sample of 30 mothers the number and the particulars of the questions not understood or which failed to convey the concept were noted. Similarly the vouchers and particulars of the questions that brought out a changed response (for e.g. No. 10 Not known) were also noted.

The responses of 5 teacher mothers and volunteers were subjectively evaluated.

5.3 STATISTICS

5.3.1 Percentages

Percentages of the following, for each group were calculated.

1. Educated and uneducated mothers.
2. Less educated (Below VII Std.) and more educated (Vii Std. or above).
3. Urban and Rural mothers.
4. Hospital and Home, and Supervised and Non-supervised deliveries.
5. Number of questions asked, answered and not answered.
6. Number of Risk answers and no risk answers.
7. Total risk population.

5.3.2 Chi. Square Statistic (X^2)

The Chi-Square Test represents a useful method of comparing experimentally obtained results with those to be expected theoretically on some hypothesis. The differences between the observed and expected frequencies are squared and divided by the expected number in each case and the sum of these quotients is X^2 (Garrett, 1966).

X^2 was applied to the following to test the Null Hypotheses framed.

i) Total number of Risk Vs. No-Risk answers in all 3 groups.

ii) Number of Risk Vs, No-Risk answers for each of the questions in all three groups.

iii) Total number of Risk Vs. No-Risk answers between I.I. and VI groups, I.I. and W.Q. and V.I. and W.Q. groups.

iv) Number of Risk Vs. No-Risk answers for each of the questions between I.I. and V.I. groups, I.I., W.Q., groups and V.I. and W.Q. groups.

In all 88 X^2 calculations were carried out.

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CHAPTER 6

RESULTS AND DISCUSSION

6.1 DATA COLLECTION

6.2 USING VOLUNTEERS

6.3 WRITTEN QUESTIONNAIRE

6.4 MOTHER'S DATA

6.5 CHILDREN'S DATA

6.6 NULL HYPOTHESES TESTED

6.7 QUESTIONNAIRE VALIDITY

6.8 QUESTIONNAIRE EFFICACY

Discussion on the compitation of the risk items and development of the questionnaire has been dealt with in chapter 3 and 4 respectively. Chapter 5 has dealt with the process of data collection and Analysis. This chapter will deal with the main objective of the study – to investigate whether one can collect dependable risk information using a questionnaire through different means.

6.1 DATA COLLECTION

Generally data collection had not been difficult. However, there were problems. Fore most was the search for a representative sampte. Though authorities of most hospitals were sympathetic many, specially in private hospitals expressed their inability to allow the investigator to interview their patients on the grounds that the patients would themselves object to it. In the two locations selected none of the mothers objected.

The problem of acceptability and motivation on the post of the mother was seldom a problem. This was probably because the investigator made the whole process appear as a routine hospital work, often with the assistance of hospital staff.

6.2 Using Volunteers

Utilizing volunteers had been most rewarding. They were enthusiastic despite being preoccupied with their own chores and examinations. They would have collected more data if only they had been allowed more time. In fact, many forms were being returned even often the completion of the project.

Only one volunteer reported of facing problems while motivating mothers, especially uneducated mothers. Another volunteer reported that one of her subjects felt slyy when asked certain questions. But generally volunteers had very little problem. That they being girls, enjoyed more confidence with mothers is a matter beyond the purview of this study.

Though volunteers were well versed with interviewing and recording of case histories, they were further trained by the investigator. Still, there were some lapses. As many as 205 responses (11.37% of total questions) had to considered as 'not answered' because response spaces were left blank. (See Table 2). They typically skipped questions 6.6 and 6.7 if the response to 6.1 (on jaundice) was negative. Similarly, they skipped 8.2 and 8.3 if the response to 8.1 (any severe illness in neonatal period) was negative. Response columns for questions 3b, 3c and 3d was often blank.

T A B L E. 2

Number of Questions asked	4484	1890	1365
Number of Questions answered %	4483 97.57%	1675 88.62%	1202 88.06%
Number of Questions not Answered %	111 2.47%	215 11.38%	163 11.94%

Two explanations can be offered. One, moa likely, they mistook these questions as optional to be asked if the response to the first questions as optional to be asked if the response to the first question in the category was positive or they were misted by the requencing of the questions. Two, which is less likely, they knowingly overlooked the questions or forgot to record the response. Both these point to the investigator's lapse in training the volunteers.

6.2 WRITTEN QUESTIONNAIRE

Getting the mothers to fill the written questionnaire was sometimes problematic. Some mothers were in a hurry. Many were even allowed to take the questionnaire home and to return it to the hospital staff on their next visit. Very few, however did return it. However, generally most mothers willingly filled the questionnaire on the spot.

In this data also, as many as 163 (11.94%) response columns were left blank (see Table 2). Question 8.3 had 40 'no-responses' (See Table 8). It appears, however, that they too typically overlooked these questions thinking that they were not applicable to them, though instructions printed on top asked them to answer every question. They night have skipped the question because of requencing also. Carry over from answering questions 1 to 3 where they could skip the sub-questions if the answer to the main question was negative, might also be a factor. Written questionnaire, thus needs many modifications.

6.4 MOTHERS' DATA

Tables 3,4 and 5 present the mothers' bio-data.

The investigator interviewed 88 mothers, 47 (53.41%) urban and 41 (46.59%) rural. 30 (34.09%) of them were educated beyond VII standard and 58 (65.51%) were mostly not educated at all or were less educated below VII Standard (3.5% of the total or 6% of uneducated group). 31 (35.25%) were married consanguineously (as determined by preliminary yes-no screening of response to question 2) and between them they and 72 children.

Volunteers interviewed 52 mothers. 49(94.23%) were educated and only 1 (1.92%) was illiterate. 47(90.38%) were urban dwelling and only 2(3.85%) were rural mothers. Thus the volunteers' sample compressed of predominantly urban and educated mothers. In this group, 12(23.08%) were married among relatives and between them they had 21 children.

In the WQ group, 34(85%) were urban and 6(15%) were rural living Obviously all 40 were educated. 38 of them had passed SSLC and only 2 had middle school education. Only 4 mothers (10%) were married consanguineously and 36 were not. Between them, these 4 mothers had 5 children. Thus this sample also was comprised of mostly urban and educated mothers.

Thus it appeared that the investigator's sample was more representative of all 3 groups.

MOTHERS' BIO-DATA

II (N = 88), VI (N = 52) and WQ (N = 40)

Groups	II	VI	WQ
Urban	47 (53.41)	47 (90.38%)	34 (85%)
Rural	41 (46.59%)	2 (3.85%)	6 (15%)
No Details	- 	3 (5.77%)	-

Table 3 Place of Dwelling

Groups	II	VI	WQ
Educated	30 (34.89%)	49 (94.23%)	40 (100%)
Not Educated	58 (65.01%)	1 (1.92%)	-
No Details	- 	2 (3.85%)	-

Table 4 Education

Groups	II	VI	WQ
Consanguineous Marriage	31 (35.23%)	12 (23.08%)	4 (10%)
Non-consanguineous Marriage	55 (62.5%)	40 (76.92%)	36 (90%)
No Details	2 (2.27%)	- 	-

Table 5 Consanguineous Marriage

6.5 CHILDREN'S DATA

Only birth data was considered. Table 6 provides the figures.

Groups	II	VI	WQ
Hospital Deliveries	127 (59.35%)	84 (93.33%)	61 (93.85%)
House Deliveries	81 (31.85%)	6 (6.67%)	4 (6.15%)
No details	6 (2.81%)	-	-

Table 6 Children's Data: Place of Delivery

In the II sample 127 (59.35%) were born in hospitals as against 84 (93.23%) in VI sample and 61 (93.85%) in WQ sample. Thus, the VI and WQ samples had mostly children born in hospitals and thus medically supervised.

6.6 NULL HYPOTHESES TESTED

Table 7 presents Chi-square values for Risk Vs Non-Risk responses between all 3 groups and between the groups.

Group combinations		Between all 3 Groups	Between II & VI	Between II & WQ	Between VI & WQ
Risk Vs Non-Risk Answers		6.83	4.24	4.46	0.06
Total	0.01 level	9.210	6.635	6.635	6.635
Value	0.05 level	5.991	3.841	3.841	3.841

Table 7 X^2 values for Risk Vs No-Risk answers

It can be noted that the Chi-square value between all 3 groups is 6.83 which is much below the table value of 9.21 at 0.01 level of confidence at 2 degrees of freedom. Between II and VI groups X^2 value is 4.24, and between II and WQ groups it is 4.46 and between VI and WQ groups it is 0.06. All values are much below the table value of 6.635 at 0.01 level of confidence at 1 degree of freedom.

Thus, these results support the acceptance of the first null hypothesis. It can be inferred that the risk responses of these 3 groups are independent of sampling variations. The difference these groups has not influenced the responses or are not reflected in the response. Risk responses of these 3 sample subjects are independent of group differences.

Tables 8, 9 and 10 show the response categorizations for each of the questions for each of the 3 groups of data.

Risk and No-Risk responses to each of the 21 questions between all 3 groups and between groups of 2, were also subjected to Chi-square test to answer the null hypotheses. Table provides the X^2 values for each of the 21 questions. Responses to question 6.6 could not be subjected to X^2 test because it consistently elicited 'Yes' answers in all 3 groups.

It can be seen that, except in question 2 (on consanguinity) and 9 (on only injections given to the child), in all questions X^2 values between all 3 groups an between groups of two, fall below the table value of X^2 at both 0.01 level and 0.05 levels of confidence.

Table 8 Response categorization of II group (N = 214)

Qn. No.	Questions	Risk	No Risk	Not sure	Not Known	Not Available
1	Family History	29 (13.55%)	177 (82.71%)	1 (0.47%)	1 (0.47%)	6 (2.80%)
2	Consanguinity	72 (33.64%)	140 (65.42%)	0 0	0 0	2 (0.94)
3a	Maternal viral Infections	2 (0.94%)	205 (95.79%	0 0	0 0	7 (3.27%)
3b	Any maternal Illness	23 (10.75%)	191 (89.25%)	0 0	0 0	0 0
3c	Threatened Abortion	5 (2.34%)	208 (97.2%)	1 (0.47%	0 0	0 0
3d	Maternal Medication	65 (30.32%)	149 (69.23%)	0 0	0 0	0 0
4.1	Delivery Problems	26 (12.15%)	184 (85.98%)	0 0	0 0	4 (1.87%)
4.2	Birth Asphyxia	13 (6.07%)	193 (90.19%)	0 0	4 (1.87%)	4 (1.87%)
4.3	Cyanosis	18 (8.41%)	188 (87. 85%)	0 0	6 (2.8%)	2 (0.94%)
5	Smallness at Birth	21 (9.81%)	193 (90.19%)	0 0	0 0	0 0
6.1	Jaundice	11 (5.14%)	184 (85.98%)	1 (0.47%)	2 (0.94%)	6 (2.80%)

Table 8 (Continued)

Qn. No.	Questions	Risk	No Risk	Not sure	Not Known	Not Available
6.6	Blood Transfusion	0 0	199 (92.99%)	0 0	7 (3.27%)	8 (3.74%)
6.7	Rh/Blood group Incompatibility	1 (0.47%)	192 (89.72%)	0 0	10 (4.67%)	11 (5.14%)
7	Birth Deformities	6 (2.80%)	204 (95.38%)	0 0	0 0	4 (1.87%)
8.1	Neonatal Illness	22 (10.28%)	185 (86.45%)	0 0	0 0	7 (3.27%)
8.2	Siezures	16 (7.48%)	185 86.45%)	0 0	0 0	13 (6.07%)
8.3	'unconscious' Episodes	9 (4.21%)	183 (85.51%)	0 0	0 0	22 (10.28%)
9	Injections to child	106 (49.53%)	103 (48.13%)	0 0	0 0	5 (2.34%)
10.1	Parental Concern on Hearing	3 (1.4%)	197 (92.06%)	3 (1.4%)	11 (5.14%)	0 0
10.2	Hearing Evaluation	4 (1.87%)	190 (88.78%)	4 (1.87%)	15 (7.01%)	1 (0.47%)
10.3	Speech Evaluation	11 (5.14%)	190 (84.11%)	5 (2.34%)	17 (7.94%)	1 (0.47%)

Table 9 Response categorization of VI group (N = 90)

Qn. No.	Questions	Risk	No Risk	Not sure	Not Known	Not Available
1	Family History	6 (6.67%)	82 (91.11%)	0 0	0 0	2 (2.22%)
2	Consanguinity	21 (23.33%)	68 (75.56%)	0 0	0 0	1 (1.11%)
3a	Maternal viral Infections	3 (3.33%)	87 (96.67%)	0 0	0 0	0 0
3b	Any maternal illness	3 (3.33%)	71 (78.89%)	0 0	0 0	16 (17.78%)
3c	Threatened Abortion	5 (5.56%)	75 (83.33%)	0 0	0 0	10 (11.11%)
3d	Maternal Medication	19 (21.11%)	48 (53.33%	0 0	0 0	23 (25.56%)
4.1	Delivery Problems	17 (18.89%)	73 (81.11%)	0 0	0 0	0 0
4.2	Birth Asphyxia	9 (10%)	77 (85.56%)	1 (1.11%)	0 0	3 (3.33%)
4.3	Cyanosis	9 (10%)	78 (86.67%)	2 (2.22%)	0 0	1 (1.11%)
5	Smallness at Birth	5 (5.56%)	83 (92.22%)	1 (1.11%)	0 0	1 (1.11%)
6.1	Jaundice	1 (1.11%)	89 (98.89%)	0 0	0 0	0 0

Table 9 (Continued)

Qn. No.	Questions	Risk	No Risk	Not sure	Not Known	Not Available
6.6	Blood Transfusion	0 0	54 (60%)	0 0	0 0	36(40%)
6.7	Rh/blood group Incompatibility	2 (2.22%)	53 (58.89%)	5 (5.56%)	0 0	30 (33.33%)
7	Birth Deformities	3 (3.33%)	87 (96.67%)	0 0	0 0	0 0
8.1	Neonatal Illness	10 (11.11%)	77 (85.56%)	0 0	0 0	3 (3.33%)
8.2	Siezures	4 (4.44%)	58 (64.44%)	0 0	0 0	28 (31.11%
8.3	'Unconscious' Episodes	1 (1.11%)	60 (66.67%)	0 0	0 0	29 (32.22%)
9	Injections to child	15 (16.67%)	67 (74.44%)	0 0	0 0	8 (8.89%)
10.1	Parental concern on Hearing	3 (3.33%)	83 (92.22%)	1 (1.11%)	1 (1.11 %)	2 (2.22%)
10.2	Hearing Evaluation	4 (4.44%)	75 (83.33%)	0 0	0 0	11 (12.22%)
10.3	Speech Evaluation	6 (6.67%)	73 (81.11%)	0 0	0 0	11 (12.22%)

Table 10 Response categorization of WQ group (N = 65)

Qn. No.	Questions	Risk	No Risk	Not sure	Not Known	Not Available
1	Family History	2 (3.03%)	62 (95.38%)	0 0	0 0	1 (1.54%)
2	Consanguinity	5(7.69%)	58 (89.23%)	1 (1.54%)	0 0	1 (1.54%)
3a	Maternal viral Infections	1 (1.54%)	62 (95.38%)	0 0	0 0	2 (3.08%)
3b	Any maternal Illness	4 (6.15%)	56 (86.15%)	0 0	0 0	5 (7.69%)
3c	Threatened Abortion	2 (3.08%)	57 (87.69%)	0 0	0 0	6 (9.23%)
3d	Maternal Medication	25 (38.46%)	34 (52.31%)	0 0	0 0	6 (9.23%)
4.1	Delivery Problems	17 (26.15%)	45 (69.23%)	0 0	0 0	3 (4.62%)
4.2	Birth Asphyxia	2 (3.08%)	60 (92.31%)	0 0	0 0	3 (4.62%)
4.3	Cyanosis	2 (3.08%)	59 (90.77%)	0 0	2 (3.08%)	2 (3.08%)
5	Smallness at Birth	5 (7.69%)	56 (86.15%)	0 0	2 (3.08%)	2 (3.08%)
6.1	Jaundice	4 (6.15%)	59 (90.77%)	0 0	1 (1.54%)	1 (1.54%)

Table 10 (Continued)

Qn. No.	Questions	Risk	No Risk	Not sure	Not Known	Not Available
6.6	Blood Transfusion	0 0	47 (72.31%)	0 0	1 (1.54%)	17 (26.15%)
6.7	Rh/blood group Incompatibility	0 0	48 (73.85%)	0 0	1 (1.54%)	16 (24.62%)
7	Birth Deformities	0 0	65 (100%)	0 0	0 0	0 0
8.1	Neonatal Illness	3 (4.62%)	42 (64.62%)	2 (3.08%)	0 0	18 (27.69%)
8.2	Siezures	2 (3.08%)	50 (76.92%)	0 0	0 0	13 (20%)
8.3	'Unconscious' Episodes	2 (3.08%)	23 (35.38%)	0 0	0 0	40 (61.54%)
9	Injections to child	33 (50.77%)	28 (43.08%)	1 (1.54%)	0 0	3 (4.62%)
10.1	Parental concern on Hearing	3(4.62%)	55 (84.62%)	0 0	0 0	7 (10.77%)
10.2	Hearing Evaluation	5 (7.69%)	51 (78.46%)	0 0	2 (3.08%)	8 (10.77%)
10.3	Speech Evaluation	5 (7.69%)	50 (76.92%)	0 0	1 (1.54%)	9 (13.85%)

Thus, barring the responses to these two questions, ie., questions 2 and 9, risk responses in all other questions support the acceptance of second and the third null hypotheses. Thus, these two null hypotheses may be deemed accepted in all but questions 2 and 9.

With respect to question 2, it can be seen from Table 11 that, X^2 value for responses between II and VI groups is 3.15 which to again below the table value at both 0.01 and 0.05 levels of confidence. Thus, the third null hypotheses may be deemed accepted between the II and VI groups of data. Between II-WQ and VI-WQ groups, however the third null hypothesis may be deemed rejected.

With respect to question 9, again, it can be noted that X^2 value for II and WQ groups in 0.22 which is much below the table value at both 0.01 and 0.05 levels of confidence. Thus, the third null hypothesis can be accepted with respect to these two samples. It is, however, rejected for II-VI and VI-WQ combinations of samples.

It can thus be inferred that, difference in responses to all questions but 2 and 9 were not influenced by sampling variations and whatever the differences there are, they are due to within sample differences ie., individual differences.

With respect to question 2 and 9, it can be inferred that sampling differences have influenced the responses and these differences are reflected in the scores. However, sampling variations have not influenced the responses to question 2 in II and VI groups of data and responses to question 9 in II and WQ samples of data.

II

CHI SQUARE VALUES FOR RISK – NO RISK ANSWERS TO EACH OF 21 QUESTIONS

Table values for significance : Between 3 groups : 9.210 at 0.01 level and
5.991 at 0.05 level

Between 2 groups : 6.635 at 0.01 level and
3.841 at 0.05 level

Qn. No.	Questions	Between all 3 groups	Between II &VI	Between II & WQ	Between VI &WQ
1	Family History	7.50	3.10	5.72	1.02
2	Consanguinity	27.86	3.15	8.45	6.39
3a	Maternal viral Infections	2.14	2.10	0.17	0.45
3b	Any maternal Illness	3.47	2.98	0.88	0.46
3c	Threatened Abortion	2.68	2.68	0.2	0.58
3d	Maternal Medication	3.58	0.07	3.01	2.72
4.1	Delivery problems	8.28	2.17	8.14	1.54
4.2	Birth asphyxia	3.15	1.51	0.86	2.75
4.3	Cyanosis	2.57	0.18	1.96	2.60

Continued

Qn. No.	Questions	Between all 3 groups	Between II &VI	Between II & WQ	Between VI &WQ
5	Smallness at Birth	1.37	1.35	0.15	0.37
6.1	Jaundice	3.41	3.13	0.04	3.21
6.6	Blood Transfusion				
6.7	Rh/Blood group Incompatibility	4.71	3.44	0.25	1.77
7	Birth Deformities	2.05	0.04	1.90	2.22
8.1	Neonatal Illness	0.70	0.15	0.65	0.78
8.2	Siezures	1.10	1.13	1.06	0.39
8.3	'Unconscious' Episodes	1.93	1.13	0.5	2.14
9	Injections to Child	28.36	25.2	0.22	20.10
10.1	Parental concern on Hearing	2.71	1.76	2.66	0.24
10.2	Hearing Evaluation	5.75	0.32	5.88	0.79
10.3	Speech Evaluation	0.86	0.04	0.78	0.098

With respect to question 2, it can also be inferred that, the investigator and the volunteers have tackled similar samples but both these samples differ from WQ group of sample. Simply, it means that, with respect to 'Consanguinity' WQ is a different kind of sample.

This can be explained. As can be seen from Table the II group has 33 (35.23%) mothers married consanguineously. These mothers have 72 (83.64%) between them. In the VI group, 12 (23.08%) are married consanguineously and they have 21 children (23.33%). But, in the WQ sample, only 4 out of 40 (10%) are married consanguineously and these 4 have only 5 children who form only 7.69% of the total sample. Clearly, the WQ sample in a much different sample. Further analysis could explain why this sample differs from the other two.

With respect to question 9, again, it can be seen that it is VI group which differs from both II and WQ groups. X^2 value for all 3 groups was 28.36 and between II and VI group it was 25.2, between VI and WQ groups it was 20.10, all much above the table values. However, X^2 value for between II and WQ groups it was only 0.22, a very low value.

This could also be explained. It can be hypothesized that volunteers had a tendency to screen off responses concerning immunization injections which characterize most 'Yes' answers in both II and WQ groups. As can be seen in Tables 8, 9 & 10. 49.33% of children in II group and 50.77% in WQ group were reported to have received some injection, while only 16.67% in VI group had received some injection or the other.

Thus, it can be stated again, that responses to the

questionnaire barring question 2 and 9 have not been influenced by sampling variations and whatever difference seen are due to within sample variations, or individual variations.

6.7 VALIDITY OF THE QUESTIONNAIRE

A sample of 20 mothers who had been interviewed consecutively had been subjected to cross questioning, after their responses to the questionnaire had been recorded. Small group of 5 teacher-mothers had also been interviewed. 7 volunteers also answered a written quarry. Due to the nature of the data no statistical analysis was carried out. Since no controls has been instituted the results of the data and their discussion can be viewed as subjective.

Of the 20 mothers in the II group, 7 were urban and 13 were rural. 17 were Hindu, Kannada speaking mothers while 3 were muslims who said they understood kannada. Between them these 20 mothers had 47 children, 23 of whom were born in hospitals and 32 were home deliveries, mostly supervised by family members.

On cross questioning it was found that 1 did not understand 4.3, 4 had difficulty to understand question 6.1. Most mothers had difficulty with understanding questions 6.6 and 6.7. One mother was shy when asked about question 3c.

Question 4.3 was not understood by 1 because of rapid questioning and sequencing. 4.1 and 4.2 obtained 'Yes' responses, delivery was normal and the baby cried soon after birth. She said 'Yes' to 4.3 "was the baby blue at birth?" also. However when asked again she corrected

her response to 'No'.

4 mothers had problems with 6.1, of whom there were 2 mulsims, one said that the child was very red and that she had not been told that it was due to 'Kamale' (Kannada term for Jaundice). However, none corrected their responses.

Questions 6.6 and 6.7 were not understood by most mothers. All had said 'NO' to 6.6 on blood transfusion and only one had said 'Yes' to 6.7 'was there any Rh problem?" 5 mothers had undergone blood tests. Only 2 mothers understood the significance of both 6.6 and 6.7. One was a medico social worker with a history of one aborted pregnancy and one of her children had breast-jaundice soon after birth. The other was the Rh negative woman with a M.Sc. degree. Her child, the first and only child, too had jaundice and she said 'doctor called it physiologic jaundice'. Significantly, none of the mothers changed their answers after education.

The following inferenies have been drawn :

(1) Except 6.6 and 6.7 all questions were understood.

(2) Question 6.1, on jaundice, appeared to carry the concept of significant jaundice. Most mothers described a jaundiced child as with phrases like 'face becomes swollen', child becomes yellow or pale' etc. Thus, they appeared to screen out common physiologic jaundice.

(3) With respect to 6.6 and 6.7, neither the questions, nor their concept seemed to be understood, irrespective of whether the mother was educated or was urban. It was understood by two mothers and both their children had the risk of either of the problems. Both questions seemed to carry some social overtones. 1 volunteer and 1 teacher mother concurred.

(4) Question 3.c seemed to carry significant social disapproval. However, 4 of the 5

volunteers said they did not think so. All teacher-mothers felt that it may be problem for male interviewers but most of them said that as long as one asks it in a hospital they did not think that it did mother.

(5) All questions did elicit required information. Significantly, there was only one change of response out of a possible 947 responses.

(6) The flexibility of the interview method makes ample room for the question to be understood, concept to be conveyed and thus obtained desited responses.

6.8 QUESTIONNAIRE EFFICACY

Table 12 provides the figures for relative estimation of risk population computed, bases on the preliminary risk-no risk (Yes-No) screening.

Groups	II N = 214	VI N = 90	WQ N = 65
Total Risk Population (Rise response to any one or all questions)	160 (74.77%)	54 (60.00%)	57 (87.6%)
Risk population when answers to questions 3 and 9 are eliminated	111 (51.87%	47 (52.22%)	26 (40.0%)

Table 12 Estimation of Risk population based on preliminary Yes-No response screening.

On the basis of preliminary screening, as much as 74.77% of the II group, 60% of the VI group and 87.6% of the

WQ group would have to be considered 'at-risk' population. This is an unmanageable population for follow up.

There are two plausible explanations for this viz.,

(1) The questionnaire includes too many risk items. This had to be so because of the exploratory nature of the study. Elimination of certain factors would bring this figure down.

(2) It may have many false positive responses. This is more than likely, if was noted that most of the responses to 3d (on maternal injections) and 9 (injections given to the child) elicited responses concerning immunization injections. It was also noted that if one eliminated 3d or 9 then II sample would have a risk population of 51.87%, VI would have 52.2% and WQ sample would have 40% follow up population. Still this figure is very high and no where near the Down's (1978) estimate of 7% for an ideal follow up program.

Screening out false-risk responses using responses to sub-questions would reduce the figure further. It was noted that, of the 12 who said 'Yes' to 6.1 on jaundice, only one said 'Yes' to sub-question 6.5 "was the palms and heels distinctly yellow?" We could perhaps consider 11 as false positives. Once could thus perhaps will be able to reach the Down's criteria.

Investingly, 2 deaf siblings were identified in the normal population. Both were seen in the hospital, in the II sample. They both fell under risk group. Both were born of consanguineous parents and due of them had a history of difficult labor. Their only normal hearing sibling, a

girl died at the age of 9 months, the reasons for which were not clear. She reportedly died after an attack of roshes.

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CHAPTER-VII

SUMMARY AND CONCLUSIONS

7.1 Summary

7.2 Conclusions

7.3 Implications

7.4 Limitation

7.5 Recommendation.

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7.1 SUMMARY

This study was an attempt at utilizing a questionnaire to collect risk information which can be used for risk categorization for hearing loss children.

A list of high risk factors were compiled from the literature on high risk register programs, etiological and epidemiological studies. The list also included factors suggested by various authorities in India and abroad. Finally, a list of 21 high risk indicators were considered for the study.

Based on this list a preliminary questionnaire was prepared and was pretested on ten mothers. Based on the results of the pretest the project questionnaire was developed which could be used both as an interview schedule and a written questionnaire. The questionnaire was so constructed as to enable the investigator to arrive at an identification of a true high risk factor utilizing information obtained from the main question and its sub-questions. The questionnaire was in Kannada and was so worded and phrased as to be easily understood. A data recording sheet designed to enable speedy recording of responses was also developed.

Utilizing this questionnaire in three modes – Interview by the Investigator, Interview by the Volunteers and Written quarry of mothers, data on 369 children born to 193 mothers were collected. Data thus collected were subjected to statistical analysis to see if the information they provide had been influenced by sampling differences. In addition, a small sample of 20 mothers within the Investigator's interview sample was subjected to cross questioning to check the validity of the sample. Opinions of volunteers and 5 teacher-mothers was also sought to answer the validity questions.

7.2 CONCLUSIONS

The following tentative conclusions could be drawn from the study.

1. The questionnaire could be effectively used to collect risk information both through

interview and through written quarry of mothers.

2. There were a few problems in interviewing mothers. But, despite these problems, and the limitations imposed in terms of time and resources, a relatively large sample of data could be collected within a short span of 2 mothers. The written questionnaire posed relatively more problems. It appeared, from the experience of the investigator, that mothers who are less educated (Say below 9^{th} or 10^{th} standard) would find it difficult to answer the written questionnaire.

3. Volunteers could be effectively utilized to collect risk information after little training. There were some lapses on the part of the investigator in terms of their training, but these lapses have not influenced their effectiveness significantly.

4. Though the investigator, the volunteers and the written questionnaire have tackled different samples of mothers, different in terms of education and place of dwelling, there sample differences have not influenced the responses of the mothers to the questions. The risk information obtained from all three sample has been statistically free from sampling variations.

5. On individual questions, except in question 2(on consanguinity) and question 9 (on any injections given to the child), the sampling variations have not influenced the risk Vs. no-risk responses given by the mother.

It appeared that the written questionnaire sample differs significantly from the investigator's sample and the volunteer's sample with respect to information on consanguinity. Further analysis is required to confirm and explain the difference.

Similarly, the volunteers' sample appeared to differ significantly from both the Investigator's sample and the written questionnaire sample in terms of risk information an any injections given to the child. It appeared, that this could be due to tendency on the part of the volunteers to screen out responses concerning immunization injections, which they felt ferelevant.

6. On the basis of the responses to cross questioning of a small sample of mothers, an Interview of 5 teacher-mothers and a written quarry of volunteers, it can argued that the questionnaire is valid, atleast in terms of its effectiveness in obtaining desired responses. Though some of the questions were frequently not understood and some had a sense of social unacceptability, these have not reflected themselves in responses to the question.

7. The questionnaire indeed needs modifications, in terms of

i) Rephrasing certain questions to obtain a uniform 'Yes' or uniform 'No' so that response recording could not be affected in terms of wrong marking.

ii) Re-organization to emphasise important questions.

iii) Addition or deletion of certain questions based on the results of this study and on further analysis of true risk-false risk answers.

iv) Limiting the length of the questionnaire after further analysis.

7.3 IMPLICATIONS

1. The same questionnaire, after due modifications could be tried on a already risk group – like confirmed deaf children.

2. The data collected by the Interviewer, the volunteers and through written questionnaire can be suitably clubbed to make up a larger body of data for further analysis.

3. The data collected here can be individually or in combinations can be used as a 'control' data for comparison with data collected on deaf children.

4. A High Risk Register consisting of high risk histories can be developed.

7.4 LIMITATIONS

1. This study was only an exploratory study and as such embodies all the hit miss limitations of an exploratory study.

2. Limitations of time and resources have reduced the scope of the study.

3. Due to exploratory nature of the study the questionnaire constructed includes too many items.

4. On the same count, the questionnaire constructed may be considered too long. Whether this could have affected data collection, or more specifically, motivation on the part of respondents is debatable.

5. Response columns classified as 'not available' may have or may influence the results of risk factor and risk population estimations.

6. Check on reliability of the responses has not been attempted.

7. Validity of the questionnaire has been subjectively justified.

7.5 RECOMMENDATIONS

1. The questionnaire can be validated on stratified samples, or on captive populations.

2. Utilization of services of Auxiliary Nursing Staff and medical-social worker can be investigated.

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APPENDIX I

Supplementary Statement OF Joint Committee on Infant Screening
(July, 1972)

In light of the urgent need to detect hearing impairment as early as possible, a 1970 statement of the Joint Committee urged further investigation of Screening methods but discouraged routine hearing screening which is not research oriented. In consonance with that statement and in view of the information that application of high risk data can increase the detect ability of congenital hearing Impairment perhaps as much As tenfold, the Committee considers it appropriate to make additions to the 1970 statement.

The Committee recommended that, since no satisfactory technique is yet established that will permit hearing screening of all newborns, infants AT RISK for hearing impairment should be identified by means of history and physical examination. These Children should be tested and followed0up as hereafter described.

I. The criterion for identifying as newborn as AT RISK for hearing impairment is the presence of one or more of the following:
   A. History of hereditary childhood hearing impairment.
   B. Rubella or (e.g., cytomegalovirus infections, Herpes infection).
   C. Defects of ear, nose, or throat lip or palate (including

Sub mucous cleft); any residual abnormality of Otorhinolaryngeal system.

D. Birth weight less than 1500 grams.

E. Bilirubin level greater than 20 mg/100 ml serum.

II. Infants falling in this category should be referred for an in depth audio logical evaluation of hearing during their first two months of life and, even if hearing appears to be normal, should receive regular hearing evaluations thereafter at office or well-baby clinics. Regular evaluation is important since familial hearing impairment is not necessarily present present at birth but may develop at an uncertain period of time later.

Note:----1 Ref: Early Diagnosis of Hearing Loss
Gerber, S.E and Mencher, G.T (Eds.)
Grune & Stration, New York, 1978.

Appendix II

Recommendation from the Nova Scotin Conference on the

Early Identification of Hearing Loss 1,2

1)Resolved: A high rink register or file should be universally implemented on the basis of the five points of the 1973 supplementary statement of the Joint Committee on Infant Hearing Screening. And the follow-up procedures of that statement should also be universally implemented. We recommend that the world Health organization, National and Local governments and health agencies adopt this program by legal mandate.

This conference also recognizes that children who fall into the designate high risk categories delineated by the joint committee on Infant Hearing Screening of ten suffer from other communication disorders.

2)Resolved: As a Supplement to the high risk register an agency may employ behavioral screening tests as in the appended model.

3) Resolved: Because the high risk register or other screening program cannot be expected to detect all hearing impairment, a provision within the health care system should be made for hearing testing later in infancy as part of any public health-well baby care program.

Note:----------1 Modified by the editor and several of the Conference participants and adopted by the National Joint

(Cont....)

Committee on Infant Hearing Screening, Las Vegas, Nevada, November, 1974.

Early Identifi cation of Hearing loss, George T. Meneher (ed.) Nova Scotia Conf., Halifax, 1974,pp.1-13 Karger, Basel – 1976.

----------2 only appropriate text quoted.

APPENDIX III

Recommendations of the Saskatoon Conference on the EARLY Diagnosis of Hearing Loss 1,2

Re: 1. Significant Asphyxia associated with Acidosis

2. Parental concern

1) Whereas, anoxia at birth has been associated with a significant number of hearing losses.

Resolved: A category is to be added to the high risk register as follows "Significant Asphyxia associated with Acidosis."

2) Whereas, the parent is often the earliest identifier of a hearing loss.

Resolved: In cases of parental concern about hearing impairment, it is recommended that child of any age, be immediately referred for audiologic evaluation.

Note: ------- 1 Early Diagnosis of Hearing loss, Sanford E. Gerber and Gerrge T. Mencher (Eds.) Grune & Stratton, Inc 1978.

----------2 Only appropriate text quoted.

A HIGH RISK QUESTIONNAIRE FOR HEARING LOSS IN CHILDREEN

A FEASIVILITY STUDY ON AN INDIAN POPULATION

1. Has any of your relatives had a hearing loss SINCE BIRTH ?
ನಿಮ್ಮ ಹತ್ತಿರದ ಸಂಬಂಧದಲ್ಲಿ ಯಾರಾದರೂ ಚಿಕ್ಕಂದಿನಿಂದಲೇ ಅಥವಾ ಹುಟ್ಟಿನಿಂದಲೇ ಕಿವುಡರಾಗಿದ್ದಾ

1.1. How is he/she related to the child? How old is he/she now ?
ಅವರು ಮಗುವಿಗೆ ಏನಾಗಬೇಕು? ಈಗ ಅವರ ವಯಸ್ಸೆಷ್ಟು?

1.2. Do you know how he became deaf ?
ಅವರು ಹೇಗೆ ಕಿವುಡರಾದ್ರು ಎಂದು ನಿಮಗೆ ಗೊತ್ತಾ?

1.3. Do you know when he/she became deaf ?
ಅವರು ಯಾವಾಗ ಕಿವುಡಾದ್ರು?

1.4. How is he/she now ? Can he/she speak ? ಈಗ ಅವರಿಗೆ ಹೇಗೆ ಕೇಳಿಸುತ್ತಾ? ಮಾತಾಡ್ತಾರೆಯೇ?

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2. Have you married any of your relatives ? ನೀವು ನಿಮ್ಮ ಸಂಬಂಧದಲ್ಲೇನಾದ್ರೂ ಮದುವೆ ಮಾಡಿಕೊಂಡಿದ್ದೀರಾ?

2.1. Do you consider him your close/distant relative ?
ಹತ್ತಿರದ ಸಂಬಂಧಿನೋ ದೂರದಸಂಬಂಧಿನೋ?

2.2. Please specify the relationship. ಏನು ಸಂಬಂಧ ಅಂತ ವಿವರ ಕೊಡಿ

3.a. During your pregnency did you have a rash with fever ? ಬಸುರಿಂಯಾಗಿದ್ದಾಗ ನಿಮಗೆ ಜ್ವರದ ಅಮ್ಮ ಅಥವಾ ಗಂಧ್ಗ ಏನಾದ್ರೂ ಎದ್ದಿತ್ತಾ?

a.1. When was it ? I Quarter/II Quarter/ Last Quarter. ಯಾವಾಗ

a.2. Did it leave any spots ? ಕಲೆ ಬಿದ್ದಿತಾ?

a.3. When did it subside ? ಯಾವಾಗ ಇಳೀತು?

a.4. Did any body call it chickenpox/measles/3 day or German Measles? ಏನಾಗಿತ್ತು : ಆಬಡಮ್ಮ: ಅಮ್ಮ: ದಡಾರ:ಗೊಳ್ಳಿತಬ್ಬ

3.b. During your pregnency did you have any other illness, like Malaria, Diabetes ? Give details. ಬಸುರಿಂಯಾಗಿದ್ದಾಗ ಚಳಿ, ಜ್ವರ, ನಕ್ರಿರೋಗ ಅಥವಾ ಬೇರೆ ಏನಾದ್ರೂ ತೊಂದರೆ ಇತ್ತಾ? ವಿವರ ಕೊಡಿ?

3.c. During the first three months was there any excessive bleeding? ಮೊದಲು ಮೂರು ತಿಂಗಳಲ್ಲಿ ನಿಮಗೆ ಕೆಂಪು ಮಬ್ಬು ಜಾಸ್ತಿ ಆಯ್ತಾ?

3.d. During your pregnency were you given any injections or tablets? ಬಸುರಿಂಯಾಗಿದ್ದಾಗ ನಿಮಗೆ ಇಂಜಕ್ಷನ ಅಥವಾ ಗುಳಿಗೆ ಏನಾದ್ರೂ ಕೊಟ್ಟಿದ್ದಾ?

3.e. Do you know why ? ಏತಕ್ಕೆ ಕೊಟ್ಟಿದ್ದು

4.1. Was the delivery nowmal ? ಹೆರಿಗೆ ನರ್ಮಲ್‌ಆಗಿ ಆಯ್ತಾ?

4.2. Did the baby cry soon after birth? ಮಗು ಹುಟ್ಟಿದ ತಕ್ಷಣ ಆಳ್ತಾ?

4.3. Was the baby blue at birth ? ಮಗು ಹುಟ್ಟಿದಾಗ ನೀರಿ ಆಗಿತ್ತಾ ?

5.1. Was the baby very small at birth? ಹುಟ್ಟಿದಾಗ ಮಗು ತೀರಾ ಪುಟ್ಟದಾಗಿತ್ತಾ?

5.2. What was its birth weight ? ಆದರ ತೂಕ ಎಷ್ಟಿತ್ತು?

5.3. At hospital was the baby kept with you or was it kept in a separate room in a glass-box ? ಆಸ್ಪತ್ರೆಲಿ ಮಗುನ ನಿಮ್ಮತ್ತಾನ ಇಟ್ಟಿದ್ದಾ,

6.1Did the baby suffer from jaundice soon after birth ? ಮಗು ಹುಟ್ಟಿದಕೂಡಲೇ ಕಾವಾಲಿ ಆಗಿತ್ತಾ?

6.2. When did you notice it first ? First day/ Second day/ later. ಎಷ್ಟಾವಾಗ ನಿವದನ್ನು ನೋಡಿದ್ರಿ?

6.3. When did it subside ? ಎಷ್ಟಾವಾಗ ಕಡಿಮೆ ಆಯಿತ್ತು?

6.4. Describe what all parts had become yellow ? ಮಗಾಗೆ ಎಲ್ಲಿಂಯ ವರೆಗೆ ಹಳದಿ ಕಚ್ಚಿತ್ತು? ಎಷ್ಟಾವ ಎಷ್ಟಾವ ಭಾಗ ಹಳದಿಯಾಗಿತ್ತು?

6.5. Was his palms and soles deeply yellow stained ? ಅಂಗೈ ಮತ್ತು ಹಿಮ್ಮಡಿ ಹಳದಿಂಯಾಗಿತಾ?

6.6. Was the baby given any blood transfustion ? ಹುಟ್ಟಿದ 2-3 ದಿನಗಳಲ್ಲಿ ಮಗುನ ರಕ್ತ ಏನಾದ್ರೂ ಬದಲಾಯಿಸಿದ್ರಾ?

6.7. Did anybody mention of a 'Rh' problem bwtween your blood and that of your husband's ? ನಿಮ್ಮ ಹಾಗೂ ನಿಮ್ಮವರ ರಕ್ತದ ವರ್ಗ ಹೊಂದಲ್ಲಅಂತ ಏನಾದ್ರೂ ಹೇಳಿದ್ರಾ?

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7. Did you notice any defects in your baby's head, ears, nose or throat : ಹುಟ್ಟಿದಾಗ ಮಗುವಿನ ತಲೆ, ಕಿವಿ, ಮೂಗಾಗ್ಲಿ, ಬಾಯಾ ಏನಾದ್ರೂ ದೋಷ ಕಂಡು ಬಂದಿತಾ? ಸ್ವಲ್ಪ ವಿವರ ಕೊಡಿ?

7.1. Please describe.

8.1. Has the baby been seriously ill soon after birth? Describe. ಹುಟ್ಟಿದ ಸ್ವಲ್ಪ ದಿನಗಳಲ್ಲಿ ಮಗುವಿಗೆ ತುಂಬಾ ಖಾಯಿಲೆ ಆಥವಾ ತೊಂದರೆ ಏನಾದ್ರೂ ಆಗಿತ್ತಾ?

8.2. Did he have any convulsions ? ಅದುರುವುದು, ಫಿಟ್ಸ್ ಏನಾದ್ರೂ ಬಂದಿತ್ತಾ?

8.3. Did he loose consciousness? For how long ? ಪ್ರಜ್ಞೆ ಏನಾದ್ರೂ ತಪ್ಪಿತ್ತಾ? ಎಷ್ಟು ಹೊತ್ತು ಪ್ರಜ್ಞೆ ಇರಲಿಲ್ಲ ?

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9. Did the baby receive any injections ? ಮಗುವಿಗೆ ಏನಾದ್ರೂ ಇಂಜಕ್ಷನ್‌ಗಳು ಕೊಡಿಸ್ದಾ? ಏ

9.1.For how long ? ಎಷ್ಟು ದಿವಸ ಕೊಡಿಸಿದ್ರಿ?

9.2. Do you know why he was given injections ? ಅವನಿಗೆ ಏನಾಗಿತ್ತು?

9.3. Had he been given any tablets/capsules also? For how long ? ಜೊತೆಗೆ ಗುಳಿಗೆ ಏನಾದ್ರೂ ಕೊಟ್ಟಿದ್ದಾ? ಎಷ್ಟು ದಿವಸ ಕೊಡಿಸಿದ್ರಿ?

10.1. Did you have any doubts, any time, about your childs hearing? ನಿಮ್ಮ ಮಗುವಿಗೆ ಕಿವಿ ಕೇಳಿಸ್ಲೋದರ ಬಗ್ಗೆ ನಿವುಗೆ ಎಂತಾವಾಗಾದ್ರೂ ಅನುಮಾನ ಇತ್ತ?

10.2. Does he hear as well as other children of his age ? ಅವನ ವಯಸ್ಸಿನ ಬೇರೆ ಮಕ್ಕಳ ತರಹ ಅವನಿಗೆ ಕಿವಿ ಕೇಳಿಸುತ್ತಾ?

10.3. Does he speak as well as other children of his age ? ಅವನ ವಯಸ್ಸಿನ ಬೇರೆ ಮಕ್ಕಳ ತರಹ ಮಾತಾಡ್ತಾನಾ?

ಈ ಪ್ರಶ್ನಾವಳಿ ನಿಮ್ಮ ತರಗ ಹಾಗೂ ನಿಮ್ಮ ಮಕ್ಕಳ ಕಿವಿ ಕೇಳಿಸುವಿಕೆಗೆ ಸಂಬಂಧಪಟ್ಟದ್ದು. ಪ್ರತಿ ಒಂದು ಪ್ರಶ್ನಾವಳಿ ಕೇವಲ ಒಂದು ಮಗುವಿಗೆ ಹಾಗೂ, ಮಗುವಿನ ತಿರಿಗೆಗೆ ಮಾತ್ರ ಅನ್ವಯಿಸುವುದು. ಅಂದರೆ ನಿಮಗೆ ಮೂರು ಮಕ್ಕಳಿದ್ದರೆ ಮೂರು ಫಾರ್ಮ್ ತುಂಬಿ. ಹಲವಾರು ಪ್ರಶ್ನೆಗಳಿಗೆ ಹೌದು ಇಲ್ಲ — ಇರಬಹುದು — ಗೊತ್ತಿಲ್ಲ ಎಂಬ ಉತ್ತರಗಳಿರುತ್ತವೆ. ನೂಕ್ಕ ಉತ್ತರಕ್ಕೆ ನೀವು ಸೊನ್ನೆ ಹಾಕಿ ಗುರುತಿಸಿ. ಹಾಗಿಲ್ಲದಿದ್ದರಿಲ್ಲ ಅಥವಾ ಹೆಚ್ಚಿನ ಮಾಹಿತಿ ಇದ್ದರಿಲ್ಲ ಪಕ್ಕದಲ್ಲಿ ಬರೆಯಿರಿ. ಪ್ರತಿ ಪ್ರಶ್ನೆಯನ್ನೂ ಉತ್ತರಿಸಿ.

APPENDIX 5

ತಾಯಿ ಹೆಸರು: ವಯಸ್ಸು: ವಿದ್ಯಾರ್ಹತೆ:

ತಂದೆ ಹೆಸರು: ಕಸುಬು: ವಿದ್ಯಾರ್ಹತೆ:
ವರಮಾನ: ವಿಳಾಸ:

ಪಾಸ: ಹಳ್ಳಿ ಅಥವಾ ಪಟ್ಟಣ
ಹುಟ್ಟಿರುವ ಮಕ್ಕಳ ಸಂಖ್ಯೆ: ಇರುವ ಮಕ್ಕಳ ಸಂಖ್ಯೆ:
ಸತ್ತು—ಹುಟ್ಟಿದ ಮಕ್ಕಳು : ಗರ್ಭಪಾತಗಳು:

ಮಗುವಿನ ಹೆಸರು: ವಯಸ್ಸು: ಗಂಡು—ಹೆಣ್ಣು ಎಷ್ಟನೆಯ ಮಗು:
ಜನನ: ಮನೇಲಿ—ಆಸ್ಪತ್ರೇಲಿ ಮೇಲ್ವಿಚಾರಣೆ: ಡಾಕ್ಟರು—ನರ್ಸು—ನೂಲಗಿತ್ತಿ—ಮನೆಯವರು

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1 ನಿಮ್ಮ ಹತ್ತಿರದ ಸಂಬಂಧಿಕರಲ್ಲಿ ಯಾರಾದರೂ ಚಿಕ್ಕಂದಿನಿಂದಲೇ ಅಥವಾ ಹುಟ್ಟಿನಿಂದಲೇ ಕಿವುಡರು ಇದ್ದಾರೆಯೇ? : ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

1.1 ಅವರ ವಯಸ್ಸೆಷ್ಟು? ಹಾಗೂ ಅವರು ಮಗುವಾಗಿ ಏನಾಗಬೇಕು?

1.2 ಅವರು ಹೇಗೆ ಕಿವುಡಾದರೆಂದು ನಿಮಗೆ ಗೊತ್ತೆ?

1.3 ಅವರು ಯಾವಾಗ ಕಿವುಡಾದರೆಂದು ನಿಮಗೆ ಗೊತ್ತೆ?

1.4 ಈಗ ಅವರಿಗೆ ಕಿವಿ ಹೇಗೆ ಕೇಳಿಸುತ್ತೆ? ಮಾತನಾಡ್ತಾರೆಂತೇ?

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2 ನಿಮ್ಮ ಸಂಬಂಧದಲ್ಲಿ ಮೊದಲೆ ನಾದರೂ ಮಾಡಿಕೊಂಡಿದ್ದೀರಾ? : ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

2.1 ಹತ್ತಿರದ ಸಂಬಂಧವೋ, ದೂರದ ಸಂಬಂಧವೊ?

2.2 ಏನು ಸಂಬಂಧ ಅಂತ ವಿವರ ಕೊಡಿ:

3.ಎ ಬಸುರಿಂತಾಗಿದ್ದಾಗ ನಿಮಗೆ ಜ್ವರದ ಜೊತೆ ಗಂಧಿ, ಅಥವಾ ಅಮ್ಮ ಎದ್ದಿತ್ತಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

ಎ.1 ಎಷ್ಟನೇ ತಿಂಗಳಲ್ಲಿ ಎದ್ದಿತ್ತು?

ಎ.2 ಕರಿ ಬಿದ್ದಿತ್ತಾ? : ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

ಎ.3 ಎಷ್ಟು ದಿವಸಕ್ಕೆ ಇಳೀತು?

ಎ.4 ಏನಾಗಿತ್ತು ಅಂತ ಹೇಳಿದರು?

ಬಿ ಬಸುರಿಂತಾಗಿದ್ದಾಗ ಚಳಿ, ಜ್ವರ, ನಕ್ಕೆರೋಗ ಅಥವಾ ಬೇರೆ ಏನಾದ್ರೂ ತೊಂದರೆ ಆಗಿತ್ತಾ? ವಿವರ ಕೊಡಿ.
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

ಸಿ ಮೊದಲ ಮೂರು ತಿಂಗಳಲ್ಲಿ ಕೆಂಪು ಮುಟ್ಟು ಜಾಸ್ತಿ ಹೋಗುತ್ತಿತ್ತಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

ಡಿ ಬಸುರಿಂತಾಗಿದ್ದಾಗ ಇಂಜಕ್ಷನ್ ಅಥವಾ ಮಾತ್ರೆ ಏನಾದ್ರೂ ಕೊಟ್ಟಿದ್ದಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

ಇ ಏನಕ್ಕೆ ಕೊಟ್ಟಿದ್ದು? ಎಷ್ಟು ಕೊಟ್ಟಿದ್ದು?

4.1 ತಿರಿಗೆ ನರೀನಾಗಿ ಆಯ್ತಾ? ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ
ಹೌದಾದರೆ ಆದಿದ್ದು ವಿವರ ಕೊಡಿ:

5.1 ಹುಟ್ಟಿದಾಗ ಮಗು ತೀರಾ ಸಣ್ಣದಾಗಿತ್ತಾ? ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ
ಹೇಗಿತ್ತು?

5.2 ತೂಕ ಎಷ್ಟಿತ್ತು?

5.3 ಆಸ್ಪತ್ರೇಲಿ ಮಗೂನ ನಿಮ್ಮ ಜೊತ್ತೇಗೇ ಇಟ್ಟಿದ್ರಾ ಅಥವಾ ಬೇರೆ ರೂಮಲ್ಲಿ ಗಾಜಿನ
ಪೆಟ್ಟಿಗೆಯಲ್ಲಿ ಏನಾದ್ರೂ ಇಟ್ಟಿದ್ರಾ? ಯಾಕೆ ಅಂತ ಗೊತ್ತಾ?

6.1 ಮಗುವಿಗೆ ಹುಟ್ಟಿದ ಕೂಡಲೇ ಕಾವಾಳಿ ಆಗಿತ್ತಾ? ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

6.2 ನೀವು ಎಷ್ಟನೇ ದಿವಸಕ್ಕೆ ಆದನ್ನು ನೋಡಿದಿರಿ?

6.3 ಯಾವಾಗ ಕಡಿಮೆ ಆಯಿತು?

6.4 ಎಲ್ಲಿಯವರೆಗೆ ಹಳದಿ ಕಟ್ಟಿತ್ತು? ಯಾವಯಾವ ಭಾಗ ಹಳದಿ ಆಗಿತ್ತು?

6.5 ಅಂಗೈ ಮತ್ತು ಹಿಮ್ಮಡಿ ಹಳದಿ ಆಗಿತ್ತಾ? ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

6.6 ಹುಟ್ಟಿದ ಎರಡು ಮೂರು ದಿನಗಳಲ್ಲಿ ಮಗುವಿನ ರಕ್ತ ಬದಲಾಯಿಸಿದ್ರಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

6.7 ನಿಮ್ಮ ಹಾಗೂ ನಿಮ್ಮ ಯಜಮಾನರ ರಕ್ತದ ವರ್ಗ ಹೊಂದಲ್ಲ ಅಂತ ಯಾರಾದ್ರೂ
ಹೇಳಿದ್ರಾ? — ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

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7 ಹುಟ್ಟಿದಾಗ ಮಗುವಿನ ತಲೆ, ಕಿವಿ, ಮೂಗು ಹಾಗೂ ಬಾಯಿಯಲ್ಲೇನಾದರೂ ದೋಷವಿತ್ತಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

7.1 ಇದ್ದಲ್ಲಿ ವಿವರ ಕೊಡಿ:

8.1 ಹುಟ್ಟಿದ ಸ್ವಲ್ಪ ದಿನಗಳಲ್ಲಿ ಮಗುವಿಗೆ ಏನಾದರೂ ಖಾಯಿಲೆ ಆಗಿತ್ತಾ?
ಆಗಿದ್ದಲ್ಲಿ ವಿವರ ಕೊಡಿ:

8.2 ಮಗುವಿಗೆ ಫಿಟ್ಸ್ ಅಥವಾ ಅದುರುವುದು ಬಂದಿತ್ತಾ? ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

8.3 ಪ್ರಜ್ಞೆ ಯಾವಾಗಾದ್ರೂ ತಪ್ಪಿತ್ತಾ? ಎಷ್ಟು ಹೊತ್ತು ಪ್ರಜ್ಞೆ ಇರಲಿಲ್ಲ?

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9 ಮಗುವಿಗೆ ಯಾವುದಾದ್ರೂ ಇಂಜಿಕ್ಷನ್ ಕೊಡಿಸಿದ್ರಾ? ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

9.1 ಎಷ್ಟು ಕೊಡಿಸ್ಸಿದ್ರಿ? ಎಷ್ಟು ದಿವಸ ಕೊಡಿಸಿದ್ರಿ?

9.2 ಮಗುವಿಗೆ ಏನಾಗಿತ್ತು?

9.3 ಜೊತೆಗೆ ಮಾತ್ರೆಗಳೇನಾದರೂ ಕೊಟ್ಟಿದ್ರಾ? ಎಷ್ಟು ದಿವಸ ಕೊಡಿಸಿದ್ರಿ?

10.1 ನಿಮ್ಮ ಮಗುವಿಗೆ ಕಿವಿ ಕೇಳಿಸುವುದರ ಬಗೆಗೆ ನಿಮಗೆ ಯಾವಾಗಾದರೂ ಅನುಮಾನವಿತ್ತಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

10.2 ಅದೇ ವಯಸ್ಸಿನ ಬೇರೆ ಮಕ್ಕಳ ತರಹ ಈ ಮಗುವಿಗೆ ಕಿವಿ ಕೇಳಿಸುತ್ತಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

10.3 ಅದೇ ವಯಸ್ಸಿನ ಬೇರೆ ಮಕ್ಕಳ ತರಹ ಈ ಮಗು ಮಾತಾಡುತ್ತಾ?
ಹೌದು—ಇಲ್ಲ—ಇರಬಹುದು—ಗೊತ್ತಿಲ್ಲ

ಬೇರೆ ಏನಾದರೂ ಮಾಹಿತಿ ಇದ್ದಲ್ಲಿ ಇಲ್ಲಿ ಬರೆಯಿರಿ:

_____ DATA SHEET _____

Register No . Classification Code

Mother's Name:
Father's Name Education: Age:
Income:
Dwelling: Urban/Rural.
No. of Children born: No. of children living: Abortions: Stillir:

Child's Name: Age: Sex: Parity:
Delivery place: Home/Hospital.
Supervision: Doctor/Nurse/Dadi/Others.

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1. Yes/No/?/NK
1.1. 1.3.
1.2. 1.4.

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2. Yes/No/?/NK 2.1. Close /Distant. 2.3

3.a.Yes/No/?/NK
a.1. Iqrt/IIqrt/IIIqrt. 3.b.
a.2. Yes/No/?/NK c.
a.3 d.
a.4 e.

4.1.Yes/No/?/NK 4.3. Yes/No/?/NK
4.2. Yes/No/?/NK

5.1 Yes/No/?/NK 5.3.
5.2.

6.1. Yes/No/?/NK 6.5. Yes/No/?/NK
6.2.Iday/IIday/ Later 6.6. Yes/No/?/NK
6.3. 6.7. Yes/No/?/NK
6.4.

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7. Yes/No/?/NK 7.1

8.1. Yes/No/?/NK
8.2. Yes/No/?/NK 8.3. Yes/No/?/NK

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9. Yes/No/?/NK 9.2.
9.1. 9.3.

10.1. Yes/No/?/NK
10.2. Yes/No/?/NK
10.3. Yes/No/?/NK

Interwiewer's Remarks:

Recommendations :

Follow-up: Recommended/Not Recommended/ Recommended at a later date.