The way forward in medical and ethical antenatal counselling for neurological anomalies

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When disclosing fetal neurological anomalies to prospective parents, communication, interpersonal relationships, and attention to context and needs is key. Medical guidance is also welcomed. The multi-institutional team led by Dr Anthony Hart[1,2] should be commended for reviewing the medical management of some of the most important fetal neurological anomalies, and how prospective parents are best advised by medical professionals. Indeed, there is very little time between detection of an anomaly and the decision-making that must ensue. Further testing is sometimes necessary to complete the clinical picture and prognosis can add untimely delays, ranging from days to weeks. The window of opportunity to terminate a pregnancy prior to viability may be well over by then and complicate the emotional and practical aspects of the decision-making process. The longer the wait, the more distress experienced by families. Physicians are therefore under pressure to gather information, sometimes forced to expediency in their research of the most up-to-date clinical evidence. As Hart et al. acknowledge, despite the pressing need for greater and stronger evidence, there are several limiting factors to evidence-informed programs and medical care. We single out two important stumbling blocks in the hope of raising awareness and further mobilizing efforts to tackle them.

Communication of adverse outcomes is a challenging task hindered by the complexity and applicability of statistical data. Physicians commonly avoid discussions of prognosis.[3] Prognosis touches upon the uncomfortable subjects of death and disability, which are fraught with uncertainty. Prognosis communication is seldom taught adequately in the medical curriculum.

When prognosticating, physicians tend to overestimate the impact of impairment on quality of life and have an excessive fear that parents will experience decisional regret if they pursue with the pregnancy and have a child with a neurological impairment. Physicians must be diligent in discussing all possible bad outcomes during antenatal counselling. The literature indicates that physicians are much more negative than patients or patient-proxies, sometimes even considering life with impairment as worse than death.[4]

Antenatal counselling research has focused on parental perspectives before delivery. Most parents have never had the experience of raising a child with a neurological anomaly when asked to predict what their needs for information would be. They may afterwards have a very different understanding of what information given to them prior to delivery would have been the most useful. Studies on antenatal counselling parental needs after having had a child with a neurological anomaly are needed.

Good outcome data on neurological prognosis of newborn infants are rare,[5] yet access to systematic reviews of contemporary evidence for estimation of prognosis is essential to allow families to make critical decisions during pregnancy.

Increasing knowledge of risk outcomes is certainly a significant step towards improving discussions of prognosis when counselling families. But one must not forget the importance of implicit biases in physicians' interpretation of adverse outcomes.

As noted by Hart et al., how a prognosis is delivered can strongly influence prospective parental choices. Furthermore, physicians have been shown to demonstrate biases in their prognosis, being either overly pessimistic or overoptimistic, or simply variable from one physician to another. These biases are not solely caused by lack of access to information but can be attributable to physician factors as well as patient factors or clinical environment. Some factors such as the patient characteristics are better accounted for, but factors related to the physicians' clinical experience and values need greater attention. There is a need for research on strategies to reduce these biases, and to include the proper communication of prognosis into ongoing training of physicians.[6]

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