BEYOND THE ASEXUAL MYTH

Sexual & Reproductive Health in Adolescents with Spina Bifida

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A CLINICAL MOMENT

Picture this patient.

She is seventeen.

Wheelchair. Shunt. Catheterizes five times a day.

You have known her since she was a baby.

The visit is winding down. Mom steps out for coffee.

She leans across the desk and asks, very quietly:

"Can I have a baby someday?"

How prepared are you to answer?

Sexual health is not the absence of dysfunction.

> *“A state of physical, emotional, mental, and social well-being in relation to sexuality — not merely the absence of disease, dysfunction, or infirmity.”*
>
> — Definition of sexual health, World Health Organization

AAIDD FRAMING

Sexual rights, not privileges.

01

Dignity

and respect within all relationships.

02

Expression

and individualized education that supports informed decision-making.

03

Protection

from sterilization solely on the basis of disability.

— American Association on Intellectual and Developmental Disabilities; The Arc. Sexuality position statement.

Where we are going.

PART 1

Setting the stage

- Normal adolescent development
- Sexual orientation & gender identity
- Vulnerability, abuse, and safety

PART 2

Spina bifida specifics

- Central precocious puberty
- Sexual function & disclosure
- Reproductive health & contraception
- The education gap & how to close it

Closing: an age-stratified clinical framework you can use

PART ONE

Setting the stage

Sexuality, identity, and reproductive health in all adolescents

Adolescence is biopsychosocial — always.

Body

Secondary sexual characteristics, gonadal axis activation, neuroendocrine remodeling.

Mind

Abstract reasoning, future orientation, self-concept, identity rehearsal.

Social world

Peers eclipse parents, attractions emerge, autonomy negotiated.

The adolescent with spina bifida is, first, an adolescent. Mechanics may differ — emotional architecture does not.

Compounded stigma is multiplicative, not additive.

Higher rates of harassment & abuse

among LGBTQ+ youth with disabilities vs. either group alone.

Default to inclusive scripts

“Are you in a relationship?”

“Are you attracted to anyone?”

“Tell me how you describe your gender.”

Patients who feel seen tell you things. Patients who don’t, don’t.

Data shows vulnerability.

Children with disabilities vs. peers without disabilities

3×

more likely to be sexually abused

Young women with physical disabilities: OR 1.49 for rape

Perpetrators are usually known

- Family members
- Acquaintances
- Care providers and personal attendants

— the abusers are sometimes the people in the waiting room

Murphy NA, Elias ER; Council on Children With Disabilities. Promoting healthy sexuality for children and adolescents with disabilities. *Pediatrics*. 2021;148(1):e2021052043.

Four clinical responses.

01

Teach body autonomy

From toddlerhood. The two-year-old who can say no to a hug becomes the seventeen-year-old who can name harm.

02

Teach safety skills

Whose touch is welcome where, what “private” means, whom to tell. Use the SBA age-stratified sequence.

03

Screen at every visit

One question while the caregiver steps out: “Do you ever feel unsafe with anyone who helps take care of you?”

04

Report when mandated

Disclosure may be partial. The patient may have cognitive impairment. The mandate is not modulated by inconvenience.

Houtrow A, Roland M. Sexual health and education guidelines for the care of people with spina bifida. *J Pediatr Rehabil Med*. 2020;13(4):611-619. doi:10.3233/PRM-200743

PART TWO

Honing in

Spina bifida–specific considerations

Central precocious puberty is the rule, not the exception.

Prevalence of CPP in girls with myelomeningocele

50%

Prevalence of CPP in boys with myelomeningocele

10-30%

Why?

- Increased perinatal ICP
- Hydrocephalus
- Chiari II malformation
- Brainstem dysfunction (boys)

Remember the number: 50.

Half of girls. Up to a third of boys.

Almutlaq N, O'Neil J, Fuqua JS. Central precocious puberty in spina bifida children: Guidelines for the care of people with spina bifida. *J Pediatr Rehabil Med*. 2020;13(4):557-563.

DON’T MISS THE WINDOW

Clinical action plan for CPP.

Medical concerns

Compromised adult height, advanced bone age. GnRH agonists (leuprolide, triptorelin, histrelin) are well tolerated and reversible — PREFER study confirms preserved fertility.

Psychosocial reality

A 6-year-old menstruating who catheterizes. An 8-year-old in an adult-sized body. Body-image distress and peer discordance are heavier than the endocrine numbers.

What to do

Tanner stage at every well-child visit from age 6. Bone age + endocrinology referral if suspected. Early family counseling. Do not under-resource the psychosocial side.

Women with SB — fertility normal, function altered.

28–63%

unable to experience orgasm

Hughes et al., Urology 2021

What patients describe

- **Generally normal fertility**
- Incomplete vulvar engorgement
- Reduced vaginal lubrication
- Dyspareunia → avoidance → relationship strain

Counsel about water-based, glycerin-free, latex-compatible lubricants. Almost no one is having this conversation.

Men with SB — wide ED range, almost-universal ejaculation changes.

12–88%

erectile dysfunction

Range driven by lesion level. Lower = better function.

Hughes et al., Urology 2021

Almost universal

- Retrograde, absent, or incomplete ejaculation
- Altered fertility — even when erections are present
- Variable sensation; restored sensation → better satisfaction

Refer to reproductive urology. Bladder flushing post-ejaculation can rescue retrograde sperm. Don't write off male fertility.

Two predictors worth remembering.

01

Lower lesion level

→ higher sexual satisfaction

→ greater likelihood of partnered activity

Anticipate more preserved function in lumbar/sacral lesions; calibrate counseling accordingly.

02

Hydrocephalus

→ more sexual function problems

→ more relationship difficulties

Independent predictor — the patient with complex hydrocephalus needs a more proactive conversation, earlier.

WHAT WE DON'T TALK ABOUT

The single biggest barrier patients name: continence.

Five practical things that change everything

1. Catheterize before sexual activity.
2. Catheterize after sexual activity.
3. Empty the bowel ahead of planned intimacy.
4. Place a towel — normalize, do not catastrophize.
5. Communicate with your partner. Words first.

Most patients have never heard these said out loud. Saying them is the intervention.

WHAT TO ACTUALLY SAY

The 90-second speech.

"At some point — maybe now, maybe in a few years — you're going to want to be physically intimate with someone. I want you to know now, before you're in the moment, that there are things that will make that go better.

First: cathing before and after sex helps a lot of people avoid leaks.

Second: lubrication isn't optional for most women with spina bifida — it makes the experience comfortable, and there are good products that work with non-latex condoms.

Third: if anything's not working, or hurts, or doesn't feel right — that's a thing we can talk about. Your sexuality is part of your health, and it's part of what we take care of here."

THREE THEMES FROM QUALITATIVE WORK

Disclosure to a partner — the question patients ask most.

01

Importance

Patients consistently say it matters — hiding is exhausting.

02

Worries

Fear of rejection. Fear of being seen as patient first. Fear of explaining things they themselves were never taught.

03

Confidence

Patients who disclose well almost universally report deeper, not weaker, relationships.

Offer a rehearsal. We are the person who has heard the words said calmly, without flinching. That is enough.

Six pillars of reproductive health in SB.

1

Normal female fertility

Patients need contraception when they don’t want pregnancy, preconception care when they do.

2

High-risk pregnancy

ICU admission 3.4×, respiratory morbidity ≈10×. MFM + urology co-management mandatory.

3

4 mg folic acid

Ten times standard dose. Start 1–3 months pre-conception. Reduces NTD recurrence.

4

Genetic counseling

Multifactorial heritability. Refer to genetics — don’t do recurrence math from memory.

5

Altered male fertility

Ejaculatory dysfunction is the dominant mechanism. Reproductive urology referral.

6

Latex allergy

25–55% sensitized; up to 35% clinically allergic. Non-latex condoms only.

LATEX ALLERGY IN SB

Non-latex condoms aren’t a preference — they’re a prescription.

Up to 35%

clinical latex allergy

25–55% sensitized

Counsel by name

- Polyisoprene — STI protection. Use.
- Polyurethane — STI protection. Use.
- Lambskin — NO STI protection. Skip.

Driven by repeated surgical exposure, VP shunts, and atopic predisposition. A 30-second conversation that prevents an ED anaphylaxis visit.

Niggemann B, Buck D, Michael T, Wahn U. Latex provocation tests in patients with spina bifida: who is at risk of becoming symptomatic?. *J Allergy Clin Immunol*. 1998;102(4 Pt 1):665-670.

CHOOSE WITH THE COMORBIDITY PROFILE IN MIND

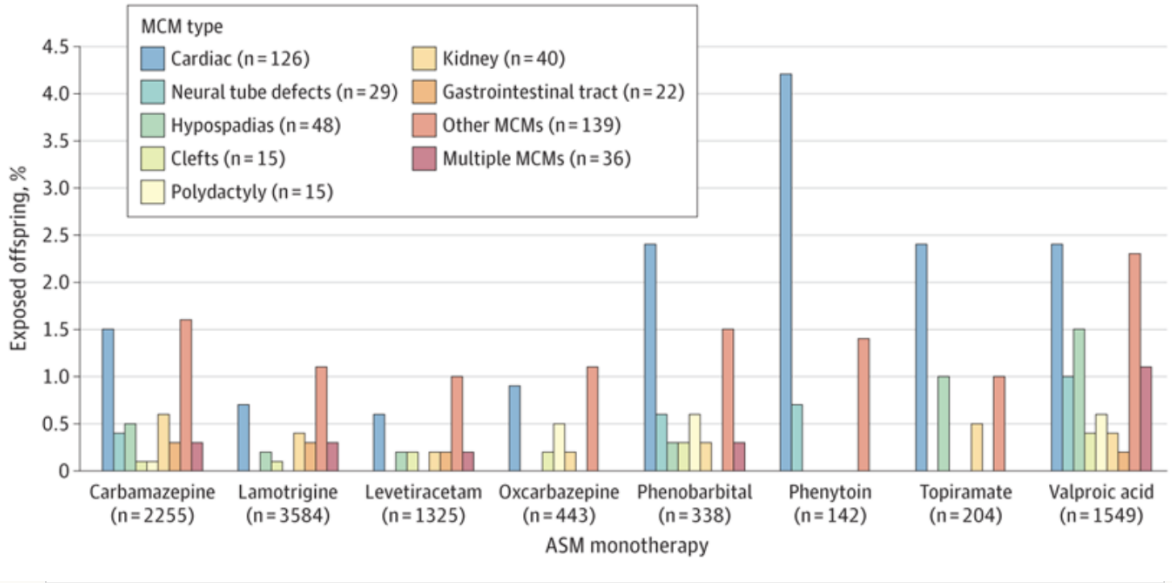
Contraception in non-ambulatory SB.

Method	Use in non-ambulatory SB	Why
LNG-IUD	**Preferred**	No VTE risk; no BMD effect; menstrual suppression bonus
Etonogestrel implant	Good option	Progestin-only; nothing to remember; no estrogen risk
DMPA	**Caution**	5–7.5% BMD loss compounds osteopenia; LNG-IUD usually better
Combined HC (pill/patch/ring)	**Generally avoid**	USMEC 3 with prolonged immobility — VTE risk

If on enzyme-inducing AED → LNG-IUD or DMPA preferred. Lamotrigine has bidirectional interactions with CHC. Avoid valproate in any patient of childbearing potential.

Antiepileptics matter. Valproate matters most.

Figure 1. Prevalence of Different Categories of Major Congenital Malformations (MCMs) After Prenatal Exposure to Monotherapy With 8 Antiseizure Medications (ASMs)



The valproate problem

- 9.9% major congenital malformation (MCM) rate
- 7.5× NTD risk vs. lamotrigine
- Already-elevated NTD recurrence in SB offspring

AAN 2024:

Avoid valproate in any patient of childbearing potential when clinically feasible.

Source: Battino, EURAP / JAMA Neurology 2024

THREE EXAM POSITIONS TO KNOW

The pelvic exam needs an adaptation

1

Side-lying knee-chest

Patient on side with knees drawn up; examiner approaches from behind.

2

Diamond

Supine with knees flexed and feet together; gentle abduction.

3

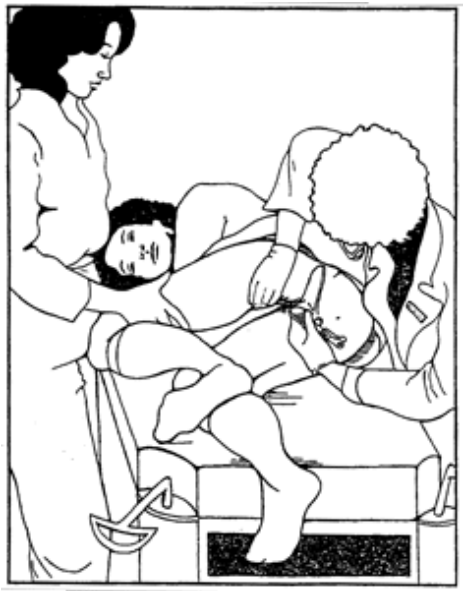
V position

Legs supported in abduction by footholds or assistants; replaces lithotomy.

Pelvic exam is NOT required to evaluate AUB (use transabdominal ultrasound) or to start contraception. Speculum begins at 21 for cervical screening. STI screening: urine NAAT.

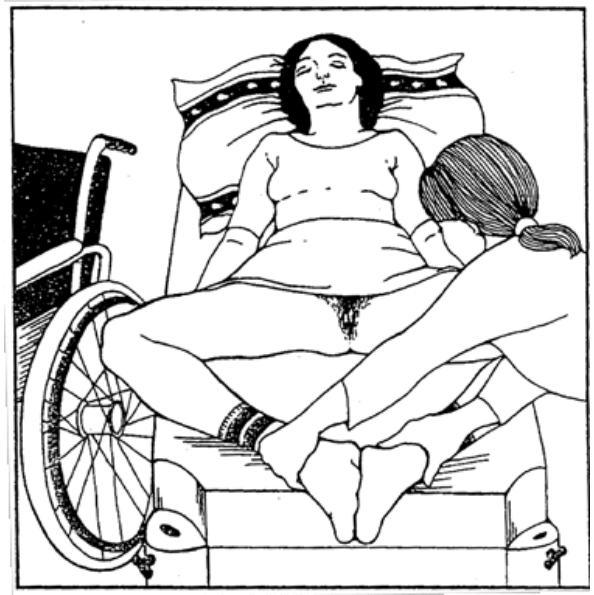
1

Side-lying knee-chest



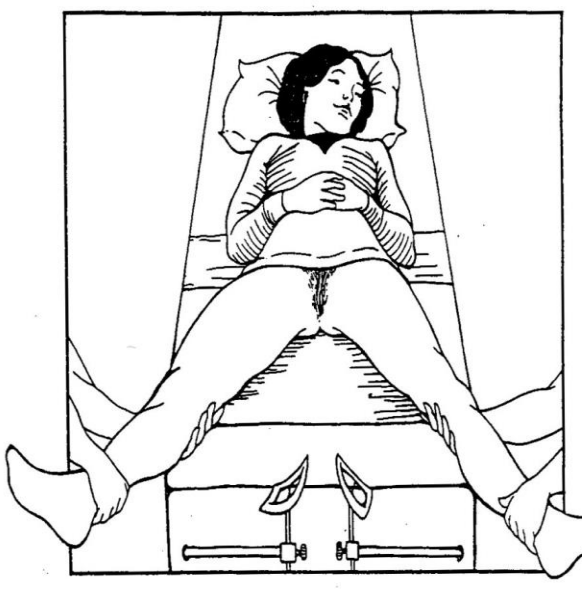
2

Diamond

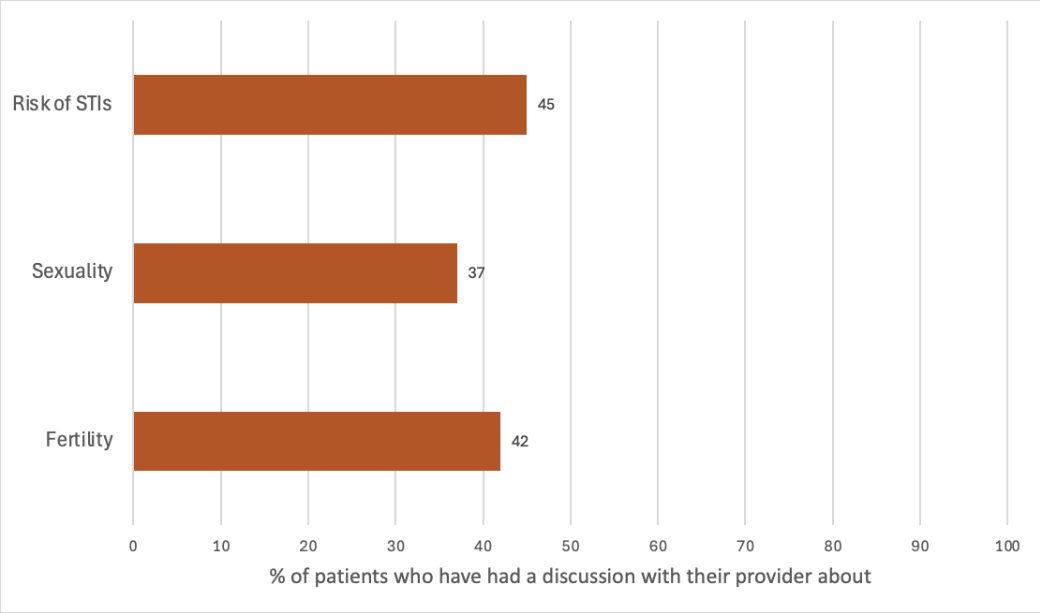


3

V position



Patients aren't getting the conversation.



Read the numbers again.

42% for fertility — in a population where fertility is altered in nearly all men and pregnancy is high-risk for nearly all women.

Lutz et al., DMCN 2023

FIVE THEMES FROM QUALITATIVE RESEARCH

What patients tell us when we ask.

1	**Being perceived as asexual**	*By providers, parents, peers — a constant background assumption.*
2	**Needing sources for sex education**	*"Nobody tells us anything. We Google it. We learn from mistakes."*
3	**Needing SB-specific education**	*General sex ed is not enough — mechanics, meds, cathing, latex.*
4	**Understanding SB's impact on sex**	*Patients want anatomical, mechanical, practical information.*
5	**Self-confidence ↔ assault risk**	*Low sexual self-confidence linked with vulnerability to exploitation.*

Theme 5 is the one that should concern us. Sexual education is, among other things, sexual safety.

An age-stratified framework you can use Monday.

Early childhood

Ages 1–5

- Body parts (real names)
- Privacy
- Appropriate vs. inappropriate touch
- Parents: model the language

School age

Ages 6–12

- School-based sex ed (with accommodations)
- Safety skill-building
- Begin pubertal teaching
- Tanner staging from age 6
- Optimize continence

Adolescence

Ages 13–17

- Open sexual health discussion
- Gender-neutral language
- Confidential time alone
- Non-latex barriers, contraception, STI
- Refer to gyn/uro with disability expertise

Young adulthood

Ages 18+

- Sexual history at every visit
- IPV screening
- Preconception: 4 mg folic acid
- Genetics referral
- Disability sexuality resources

SAY THE WORDS OUT LOUD

Topics adolescents with SB tell us they want help with.

- Fears and concerns about whether sex will work for them
- Bowel and bladder management around sexual activity
- How to talk about “it” — disclosure to a partner
- Fertility — their potential and family-building options
- Sexual sensation, pleasure, and feelings
- Masturbation — what is normal, private, healthy
- Safe sex — non-latex barriers, contraception, STI prevention

Saying the words is most of the intervention. Patients then know they can bring these topics back.

CLOSING

Back to where we started.

Mom is back from coffee. The visit is winding down. The patient catches your eye and gives a small, almost imperceptible nod. You say:

> *"Before you go — I want to make sure we've talked about something important. As you get older, the conversation about your health is going to include questions about relationships, intimacy, contraception, and someday maybe pregnancy. I want you to know that all of that is part of what we take care of here. There's no question that's off the table. So as those things come up — and they will — bring them in. We'll figure it out together."*

CARRY THESE OUT THE DOOR

Four takeaways.

01

Initiate the conversation.

Patients want this guidance. They almost never receive it. The first move has to be ours.

02

Build the system.

Standardized, age-stratified SRH education embedded in every multidisciplinary SB clinic visit.

03

Continence is the foundation.

The bladder and bowel work you already do is what makes everything else possible.

04

Empower your patients.

Knowledge plus skills plus self-advocacy. They're ready. We have to invite them in.

The myth of asexuality has had a long run. We have the data, the guidelines, the tools, and the language to retire it.

THANK YOU

Questions — and conversation.

Sexual health is a right — not a privilege. Let's build the systems to deliver on it.

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