

## SHORT REPORT

## Infant hearing screening: route to informed choice

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The decision to participate in infant screening often rests with parents. Medical ethics require that parental decision is elicited from informed choice. Such a decision is influenced by the parental knowledge and attitude towards screening and a careful evaluation of these factors is essential in seeking informed consent for infant hearing screening.

Infant hearing screening is gradually becoming a global issue as countries disadvantaged by intractable health and socioeconomic problems explore options for the early detection of congenital hearing loss.<sup>1</sup> Screening is a public health service aimed at reducing the risks accompanying diseases rather than providing a guarantee of diagnosis and cure.<sup>2</sup> However, the screening process itself is not risk free. For instance, false assurance from false negative results and maternal anxiety or stress from false positive screens have been cited in newborn hearing screening programmes.<sup>3–5</sup> A high false positive rate also places unnecessary burden on healthcare services. Screening and prevention programmes traditionally emphasised the expected benefits at the expense of the potential risks in order to maximise uptake. But this practice is no longer acceptable from an ethical perspective. Instead, screeners are required to ensure informed choice by disclosing the risks and benefits of the test before soliciting a decision that must be given freely and willingly. In this context, failure to obtain informed parental consent is unethical and undermines the quality assurance of infant hearing screening.<sup>6</sup>

**DIMENSIONS OF INFORMED CHOICE**

In following the principles and achieving the benchmarks of an efficient infant hearing screening programme healthcare providers are likely to face challenges in three areas, namely: contextual limitations, physician support, and parental acceptance.

The first area deals with the perception of hearing impairment as non-life threatening compared to other fatal childhood diseases that still have an overbearing influence on healthcare priorities in many countries.<sup>7</sup> The popular notion that “if it doesn’t kill, it doesn’t hurt”, particularly in resource-poor countries, deters a positive attitude towards early detection of hearing disorders and their timely intervention. Parental choice in this circumstance may be difficult and biased against screening if the value of the programme is not well communicated. By integrating infant hearing screening into existing well established child health campaigns, such as the Expanded Programme on Immunization (EPI) or the Baby-Friendly Hospital Initiative (BFHI), there would be no need to reinvent the wheel in promoting the programme among culturally and linguistically diverse population of mothers as we had previously proposed.<sup>1</sup>

The next area relates to the role of physicians in the early detection of infant hearing loss. Healthcare professionals are

perceived as fully knowledgeable about health conditions and parents rely on their advice before making vital medical decisions. Ironically, physicians have been noted as the cause of delayed detection of hearing loss even after being prompted by parental concern.<sup>8–10</sup> Changing the behaviour of physicians is not an easy task. It may sometimes require patient mediated interventions.<sup>11</sup> And with patients now becoming better informed through the Internet, expectations are growing for quality services particularly in more literate communities. Investment in physician education and re-orientation is therefore crucial for the effective implementation of infant hearing screening especially where it is not mandated by legislation.<sup>12</sup>

The third area deals with the parental view of hearing screening and health workers’ understanding of the dynamics of parental decision making. Behaviour is complex and difficult to predict. However, informed choice in screening is not synonymous with parental consent. Rather the primary goal is to ensure that the parental decision to accept or decline screening emanates from comprehensive information on the consequences of the possible courses of action. The General Medical Council has suggested that such information includes: the purpose of screening; the likelihood of positive and negative findings, alongside the possibility of false positive and false negative findings; the uncertainties and risks attached to the screening process; any significant medical, social, or financial implications of screening; and follow up plans, including the availability of counselling and support services.<sup>13</sup> For example, newborn hearing screening protocols would miss cases of late onset or progressive hearing loss due to asymptomatic cytomegalovirus infection, and Usher’s and Alport’s syndromes. Parents should be aware of the possibility of such false negative results and that childhood hearing screening is not a one-off affair. It is equally important to clearly explain the limitations in intervention to parents to forestall unrealistic expectations from (re)habilitation, which may occur where hearing aids are prescribed.

**DETERMINANTS OF PARENTAL DECISION**

The parental decision making process is often conditioned by a personal value system, which finds expression in a definite attitude (positive or negative) towards screening.<sup>14</sup> Thus, the principal determinants of informed choice are knowledge and attitude. To illustrate the various scenarios of informed choice we adapted our earlier action model as shown in fig 1.<sup>7</sup> A person has “good” knowledge if the amount of information available prior to making a decision is appropriate and sufficient. Similarly, a person’s attitude is regarded as “positive” if there is an inclination to consent as may readily be the case with parents of high risk babies relative to those of well babies.<sup>1</sup> Our model differs from the three-dimensional typology proposed by Marteau *et al*, which incorporated uptake as a measure of informed choice.<sup>14</sup> In our view, uptake represents a consequence rather than the goal of informed choice and was therefore excluded as a measure.<sup>15</sup>

		Attitude	
		Negative	Positive
Knowledge	Good	GN	GP
	Poor	PN	PP

Figure 1 A model for informed choice.

Parental status before screening can fall into any one of four categories in our model: poor knowledge with negative attitude (PN); poor knowledge but positive attitude (PP); good knowledge but negative attitude (GN); good knowledge with positive attitude (GP). The goal of informed choice in this model is to have everybody in the GP quadrant. As a first step, parental standing should be ascertained through a well structured questionnaire to decide what form of support is required. Those with poor knowledge should be assisted with educational information.<sup>13-16</sup> Such empowerment may influence a positive change in attitude. The major challenge thereafter would be with parents who still display a negative attitude. They would require counselling as a moral responsibility, bearing in mind any underlying personal or community values that may have led to the negative disposition such as fear of stigmatisation or unfavourable beliefs and culture.<sup>17</sup> It is important to recognise that the arrival of the newborn is an emotionally laden event and communication with parents should be handled with sensitivity.

**DEMAND FOR PARENTAL AUTONOMY**

How should the healthcare professional react to an informed decision by a parent to decline screening for her child? Professional ethics prohibits coercing patients to accept screening. In conditions such as phenylketonuria and hypothyroidism for instance, with a high index of brain damage or mental retardation, parental consent may be validly waived. Otherwise, parental autonomy must be respected even when in the physician’s judgement it does not serve the best interests of the child. This possibility has stimulated an alternative concept of community consent which involves establishing the preferences among a well informed target population.<sup>18</sup> Individual consent is therefore unnecessary if most people consider the benefits of screening to outweigh the disadvantages. However, this would violate the high ethical standards prescribed for physicians.<sup>13</sup> It is for the patient, not the physician (or community) to determine what is in the patient’s own best interest.

Healthcare professionals may be concerned that the explicit disclosure of potential risks may create anxiety among parents and result in a disproportionate decline in

screening uptake. However, further studies will be needed to verify this problem in different circumstances.

**CONCLUSIONS**

Ethical standards require that efforts to elicit parental consent for infant hearing screening should be predicated on informed choice. Service providers must understand the various contextual and personal issues that impact on parental decision making. Parental autonomy should be preserved even when an informed choice to decline screening is made for a child.

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