Prenatal decision-making for myelomeningocele: Can We Minimize Bias and Variability?

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Prenatal decision-making for myelomeningocele changed in 2011, when MOMS (Management of Myelomeningocele Study) demonstrated the effectiveness of intrauterine fetal surgery, thereby securing this intervention as an alternative to either pregnancy termination or postnatal repair. Although it is hoped that an evidence-based approach to medical decisions using the MOMS results would improve the quality of information received by pregnant patients, we believe that unless specific steps are taken, prenatal counseling for myelomeningocele (counseling that occurs in myriad locations across the United States) will be persistently marred by hidden biases and excess variability.

We believe this prenatal counseling will be affected for 3 reasons. First, the MOMS results present tradeoffs. Rates of ventriculoperitoneal shunt placement and ambulation were improved for children who underwent prenatal repair but with higher rates of prematurity and respiratory distress syndrome, as well as important maternal complications. Adding to the uncertainty, long-term outcomes are unavailable; prognosis remains difficult to predict for any given fetus; and posttrial complication rates reportedly differ from trial results, with higher rates of perinatal death (6% vs 3%) and respiratory distress syndrome (52% vs 21%) but fewer maternal complications (pulmonary edema, 2% vs 6%; maternal transfusion, 3.4% vs 9%).1 Women undergoing intrauterine surgery require cesarean deliveries for all future pregnancies. The reasoning regarding such multifaceted risk/benefit tradeoffs for obstetric and neonatal interventions is notably difficult for both physicians and patients.2

Second, physicians commonly have differing opinions regarding newer interventions that have not become standard of care, based on personal experiences and interpretations of the literature. One survey of maternal-fetal medicine and pediatrics specialists conducted before the MOMS results were published found no agreement regarding whether to recommend open intrauterine surgery for a hypothetical fetal condition similar to myelomeningocele.3 Furthermore, attitudes diverged about appropriate reasons to consider pregnancy termination in general, the importance of offering information about pregnancy termination when myelomeningocele is diagnosed, and supportiveness for patients’
decisions to terminate affected pregnancies. We do not know how such attitudes affect counseling proclivities or whether the MOMS results will change them. After publication of MOMS, experts have continued to disagree on whether prenatal or postnatal repair for myelomeningocele is the better option.

At issue is how provider differences influence decision-making and outcomes for myelomeningocele, particularly given that much of the initial counseling is provided by obstetricians in centers that do not perform the prenatal surgery and most pediatrics centers offering the surgery do not perform pregnancy termination. Similar heterogeneity in clinical practice and technological capabilities is common in obstetrics and neonatology and is associated with considerable outcome variations. Endemic variation in the treatment of and outcomes for periviable newborns raises concern that clinician biases and center predilections influence parental decisions in a hidden and undue manner. We anticipate similar dynamics regarding prenatal decision-making for myelomeningocele, for which practice and outcome variation will likely be fostered by uneven geographic and financial access to intrauterine surgery and pregnancy termination, and further exacerbated as inexperienced centers begin to offer the surgery.

Third, potential provider biases regarding prenatally diagnosed myelomeningocele may be accentuated by differences between practice guidelines issued by the Myelomeningocele Maternal-Fetal Management Task Force convened by the Eunice Kennedy Shriver Institute of Child Health and Human Development (MMCTF) and the position statement on maternal-fetal interventions issued jointly by the American Academy of Pediatrics (AAP) and the American College of Obstetricians and Gynecologists (ACOG). To facilitate optimal decision-making, the MMCTF recommends a “maternal/fetal advocate to ensure that counseling is nondirective,” whereas the AAP/ACOG recommends “an independent advocate” who “should be nondirective in his or her support of the woman’s decision and focus on meeting the woman’s decision-making needs.” Unwittingly or not, the language variance suggests value differences regarding the central focus of counseling. Furthermore, both documents endorse nondirective counseling, but only the AAP/ACOG statement explicitly acknowledges the challenge of providing unbiased information. Both statements prescribe that pregnancy termination should be discussed as an option, along with prenatal and postnatal surgery. The AAP/ACOG adds that centers offering fetal treatment also bear ethical responsibility to women considering termination to provide “appropriate mechanisms, including the ability and resources for referral...” They further recommend the availability of bereavement support for patients who terminate the pregnancy. The MMCTF does not recognize such obligations, which is an important potential source of bias. Some pediatrics-based fetal care centers may not recognize such obligations as within their domain, but further bias emerges if such support is available for a hospital’s adolescent patients with normal pregnancies but not for adult pregnant patients carrying fetuses with congenital abnormalities. Finally, the AAP/ACOG document specifies that maternal-fetal medicine specialists should direct the care of women undergoing fetal intervention and expresses concern that obstetric and pediatric practitioners may sometimes possess conflicting perspectives. The MMCTF, which represented clinical providers specific to myelomeningocele, does not stipulate who should direct the woman’s overall care and does not clearly define the maternal-fetal medicine role. In sum, the AAP/ACOG statement more clearly supports the pregnant woman’s central decision-making status. Although the proportion of centers that subscribe to either statement is unknown, preferential adherence to 1 or the other may result in considerably different counseling across clinicians and centers.

Despite calls for nondirectiveness, the complex conditions depicted here leave wide openings for undue provider and institutional influence over patient decisions and, ultimately, outcomes. Even if all options are discussed, outcomes may vary for those offered different degrees of accessibility, information, and support for any given decision. Differences regarding various counseling points may leave patients with uncertainty regarding whether the information has been selectively offered, withheld, or framed favorably or negatively and to what degree the recommendation they received is influenced by individual consultants’ values and beliefs or by particular centers’ practice characteristics. Patients may thus be uninformed regarding the accessibility and level of support for pregnancy termination and prenatal or postnatal surgery at the place where they received consultation, as well as how these features differ among institutions; these factors could hamper patients’ ability to seek care elsewhere.

We therefore urge the community of providers who diagnose, provide counseling for, and treat myelomeningocele prenatally and postnatally to establish uniform guidelines regarding the requisite information to be offered. A standardized counseling information sheet should be made available that clearly states:

1. Major treatment options for myelomeningocele, including prenatal surgery, postnatal surgery, and termination.
2. Expected outcome ranges for each option, including potential physical and psychosocial risks and benefits to pregnant women and neonates, and long-term profiles of individuals with myelomeningocele.

3. Outcome variations among centers.

4. Options the consultant’s organization offers.

5. Options recommended and why.

6. Selection criteria for patients offered prenatal surgery and how they compare with MOMS.

7. The center’s own experience with the surgery (if offered) and how center outcomes compare with MOMS.

8. What remains unknown.

9. Transparent admissions regarding providers’ limits of knowledge and experience.

10. Referral information for questions about or services for termination or surgery if not provided within the institution.

We do not seek standardization of services or recommendations. The process and content of counseling would remain the independent responsibility of the clinician. A standardized information sheet would ensure that a range of basic information and options is covered along with a summation of the key literature. Although this resource will not eliminate hidden bias and capricious variation, this practice would reduce variation in the information offered and help patients make informed decisions about what treatment to select and where to seek care.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
ACOG: American College of Obstetricians and Gynecologists
MMCTF: Myelomeningocele Maternal-Fetal Management Task Force convened by the Eunice Kennedy Shriver National Institute of Child Health and Human Development
MOMS: Management of Myelomeningocele Study

REFERENCES


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