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Review Article

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Bridging the counselling gap: a real-time digital consultant interface for antenatally-diagnosed spina bifida

Abstract

Background: The prenatal detection of spina bifida is one of the most consequential moments a family will ever face. In the space of a single conversation, parents are asked to absorb an unfamiliar diagnosis, understand a spectrum of possible outcomes and weigh options that now include termination, planned postnatal repair and open foetal surgery. Yet the person who first delivers this news is rarely the person best placed to explain the surgical trade-offs. Obstetricians and foetal-medicine specialists carry the counselling, while the paediatric surgeon or foetal surgeon who understands the operative realities is usually somewhere else, often in another hospital or another city.

Current evidence: The literature is consistent and uncomfortable on this point: families frequently describe rushed, jargon-laden and occasionally inaccurate counselling, sometimes with premature pressure toward termination.

Perspective: In this perspective, the authors argue that this is a solvable, communication-logistics problem. A real-time, mobile, consultant-to-frontline digital interface (the kind already being piloted in Indian public-sector Paediatric Surgery) can place the right specialist voice into the counselling room at the moment it is needed, capture that counselling in a structured, timeline-linked record and hold it accountable against the child's eventual outcome.

Future Direction: The priority is to embed such interfaces within existing tele-foetal-medicine networks, test structured records against long-term outcomes and develop standardised counselling scripts across specialties. The technology already exists; what is missing is the policy commitment to make it standard practice.

Keywords: antenatal counselling, foetal surgery, myelomeningocele, shared decision-making, spina bifida, telemedicine

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Introduction

There is a particular silence that follows the sentence *"we have found a problem with the baby's spine."* Every clinician at the maternal–foetal interface knows it: for the family, this diagnosis is not a data point but a rupture in the life they had imagined and what they are told must be timely, evidence-based and objective.[1,2] The stakes have grown higher since the Management of Myelomeningocele Study (MOMS) showed that repairing the defect before birth, rather than after, can change a child's neurological outcome,[3,4] so the family no longer chooses simply between continuing the pregnancy and ending it; they choose among three fundamentally different surgical futures, in a narrow window, often guided by someone not equipped to explain all three.

Spina bifida is not rare: it is the most common central nervous system anomaly, affecting roughly one in a thousand live births. Myelomeningocele, its open form, carries most of the lifelong morbidity.[5] It is increasingly diagnosed antenatally and its outcomes are unusually well described for a congenital anomaly.[6] Since the evidence to guide counselling already exists, good counselling is both possible and expected here. This perspective begins with why it so often fails regardless.

What good counselling requires

To counsel a family well after a diagnosis of spina bifida is to hold three things together at once.

Accuracy about the lesion: Open and closed neural tube defects are clinically decisive, not academic: an open defect may make a child a candidate for closure in utero and needs expedient referral, while a closed defect often needs no neonatal surgery at all.[1,7] Getting this right at the first conversation shapes the referral, the timeline and the family's sense of what is coming.

Fair account of prognosis, neither falsely reassuring nor needlessly bleak: Functional outcome in myelomeningocele tracks the lesion's anatomical level, though foetal motor function on ultrasound predicts it more reliably.[8] To bring order to this task, the senior author has previously proposed the ***Management, Outcome, Risk and Expectation (MORE) classification***, a risk-based stratification, from a PRISMA-compliant systematic review of antenatal counselling for paediatric surgical conditions, that organises each anomaly by organ system, single- versus multi-system involvement, natural history, management and effect on obstetric care.[9] MORE makes explicit what a family must be told before a decision can fairly be called informed (Table 1).

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Table 1 The MORE (Management, Outcome, Risk, Expectation) framework applied to antenatally diagnosed spina bifida

MORE domain,	Open spina bifida (myelomeningocele)	Closed spina bifida (e.g. lipomyelomeningocele, occult lesions)
Management (M)	Antenatal referral to a foetal-surgery-capable centre; choice between in-utero repair (19-26 weeks), when available and postnatal closure, usually within 24-48 h of planned caesarean delivery	Often no neonatal surgery; elective postnatal review and selective delayed repair (e.g. for tethering) where indicated
Outcome (O)	Lifelong motor, bladder and bowel dysfunction, hydrocephalus and Chiari-II-related morbidity; degree influenced by lesion level and foetal motor function on ultrasound	Frequently near-normal or milder functional outcome; morbidity depends on the specific lesion and any secondary cord tethering
Risk (R)	Prenatal repair (limited by availability) carries maternal and foetal risk (preterm birth, membrane rupture, uterine-scar dehiscence); postnatal course carries high shunt dependence	Low immediate procedural risk; principal risk is progressive neurological deficit from unrecognised tethering over time
Expectation (E) - what parents should be told	All three pathways (termination, postnatal repair, foetal surgery), their eligibility windows and trade-offs, and the need for multidisciplinary lifelong follow-up	Reassurance where appropriate, the possibility of no neonatal surgery and the importance of surveillance for late tethering
Single- vs multi-system	Commonly multi-system: neurological, urological, orthopaedic and via hydrocephalus, neurocognitive	Often single-system / localised, but requires exclusion of associated anomalies
Effect on obstetric management	Yes - alters timing and mode of delivery (planned caesarean; delivery at a centre able to offer immediate closure or prior in-utero repair)	Usually minimal alteration to routine obstetric management

Outcome percentages are from the Management of Myelomeningocele Study (MOMS): shunt placement at 12 months 40% (prenatal) vs 82% (postnatal); independent ambulation at 30 months 42% vs 21% [4].

Presentation of treatment options: Before 2011, counselling centred on prognosis and a choice between obstetric follow-up and termination. The MOMS changed that permanently: a randomised trial across three foetal-surgery centres found that prenatal repair before 26 weeks reduced the need for ventriculoperitoneal shunting and improved motor function compared with postnatal repair, a benefit strong enough to stop the trial early, though not without meaningful maternal and foetal risk, including uterine dehiscence and prematurity.[4]

An expectant mother must now choose, within a limited window, among termination, postnatal surgery or foetal surgery, each with its own risk profile. Shared decision-making is the accepted framework here, formalised specifically for myelomeningocele[3], but it is only as good as the information that reaches the parents, which is exactly where the system breaks (Table 2).

Table 2 The three management pathways after prenatal diagnosis of open spina bifida, across the axes parents must weigh

Decision Axis	Termination of Pregnancy	Postnatal Repair	Open Foetal (in-utero) Surgery
Eligibility / window	Per local legal gestational limits following prenatal diagnosis	Any confirmed open lesion; closure usually within 24-48 h of birth	Selected cases repaired at 19-26 weeks' gestation; strict maternal and foetal criteria
What it involves	Medical or surgical termination and associated counselling and support	Normal delivery or planned caesarean (obstetric indications) followed by neonatal spinal closure	Maternal hysterotomy and in-utero closure, then planned caesarean at ~37 weeks
Principal benefit	Avoids continuation where parents judge the anticipated burden unacceptable	Definitive closure with established, widely available neonatal care	Shunt placement by 12 months reduced (40% vs 82%); independent walking at 30 months increased (42% vs 21%); hindbrain herniation reduced
Maternal risk	Procedure-related risks of termination	Standard caesarean risks	Added risk: preterm birth, membrane rupture, oligohydramnios and uterine-scar dehiscence
Foetal / neonatal risk	Not applicable	Ongoing exposure of the placode until birth; higher shunt dependence	Prematurity and its sequelae; small risk of foetal loss
Availability in resource-limited settings	Generally accessible	Broadly available at centres with neonatal surgical capability	Highly centralised; available at very few centres and typically not available in most of India

Where it breaks down

The evidence base for counselling is unusually good; its delivery is not. That gap is documented, not just a clinical impression.

A systematic review of family experiences of antenatal counselling for spina bifida found a troubling pattern: shock and grief at the diagnosis were expected, but some families were offered termination almost immediately, before they understood anything meaningful

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about the condition. Teams that were gentle, jargon-free and honest about both the hard and hopeful parts of the child's likely life were remembered well; callous language, unduly negative framing and outright incorrect counselling, especially paired with pressure to terminate, were remembered with lasting resentment. As related work puts it in its title, when it comes to antenatal counselling for spina bifida, *we need to do better.*[10]

The failure is structural. The clinician present at diagnosis can detect and characterise the anomaly but does not perform the spinal closure, manage the shunt or follow the child's later care. The specialist who holds that knowledge is typically elsewhere and logistics, not ignorance, separate the family from the information it most needs.

In a well-resourced foetal-care centre this separation is trivial; across much of India and comparable health systems, it is not. Antenatal diagnosis often happens in a district hospital or private scan centre with no paediatric surgeon, let alone a foetal-surgery programme, within a hundred kilometres, so counselling is delivered on incomplete information and the family decides on that basis. Foetal surgery for myelomeningocele has always required regionalising into a few expert centres; regionalising the surgery without the counselling only means families are advised by people who have never seen the operation and cannot refer them in time.[11,12]

The shortfall, then, is not one of medical knowledge. It is one of access: the family is cut off from expertise that already exists, by nothing more than distance, scheduling and finances. This structural counselling gap is illustrated conceptually in Figure 1: the family and diagnosing clinician are separated from specialist surgical expertise by distance, logistics and time constraints, while a real-time digital consultant interface provides the bridge between them.

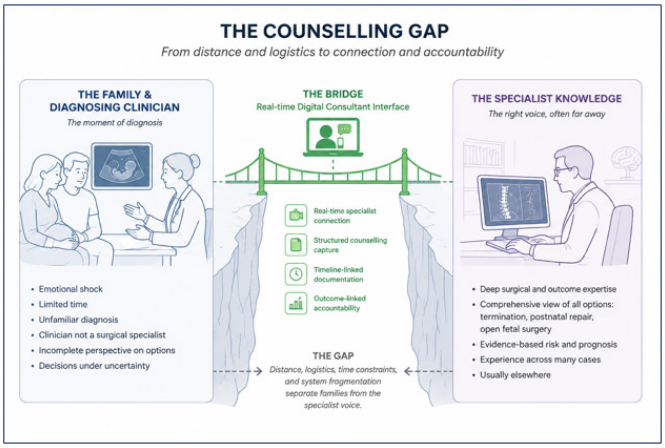

Figure 1 Conceptual model of the antenatal counselling gap and the digital bridge.

At diagnosis, the family and frontline clinician may be geographically and logistically separated from the specialist expertise required for comprehensive counselling. A real-time digital consultant interface bridges this gap by bringing specialist knowledge into the counselling encounter, while enabling structured documentation and continuity. The model emphasises that the principal barrier is access to existing expertise rather than absence of expertise.

The Proposal

The gap is logistical, the fix is infrastructural: a way to route expertise to where it is needed, at the moment it is needed. The proposal of this perspective is straightforward: build a real-time digital interface that connects the clinician counselling the family to the specialist who holds the surgical knowledge, at the moment the counselling is happening.

This is not a speculative technology. Its components are already in routine use and, relevant to the setting; they have already been assembled in the public sector. During the COVID-19 pandemic, multiple groups including the authors' institution implemented an electronic medical record-based teleconsultation service in paediatric surgery, specifically to reach families who could not physically attend a tertiary, public-funded hospital.[13] That experience taught us two things that bear directly on the counselling problem. First, that a structured, record-linked remote consultation is entirely feasible in a resource-constrained government hospital serving a very high patient load. Second, that the families who benefited most were those with an existing relationship of trust: a reminder that technology carries counselling but does not replace the human relationship at its centre.[13] The broader pandemic-era literature reached compatible conclusions: telemedicine in paediatric surgery is safe, is valued by families and surgeons, and is particularly powerful for addressing the inequity of specialist access based on where a family happens to live.[14,15] Notably, congenital malformations and urological conditions were among the most common diagnoses managed this way.[14]

Two things here are established, and one is not. EMR-linked teleconsultation is feasible in a high-volume, resource-constrained public hospital,[13] and telemedicine in paediatric surgery more broadly is safe, valued by families and clinicians, and effective at narrowing geographic inequities in specialist access.[14,15] What has not been tested is the specific application argued for here: routing that same infrastructure into the real-time antenatal counselling encounter for spina bifida, structuring it around the MORE framework and linking it to a longitudinal outcome record. That application extends proven components; it is not itself a proven intervention and it should be piloted and evaluated as one before being read as anything more.

Applied to spina bifida, the interface would do three concrete things, as illustrated in Figure 2:

1. It would **put the specialist in the room, virtually and in real time.** When an open neural tube defect is identified on a foetal scan, the counselling clinician could bring the paediatric neuro or foetal-medicine surgeon into the conversation directly, synchronously where possible and asynchronously where not, so that the family hears the surgical realities from the person who understands them, rather than a second-hand approximation. The distinction between open and closed defects, the eligibility window for foetal surgery, the honest weighing of the MOMS benefits against the maternal risks: these are exactly the points where a specialist voice changes the quality of a decision.

2. It would **structure the information so that nothing essential is omitted.** One of the quieter harms in the systematic review was not misinformation but incompleteness: families making decisions without ever being told that foetal surgery existed, or that a closed lesion might need no neonatal operation at all.[1,10] A counselling interface can embed the logic of a structured framework such as MORE: lesion type, level, single- versus multi-system involvement, prognosis range, all three management pathways and referral timelines, so that the standard of information does not depend on which clinician the family happened to meet.[9] The same discipline applies to the two adjuncts that increasingly shape modern counselling. The first is imaging: as antenatal detection of structural anomalies grows more refined, the reliability of the imaging itself carries direct implications for parental counselling and postnatal planning, a point that has been

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examined in the context of antenatal hypospadias.[16] The second is genetics: distinguishing isolated from syndromic spina bifida and conveying recurrence risk, increasingly depends on prenatal genomic testing. A complete counselling pathway must be able to carry that information too.[17]

3. It would **make timely referral the default rather than the exception.** Because foetal surgery is time-critical and centralised, the single most valuable output of the interface may simply be the elimination of delay: a diagnosis in a peripheral centre becomes, within the same clinical encounter, a documented specialist
4. opinion and, where appropriate, an expedited referral to a centre that can act within the gestational window.

Box 1 Minimum requirements for a real-time antenatal counselling interface

Trigger: antenatal detection of a suspected major structural anomaly

Frontline node: obstetrician/foetal-medicine clinician with the family

Expert node: condition-appropriate paediatric surgical specialist

Structured dataset: diagnosis, imaging, gestational age, prognosis, treatment options and referral window

Communication: synchronous video/audio where possible; asynchronous specialist response when necessary

Output: documented counselling summary and agreed decision/referral plan

Longitudinal link: pregnancy outcome → intervention → childhood outcomes

Governance: consent, secure institutional record, access control and audit trail

Continuity and accountability

A digital counselling interface does more than transmit information in the moment. It can create a record. If that record is structured as a timeline (the antenatal diagnosis, the counselling episode and what was actually said, the decision made, the surgery performed and the child's subsequent neurological, urological and developmental course), then something valuable becomes possible that is almost never available today. Counselling can be audited against outcome.

At present, the accuracy of prenatal counselling is essentially under-measured if not unmeasured. A clinician tells a family what to expect; the family leaves; whether the prediction was borne out is known only to whoever happens to follow the child years later, if anyone connects the two. A timeline-linked record closes that loop. It allows a service to ask, honestly, whether the prognoses it gives at diagnosis match the outcomes it produces and to correct its counselling accordingly. For a condition like spina bifida, where lower urinary tract dysfunction is a major long-term burden that the original MOMS outcomes did not even capture.[4,18] this longitudinal linkage between the antenatal conversation and the lifelong reality is not a luxury; without it, counselling has little basis on which to improve.

This is precisely the logic underlying record-centred models of care:[13] a stacked, synchronised, timeline- structured patient record that serves the patient's own long-term follow-up while also generating a resource for teaching, quality improvement and research. The counselling of spina bifida is an ideal first application of that logic, because the diagnosis, the decision and the outcome are all discrete, documentable events separated by predictable intervals.

Call this chain the counselling-to-outcome loop: diagnosis → prediction → counselling → decision → treatment → outcome → calibration of future counselling. The geographical counselling gap is the immediate problem to solve; the counselling-to-outcome loop points at the longer one.

Feasibility, Ethics and the Medico-legal frame

No proposal that touches the counselling of a family facing termination can be advanced without its difficulties named honestly.

The first is that the interface must serve the decision, not steer it. The quality of counselling should therefore be judged by the quality of the decision-making process, not by which decision the family ultimately makes. The documented harm in the counselling literature was pressure: families pushed toward termination before they understood their options.[10] A structured interface reduces one kind of pressure, the pressure of ignorance, but it must be designed so as not to introduce another. Its purpose is to widen the family's understanding of the genuine choices, including the choice to continue without surgery, rather than steering them toward whichever intervention the specialist happens to favour. Shared decision-making, not directive counselling, is the design principle.[3]

The second is data governance. A counselling record that links a foetal diagnosis to a maternal decision is among the most sensitive data in medicine. In the teleconsultation programme at the authors' institution, the patient data were held within the hospital's own systems rather than surrendered to a commercial platform and any counselling interface built for this purpose must hold the same line: local control, explicit consent and no repurposing of a family's most vulnerable moment.[13] The medico-legal implications, of a specialist opinion given remotely, of a documented counselling episode, of a referral not made in time, are real and must be worked through with the same seriousness as the clinical design, not bolted on afterward.

The third is that technology does not manufacture empathy. The families in the systematic review remembered kindness and remembered its absence.[10] A screen can bring the right voice into the room, but it cannot make that voice gentle. The interface is a delivery mechanism for expertise and for information completeness; the human work of sitting with a frightened family remains exactly as hard, and exactly as necessary, as it ever was.

Future evaluation

The next step should therefore be prospective evaluation rather than technological expansion. A pilot implementation could assess feasibility, time from diagnosis to specialist counselling, completeness and accuracy of information delivered, time to appropriate referral, parental understanding and decisional conflict, and family satisfaction. Longer-term linkage to postnatal outcomes would permit assessment of whether antenatal prognostic counselling was appropriately calibrated. Importantly, success should be defined not by uptake of foetal surgery or any particular pregnancy decision, but by whether families received timely, complete and balanced information on which to make an informed choice.

Spina bifida provides a particularly compelling test case, because counselling is time-sensitive and the treatment pathways are complex, but the underlying architecture is diagnosis-agnostic. The same model could plausibly support antenatal counselling for congenital diaphragmatic hernia, congenital heart disease, lower urinary tract obstruction, and other structural anomalies in which definitive expertise is concentrated in tertiary centres. Spina bifida should

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therefore be read as an exemplar on which to test the model, not its eventual boundary.

A call to action

The elements of a solution are, unusually, all in place at once. The clinical evidence to counsel from is mature: we know, from MOMS and the decade of work that followed it, what the options are and what they cost.[3,4] The problem is precisely defined: a documented, repeated failure of counselling delivery, caused by physical separation between family and specialist, not by ignorance.[10] And the enabling technological components already exist and have been tested in the exact health-system conditions where the need is greatest, including in public-funded Indian Paediatric Surgery, though their specific application to antenatal counselling remains to be piloted.[13–18]

What remains is to point these elements at each other. The authors' are arguing for a modest, specific, buildable thing: a real-time consultant interface, designed around the spina bifida counselling encounter, that brings the surgical specialist into the conversation, structures the information so that nothing essential is left out, defaults to timely referral and records the whole episode in a timeline that can later be checked against the child's outcome. It would not require building a new hospital or inventing a new operation, but it would require the workforce planning and policy commitment described above, and a decision that the quality of the conversation after a prenatal diagnosis of spina bifida matters enough to engineer for it.

Technically, this connection is already possible. The open question now is whether health systems are willing to make timely access to specialist counselling part of the standard of antenatal care. The families told us, through the research, that we need to do better.[10] We now have the means to close it, so what remains is not capability but intent.

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Conflict of interest

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