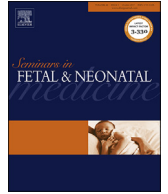




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Ethical implications of the use of decision aids for antenatal counseling at the limits of gestational viability

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A B S T R A C T

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Shared decision-making is a recent priority in neonatology. However, its implementation is at an early stage. Decision aids are tools designed to assist in shared decision-making. They help patients competently participate in making healthcare decisions. There are limited studies in neonatology on the formal use of decision aids as used in adult medicine. Decision aids are relatively new, even in adult medicine where they were pioneered; therefore, there is a lack of systematic oversight to their development and use. Despite evidence reporting a powerful effect on patients' decisions, decision aids are not subject to quality control, leading to potentially enormous ethical implications. These include: (i) possible introduction of developers' biases; (ii) use of outdated or incorrect information; (iii) misuse to steer a patient towards less expensive treatments; (iv) clinician liability if negative patient outcomes occur, since decision aids are currently not standard of care.

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1. Introduction

The importance of patient involvement in medical decision-making is widely acknowledged [1]. In neonatal medicine the statements of professional societies, such as the Fetus and Newborn Committees for the USA and Canada, consistently advocate informed decision-making at the limits of neonatal viability and respect for parents' individual preferences [2,3]. This impetus to information-sharing is universal as seen by similar activity in other industrialized countries such as the Netherlands, Switzerland, Australia, and the UK [4–8].

Shared decision-making is a process through which clinicians and patients work together to decide about treatment options. These should be based on clinical evidence and the patient's informed preferences. Currently, there is an emphasis among clinicians to involve patients (or their surrogate decision-makers) in shared clinical decision-making [9]. Patients' attitudes towards shared decision-making have changed over time. A systematic review examined patient preferences for shared decision-making prior to and after 2000. In the period before 2000 only 50% of patients preferred sharing decision roles as compared to 71% of patients in

studies published after 2000 [10]. This may reflect a change in the way society views patient autonomy and decision-making.

It is evident that parents facing premature delivery of extremely low birth weight (ELBW) and extremely low gestational age (ELGA) infants need to receive enough information about the potential outcomes of their children in an unbiased and empathetic manner in order to make a value-laden decision. However, exactly how to meaningfully implement a shared decision policy for individual parents remains unclear. There are problems in operationalizing how to provide information to make it transparent and meaningful to individual parents. Statements of recommendations by scientific and professional bodies are meant to facilitate decision-making. Regrettably, these, along with tools such as decision aids, are interpreted by some as simplistic, flawed, or are mischaracterized as simple “check-lists” [11,12].

2. Challenges of current practice during counseling

Significant hurdles complicate the process of antenatal counseling for extreme prematurity. Information-sharing during this scenario of medical decision-making is pressured by time constraints and is variable [13,14]. Miscommunication is frequent, and may in part arise from a variable knowledge of outcomes of ELBW infants by providers [15,16]. There also is no agreement as to who should decide how complete or wide-ranging the levels of

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information should be [17].

Often, the discretion and biases of the individual counselor are paramount, leading to inconsistent and inaccurate information [18]. In surveys of pediatricians, obstetricians, neonatal intensive care unit (NICU) nurses, nurse practitioners, and neonatologists, survival rates for infants <27 weeks gestation were underestimated and disability rates were overestimated by 10–50% compared to published data [15,16,19]. Bigger differences were seen when estimating outcomes in the lower gestation groups.

Perhaps these problems are responsible for the large variations in counseling practices across US hospitals [18]. Mehotra et al. found significant deficiencies across US NICUs with neonatology training programs. Almost none had standardized training for counselors, a standardized format to relay information to parents, or a standard database from which to pull information to provide to parents [18]. Clinicians often believe that they can uniquely tailor the message so that it is individualized to a family. However, Zupancic et al. found that parents recalled counseling information differently from clinicians [20]. Parents and clinicians agreed on the obstetric issues discussed, but they had poor agreement on the neonatal issues discussed. Clinicians did not accurately identify the 45% of parents surveyed who felt strongly about making their own decisions. Instead, they mischaracterized them as preferring directive, prescriptive recommendations. Moreover, parents and clinicians disagree when asked to recall the actual content of discussions during counseling for ELBW delivery. Parents feel they were not able to give input in making decisions at delivery, and they disagree with clinicians' views that parents were involved in delivery room decisions [21,22]. A multi-center study revealed that parents often do not understand their options for resuscitation nor do they recall discussing these options with their clinicians [22]. In contrast, clinicians believed that options for delivery and resuscitation had been discussed with these parents. Finally, parents and healthcare providers view outcomes differently [23,24]. Healthcare providers are far more likely than parents to view poor long-term disabilities as an outcome worse than death.

This perceptual gap between parents and clinicians may reflect a complicated medical vocabulary and terminology that parents find 'alien'. This may result in a lack of transparency and comprehension during critical discussions. Parents perceive that they are often provided with inadequate information regarding preterm delivery and therefore are unable to make informed choices about resuscitation and its consequences [25]. They want to be informed about the potential risks and outcomes for their child, but feel that information is not provided to them. Parents are usually stressed and anxious during the circumstances of an impending premature delivery, leading to a decreased ability to learn complex new information and impeding their recall [26]. Recall is especially diminished when counseling and reflection time are limited by imminent delivery. Finally, as noted above, physicians can only poorly gauge parental preferences [20].

3. Use of decision aids

Better ways to communicate complex information to parents facing extreme premature delivery are needed. Attempts to create general guidelines for physicians and to simplify parental information suggest that parents view these as useful [26–29]. It is possible that presenting detailed information to parents decreases maternal anxiety and increases knowledge of long-term problems associated with prematurity [30].

In adult medicine, physicians increasingly integrate decision aids into their clinical practice [31]. Decision aids are tools designed to help patients competently participate in making decisions about their healthcare [32]. The more successful decision aids are those

that are derived not only using physicians' medical expertise, but incorporate the views of patients who have undergone the therapeutic process presented in the decision aid [33]. Decision aids can take many forms such as cards, videos, audio-booklets, computer programs, or pamphlets [33]. They are not meant to replace clinician/patient conversations about treatment options. Rather, decision aids should be viewed as a means to supplement face-to-face discussions by communicating the best available evidence on treatment or screening options to encourage active patient participation in decision-making [32]. Such aids are best suited for health decisions that are particularly sensitive to patient preferences, or where there is no single treatment option that is correct or clearly indicated. These situations depend upon the patient's preferences, values, and cultural background. At a minimum, decision aids should describe the decision that needs to be made, the options available, the risks and benefits of these options, and the potential outcomes of these options. Decision aids therefore help quantify risks and benefits, help patients clarify their values, help patients understand the trade-offs of potential benefits relative to potential harm, and help patients appreciate scientific uncertainty [32]. Randomized controlled trials show that transparent and comprehensible decision aids improve patient-important outcomes [34–36]. A systematic review of 105 studies involving 31,043 participants showed that the benefits of decision aids include: improved patient knowledge and realistic expectations; enhanced active participation in decision-making; lowered decisional conflict; and improved agreement between patients' preferences and subsequent treatment decisions [37]. Decision aids also reduced the proportion of undecided participants and had a positive effect on patient–clinician communication. Those counseled using a decision aid were more satisfied with their decision and the decision-making process [37].

There are limited data available to use for counseling in newborn medicine. Despite an emphasis on involving parents in decision-making at the limits of viability, only limited studies in neonatology evaluate decision-making with formal decision aids [38–41]. Ideally, such aids should incorporate parent-specific views about the relevant experience. Only two decision aids were designed to incorporate specific parental experiences with antenatal counseling [38,39]. For these two decision aids, thirty parents with a history of extreme premature delivery were interviewed about their experience with antenatal counseling. These parents discussed those items that they found most relevant in their decision-making. Iterative development of these decision aids further took into consideration parent feedback. Moore et al.'s decision aid was developed using a multi-stakeholder working group that included a few selected parents of extremely premature infants [41]. Kakkilaya et al.'s decision aid did not include any parental views in its design process [40]. Validity testing of these four decision aids demonstrated improved knowledge and decreased decisional conflict after counseling [38–41]. Participants found the use of these decision aids as useful. The decision aid successfully initiated a dialogue between the counselor and each participant [38].

Hitherto there have been no published randomized trials in neonatology assessing decision aids to counsel parents, though at least one is currently ongoing [42]. Preliminary results of this randomized controlled trial show that the decision aid improved comprehension of important information and was well received by parents and clinicians. This shows that tailored decision aids with relevant information to individual parents are potentially useful.

4. Methodological considerations with ethical impact

The medical community has only recently become interested in

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