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Letter to Editor (Pages: 247-250)

Informed Consent for Lumbar Puncture and Bone Marrow Aspiration in Children and Infants: From Documenting Signatures to Assessing Parental Understanding

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Abstract

Consent for invasive diagnostic procedures in children and infants is a communication and ethical decision-making process that should not be reduced to signing a form. For lumbar puncture and bone marrow aspiration, concerns about pain, complications, and serious disease underscore the importance of clear explanations and assessment of parental understanding. Valid consent requires confirmation of decision-making authority, provision of procedure-specific information, understanding, and voluntariness. Children should participate according to their developmental capacity and clinical condition. This letter proposes a three-stage framework comprising preparation, dialogue incorporating teach-back, and documentation of the decision. Identifying family concerns and respectfully addressing misconceptions are integral to this process. Multimedia education may supplement, but should not replace, direct communication. The proposed framework has not been validated; its evaluation should assess parental understanding, child participation, and voluntariness rather than rely solely on documentation.

Key Words: Bone marrow aspiration, Child, Infant Informed consent, Lumbar puncture.

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Dear Editor,

The gap between "documented consent" and an "informed decision" is an important quality-of-care issue in invasive pediatric procedures. Lumbar puncture (LP) and bone marrow aspiration (BMA) may be proposed when families are concerned about both procedural pain and the possibility of serious disease. A signed form records permission but does not, by itself, demonstrate understanding of the procedure's purpose, risks, or alternatives. The American Academy of Pediatrics similarly describes parental permission and childhood assent as an active decision-making process (1).

Distinguishing parental permission, childhood assent, and consent by an individual with decision-making capacity is fundamental. For infants, decisions made by the legally authorized representative should prioritize the child's interests. For children capable of understanding, developmentally appropriate explanations and attention to their concerns are essential; assent should not be equated with physical cooperation alone (1). Decision-making authority must be established according to applicable local requirements. Decisions must also be voluntary: explaining the consequences of refusal or delay should not involve threats, blame, or coercion.

Consent documentation may contain important omissions. In the study by Patel et al. involving 937 emergency department patients, including 179 children, general consent was documented in 86% of records, whereas an LP-specific consent form was present in only 56%; documentation of benefits and alternatives was also incomplete (2). Missing documentation does not necessarily establish that a discussion did not occur. Conversely, general admission consent does not establish the quality of procedure-specific permission.

Evidence from Iran also highlights communication challenges. Rezvani et al. surveyed 188 accompanying family members and 23 physicians at hospitals affiliated with Shahid Beheshti University of Medical Sciences. Among family respondents, 25.9% described physicians' explanations as "never clear," and 7.6% as "mostly unclear" (3). These self-reported findings are setting-specific and should not be generalized nationally. Nevertheless, they emphasize the importance of assessing what families understand rather than relying on clinicians' perceptions of information delivery.

To improve this process, a three-stage framework is proposed: preparation, procedure-specific dialogue with assessment of understanding, and documentation of the decision. This framework is a quality-improvement proposal, not a validated instrument or a substitute for institutional policies. Its purpose is not to introduce another form but to structure communication and facilitate evaluation.

During preparation, the indication, urgency, decision-making authority, and communication needs should be established. The clinician should explain which diagnostic question the procedure addresses and how its findings may influence treatment. The family's preferred language, need for an interpreter, and principal concerns should also be identified. Urgency may limit the time available for discussion but does not automatically justify bypassing permission. When an exception applies, the basis for proceeding and attempts to contact the authorized representative should be documented according to applicable requirements (1).

Exploring concerns is integral to preparation. Masood et al. identified fear of the procedure's invasiveness, paralysis, and death, along with perceived lack of necessity and the influence of others, among reported reasons for refusing LP (4). These findings concern a specific population; parental disagreement should not invariably be attributed to inadequate knowledge. Clinicians should first elicit each family's concerns and then explain the sampling site and risk-reduction measures in accessible language. Labels such as "myths" or "folk beliefs" may dismiss legitimate concerns; misconceptions should instead be addressed respectfully.

During the second stage, information should be procedure-specific and individualized. For LP, the purpose of cerebrospinal fluid sampling, the main procedural steps, and the possibility of an unsuccessful attempt or repeat procedure should be explained. The Royal Children's Hospital Melbourne guideline emphasizes discussing benefits and potential complications (5). Pain, a traumatic or blood-stained sample, headache, and less common complications such as infection or bleeding

should be described without exaggeration or absolute reassurance. Alternatives must be presented with their limitations: a test that cannot provide equivalent diagnostic information should not be described as an equivalent substitute.

The implications of refusal should also be explained without using fear to secure agreement. Not performing LP may limit diagnostic certainty and treatment guidance, but refusal should not be portrayed as inevitably causing severe complications or death. When meningitis or sepsis is suspected, LP must not delay necessary antibiotic treatment (5). The objective is informed decision-making consistent with the child's interests, not agreement at any cost.

For BMA, the diagnostic purpose, sampling site, and distinction between aspiration and biopsy should be clarified. If both procedures are planned, the discussion and permission should cover both. Abla et al. identify written consent, sedation assessment, and evaluation of bleeding risk as components of preparation (6). Pain, bleeding, infection, and the possibility of an inadequate sample should be discussed in relation to the child's circumstances. The analgesia and sedation plan should be explained before permission is obtained; permission for sampling alone does not demonstrate understanding of sedation-related risks and requirements.

Teach-back is proposed as a means of assessing understanding: "To make sure I explained this clearly, could you tell me why this test has been recommended and what concerns you have?" The purpose is not to test parents but to identify communication gaps. Children should participate according to their developmental capacity, with opportunities to express fear or disagreement (1). For nonurgent procedures, disagreement may prompt further preparation and reassessment; situations involving a risk of serious harm require individualized clinical, ethical, and legal consideration.

Visual resources may supplement dialogue, but their superiority should not be assumed. In a study of 201 parents, Temsah et al. found that verbal and video education both improved knowledge about LP. However, perceived risk was higher in the video group, particularly among parents with lower educational attainment. The investigators emphasized direct interaction after the video (7). Multimedia materials should therefore be followed by opportunities for questions and assessment of understanding.

Finally, documentation should go beyond "risks explained." The procedure's purpose, family questions, assessment of understanding, child participation, and final decision should be recorded concisely. If permission is declined, the stated reasons and discussion of the consequences of delay should also be documented. Recording the outcome of teach-back and the pain-management plan may support clinical audit, but documentation cannot substitute for actual understanding. Future studies should compare these indicators with independent assessments of understanding and voluntariness and evaluate the framework's feasibility and workload implications.

CONCLUSION

Consent for LP and BMA in children and infants should not be defined by the presence of a signed form. Its quality depends on family understanding, decision-making authority, voluntariness, developmentally appropriate child participation, and a clearly explained pain-management plan. The proposed three-stage framework provides a basis for quality improvement and research but requires evaluation. The ultimate goal is not more signatures or reduced refusal at any cost, but an informed, documented decision consistent with the child's interests.

CONFLICT OF INTEREST: None.

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