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"Vulval Fibroid" in India: Understanding Vulvar Leiomyoma - Biology, Barriers, and Better Pathways of Care

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Abstract

Background: "Vulval fibroid" is the lay term most Indians would use for *vulvar leiomyoma*—a rare, benign smooth-muscle tumor of the vulva that is frequently misdiagnosed as a Bartholin cyst or other vulvar mass. Despite hundreds of thousands of Indian women presenting with vulvar complaints each year, true epidemiology of vulvar leiomyoma remains poorly characterized, with knowledge dominated by case reports and small series. (PMC, ClinMed Journals)

Objective: To synthesize global and Indian evidence on vulvar leiomyoma (henceforth, "vulval fibroid") and translate it into pragmatic, culturally sensitive recommendations for clinicians, health-system planners, and communities in India.

Methods: We searched peer-reviewed journals (PubMed/PMC), professional guidelines (ISSVD, ACOG), government policy documents (MoHFW, NACO; Ayushman Bharat), press releases, and credible educational media (podcasts/YouTube). Inclusion prioritized 2020–2025 publications and Indiaspecific sources; older, foundational studies were retained when necessary for rare entities and classification schemes. (PMC, NACO, Ministry of Health and Family Welfare, Apple Podcasts)

Key findings:

- 1. **Biology/diagnosis:** Vulval fibroids are ER/PR-positive smooth-muscle tumors; imaging (transperineal ultrasound → MRI) and histology/IHC (desmin, SMA, h-caldesmon) distinguish them from Bartholin lesions and other mesenchymal tumors. Surgical excision with clear margins is curative in most cases; recurrence is uncommon but reported. (ScienceDirect, PMC)
- 2. **Sociocultural:** Indian women face stigma, modesty concerns, and limited female providers, contributing to care-seeking delays—especially in rural areas and among adolescents. (PMC)
- 3. **System response:** India's **Ayushman Arogya Mandirs** and **eSanjeevani** telemedicine network are rapidly scaling access; standardized RTI/STI services (Suraksha Clinics) offer a ready gateway for vulvar complaints, yet vulvar-specific pathways are underdeveloped. (<u>Ministry of Health and Family Welfare</u>, <u>Ministry of Health and Family Welfare</u>, NACO)



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4. **Solutions:** A tiered **vulvar-mass pathway** anchored in transperineal ultrasound at primary care, point-to-specialist tele-referral, and definitive day-care excision (AB-PM-JAY/state packages such as labial cyst excision) is feasible and culturally acceptable. (PMC, Jeevandayee)

Conclusions: Vulval fibroid is uncommon but important. An India-appropriate pathway emphasizing respectful examination, ultrasound triage, and timely excision with pathology can reduce delays and misdiagnosis while leveraging national digital health assets.

Keywords: vulvar leiomyoma; vulval fibroid; transperineal ultrasound; India; Bartholin cyst; Ayushman Bharat.

1. Introduction

Global definition and context

Vulvar leiomyoma—popularly called a "vulval fibroid"—is a benign smooth-muscle tumor arising in the vulva (often labia majora/minora or clitoral region). Although uterine leiomyomas are common, extrauterine leiomyomas of the lower genital tract are **rare**; most reports emphasize frequent **preoperative misdiagnosis as Bartholin cyst/abscess** because both present as a well-circumscribed swelling near the introitus. (PMC, Tidsskrift for Den norske legeforening)

Pathologically, these tumors comprise intersecting fascicles of spindle cells with blunt ("cigar-shaped") nuclei, low mitotic index, and no tumor-cell necrosis. They are typically **desmin/SMA/h-caldesmon positive** (smooth-muscle markers) and **S100/CD34 negative**, helping to differentiate from mimics such as cellular angiofibroma (often CD34-positive) and angiomyofibroblastoma (frequently desmin positive, variably CD34). (<u>ScienceDirect</u>, <u>PMC</u>)

Imaging contributes to preoperative planning. On **transperineal ultrasound**, vulvar leiomyoma appears as a **circumscribed hypoechoic solid mass**, and color Doppler may reveal vascularity; **MRI** usually shows signal characteristics similar to uterine fibroid (low T2, with enhancement), though atypical signals occur. (<u>PMC</u>, <u>Radiopaedia</u>, <u>ScienceDirect</u>)

Indian demographics and lived reality

India lacks prevalence data for vulvar leiomyoma because cases are uncommon and obscured within the larger pool of "vulvar masses." Several **Indian case reports** highlight typical pitfalls: months to years of swelling mistaken for Bartholin disease, presentation in adolescents and multiparous women, and cultural taboos delaying care. (PMC, ijrcog.org, Gujarat Cancer & Research Institute)

"Vulvar leiomyomas can masquerade as Bartholin cyst or abscess, thus posing a huge diagnostic dilemma." (BioMed Central)

This is compounded by broader patterns: **very low gynecologic screening uptake** in India and documented barriers to pelvic examination (privacy, modesty, lack of female clinicians, costs). In NFHS-5 analyses, **only ~1.9%** of Indian women report ever undergoing cervical screening, reflecting a wider



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deficit in routine pelvic assessments where incidental vulvar masses might be detected. **Socio-economic status strongly influences screening.** (PMC)

"The proportion of women who had undergone... cervical cancer screening all over India was 1.9%." (PMC)

Multiple Indian studies describe **reluctance to seek care** for reproductive tract symptoms; barriers include stigma, spousal disapproval, and distance/time costs—factors that can keep a painless vulvar swelling "hidden" until it is large or symptomatic. (PMC, guttmacher.org)

Cultural and social context (regional variations)

While there is no evidence that vulvar leiomyoma preferentially affects any Indian region, **care pathways differ**:

- Urban North & West (e.g., Delhi, Mumbai, Ahmedabad): Greater availability of imaging and on-site histopathology; faster referrals; more female gynecologists in private sector.
- **South India:** Historically strong tertiary care networks; yet social conservatism can still inhibit early consultation, especially among adolescents; case series show under-recognition of rare vulvar mesenchymal tumors. (PMC)
- East & Northeast: Long travel distances to tertiary centers and fewer dedicated vulvar clinics can delay biopsy/excision.
- **Rural India:** Community norms around modesty and chaperoned examinations, and the scarcity of female providers at the first point of contact, contribute to late presentation. (PMC)

Problem statement and objectives

Because **vulval fibroids** mimic more common entities (Bartholin cysts) and because pelvic examinations are underutilized, Indian women experience **diagnostic delay**, unnecessary antibiotic use or cyst drainage attempts, and the anxiety of a "persistent lump." There is a need to:

- 1. Translate modern diagnostic criteria and imaging pathways to Indian primary care.
- 2. Address **sociocultural barriers** to respectful genital examination.
- 3. Leverage **Ayushman Arogya Mandirs** (former HWCs) and **eSanjeevani** tele-expertise to standardize triage and referral. (<u>Ministry of Health and Family Welfare</u>, <u>Ministry of Health and Family Welfare</u>)

Scope and limitations

This review centers on benign **vulvar leiomyoma** (vulval fibroid). We discuss its differentials (angiomyofibroblastoma, cellular angiofibroma, aggressive/deep angiomyxoma, leiomyosarcoma) to ensure safe triage. Indian epidemiology remains **case-based**, so recommendations emphasize **pathways** rather than incidence. Where India-specific guidance is unavailable, we reference international standards (ISSVD, ACOG, ESGO/BGCS), adapted to Indian systems. (<u>issvd.org</u>, <u>acog.org</u>, <u>iusti.org</u>)



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2. Methodology

Research design: A narrative synthesis with systematic elements, focusing on **2020–2025** literature supplemented by earlier landmark papers due to rarity and classification history.

Databases and sources: PubMed/PMC, professional society sites (ISSVD, ACOG, RCOG/BGCS), Indian government portals (MoHFW, NHA/NHA-HBP; NACO), press releases (PIB/MoHFW; CDAC), and educational podcasts/YouTube (ISSVD "Vulva Diaries," academic surgical videos). (<u>issvd.org</u>, acog.org, <u>Ministry of Health and Family Welfare</u>, <u>Ministry of Health and Family Welfare</u>, <u>NACO</u>, <u>Apple Podcasts</u>)

Search strategy: Terms included "vulvar leiomyoma," "vulval fibroid," "Bartholin cyst misdiagnosis leiomyoma," "vulvar smooth muscle tumor criteria Nielsen," "transperineal ultrasound vulva," "aggressive angiomyxoma vulva India," "cellular angiofibroma vulva," "WHO classification female genital tumors," and India-specific queries ("case report India," "Ayushman Arogya Mandir," "eSanjeevani telemedicine"). (PMC, Ministry of Health and Family Welfare)

Inclusion criteria: Peer-reviewed case reports/series, reviews, imaging/pathology references, guidelines, and official government documents; India-specific sources were prioritized. We also included high-quality educational media to enrich clinical translation (clearly labeled as educational, not primary evidence). (Radiopaedia, PMC)

Exclusion criteria: Unverified blogs, commercial pages without citations, and non-English sources unless policy critical.

Data extraction and analysis: Extracted variables included demographics, presentation, imaging, histopathology/IHC, management, outcomes, and system context. We cross-walked **site-specific risk stratification (Nielsen, Sayeed/Swanson)** with WHO 2020 classification to clarify benign—atypical—sarcoma thresholds. (PMC, PubMed)

Timeline and scope: Searches focused on 2000–2025 with emphasis on 2020–2025 updates (e.g., transperineal ultrasound methodology; telemedicine expansion). Policy data were taken from the latest press releases and official pages (as of **August 15, 2025**). (PMC, Ministry of Health and Family Welfare)

Limitations: The rarity of vulvar leiomyoma means reliance on case literature. India lacks registries of benign vulvar tumors; regional disparities and sociocultural nuances are inferred from broader RTI/gynecologic care-seeking studies. Educational podcasts/videos inform practice translation but are not evidence-grade. (BioMed Central)



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3. Discussion

3.1 Biological & technical factors: What actually is a "vulval fibroid"?

Origin and histology. Vulvar leiomyoma arises from smooth muscle in the vulva (e.g., vessel walls, dartos muscle). By microscopy, it shows intersecting bundles of bland spindle cells; IHC is **desmin/SMA/h-caldesmon positive**; **S100 and CD34** are typically negative, aiding distinction from neural or fibroblastic lesions. (ScienceDirect)

Hormone receptors and genetics. Many lesions are **ER/PR-positive**, supporting hormonal responsiveness akin to uterine leiomyomas; sporadic data suggest **MED12** mutations can occur in **extrauterine leiomyomas**, though less consistently than in uterine counterparts. (<u>PMC</u>, <u>PubMed</u>)

Imaging.

- **Ultrasound (first line):** A **circumscribed hypoechoic solid mass**, often with Doppler flow; easily performed transperineally with privacy preserved. (PMC)
- MRI (problem solving): Often mimics uterine fibroid signal (low T2; variable enhancement), yet atypical signals occur; MRI also maps relation to sphincters and the vestibule. (<u>Radiopaedia</u>, <u>AJR Online</u>)

Differential diagnosis matters because management diverges:

- **Bartholin cyst/abscess:** Fluctuant; labia minora typically **everted** with soft cystic feel; US shows cystic lesion; treat with Word catheter/marsupialization ± antibiotics—not excision. (<u>PMC</u>, acog.org)
- Cellular angiofibroma (CAF): Benign, CD34-positive spindle cell tumor with thick-walled vessels; surgical excision curative. Indian cases exist. (PMC, jsafog.com)
- **Angiomyofibroblastoma (AMFB):** Well-circumscribed, desmin-positive, perivascular stromal cells; recurrences are rare. (PubMed, ScienceDirect)
- Aggressive (deep) angiomyxoma (AAM/Deep AM): Infiltrative, gelatinous mass; high local recurrence; MRI shows swirling pattern; therapy may include wide excision ± GnRH analogs—not a simple enucleation. Indian series highlight misdiagnosis and recurrence. (BioMed Central, Lippincott Journals)
- **Leiomyosarcoma:** Apply **vulvar SMT criteria**—size ≥5 cm, infiltrative margins, ≥5 mitoses/10 HPF, moderate-severe atypia. **0–1 criteria = leiomyoma; 2 = atypical; 3–4 = leiomyosarcoma**. Later studies suggest uterine-style criteria also work for variant SMTs and STUMPs in the vulvovaginal tract. (PMC, PubMed)

Key clinical pearl: If "Bartholin cyst" is **firm/solid** on palpation or non-fluctuant, **think beyond cyst** - perform ultrasound, and plan excision for histology rather than drainage. (PMC)

Treatment and outcomes. The consensus is straightforward:

"Surgical excision is the only curative treatment for vulvar leiomyomas." (PMC)



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Recurrence is **uncommon**, but documented—even many months or years later—especially in epithelioid variants or if margins are close. Follow-up (e.g., 6, 12, 24 months) is prudent. (PMC, Lippincott Journals)

Take-home (technical):

- **Don't needle/aspirate** a solid vulvar mass presumed to be "cyst."
- Use transperineal ultrasound widely; MRI for deep/atypical lesions.
- Excise with margins and send for histopathology + IHC.
- Apply risk criteria (Nielsen/Sayeed/Swanson) to exclude sarcoma. (PMC, PubMed)

3.2 Sociocultural challenges in India: why do women wait?

Stigma and modesty. Qualitative and quantitative studies show Indian women often **delay pelvic/genital examination** because of embarrassment, fear of pain, lack of privacy, or absence of a female clinician - especially in rural settings. (PMC)

Adolescents and unmarried women. A striking Indian case of a **15-year-old** with a giant vulvar leiomyoma illustrates harmful advice received (e.g., "surgery will affect virginity") and prolonged suffering. (PMC)

Low screening culture. NFHS-5—based analyses show extremely low cervical/breast screening (1–2%), a sentinel of how rarely routine genital checks occur; socioeconomic gradients worsen disparities. (PMC)

Regional and linguistic considerations. Patients may describe a lump as a "गांठ (gāñṭh)," "सूजन (sūjan)," or just "सूजन/गांठ नीचे," and may prefer examinations by female providers, with a relative present, and explanations in local language—practicalities that facilitate consent.

Urban–rural divide. Urban women access imaging quickly; rural women may first meet an **ANM/ASHA**, not a gynecologist, and be redirected for STIs rather than structural lumps, delaying correct triage.

Actionable cultural sensitivity:

- Offer and normalize **chaperoned**, **female-provider** examinations.
- Begin with **external inspection** and **transperineal ultrasound**, which many patients accept more readily than internal exams. (PMC)
- Use **non-stigmatizing language** and clarify that **excision does not affect fertility or virginity** (when anatomically appropriate).
- Provide **privacy and draping** at every level of care.

3.3 Current system response and gaps (India)

Primary care platform: India's primary care transformation through **Ayushman Arogya Mandirs** (**AAMs**) has crossed **1.77 lakh operational facilities** (June 30, 2025), broadening comprehensive services near communities. (Ministry of Health and Family Welfare)



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Telemedicine: eSanjeevani has delivered >330–360 million teleconsultations nationally, enabling rapid specialist input even from sub-centres. Gynecology ranks among frequent tele-specialties. (Ministry of Health and Family Welfare, Ministry of Health and Family Welfare)

RTI/STI clinics as entry points: NACO's **Suraksha Clinics** standardize evaluation of genital symptoms; their **Operational** and **Technical** Guidelines (updated 2024) can be dovetailed with a "**vulvar mass**" **mini-algorithm** so that solid masses trigger ultrasound and surgical referral instead of syndromic STI regimens. (NACO)

Financing access: Under **AB-PM-JAY** and state schemes, many minor gynecologic procedures are covered; for example, "**Cyst—Labial**" is explicitly listed in Maharashtra's PMJAY package costs—useful for small vulvar masses that need day-care excision and histology. (Jeevandayee)

Guidelines landscape: International position papers (ISSVD, ACOG) offer principles for vulvar examination and benign conditions; while there are no India-specific vulvar leiomyoma guidelines, **WHO 2020 classification** and **vulvovaginal SMT risk criteria** are applicable. (PMC, acog.org)

Gaps:

- No national pathway for vulvar lumps at primary care.
- **Limited access** to ultrasound at sub-district level; variable comfort with **transperineal scanning**. (PMC)
- **Histopathology/IHC** turnaround times can be long; community clinicians may lack awareness of rare mesenchymal differentials.
- Sensitive exam environments (female staff, private rooms) are not uniformly available.

3.4 Innovative solutions & best practices (India-fit)

A. A simple "Vulvar Mass" pathway for primary care (AAM/PHC):

- 1. **History & respectful external exam.** Note duration, growth, pain, discharge; palpate gently. If lesion is **solid/firm**and non-fluctuant, treat as **non-cystic**. Provide **patient-centered counseling** (local language).
- 2. **Transperineal ultrasound on-site.** Document location (ISSVD map), dimensions, echogenicity, margins, and Doppler flow; photograph with consent. **Solid hypoechoic lesion** ⇒ **surgical referral**; cystic/fluctuant lesion ⇒ follow Bartholin pathway. (PMC)
- 3. **Tele-referral via eSanjeevani.** Share images and brief videos with gynecology/surgical hubs; consider **MRI** only for deep/atypical masses to plan margins. (esanjeevani.mohfw.gov.in)
- 4. **Day-care excision under regional/GA** at the nearest FRU or district hospital; ensure **specimen orientation** and margin inking; request IHC (desmin/SMA/h-caldesmon; ±CD34, S100).
- 5. **Follow-up** at 6, 12, and 24 months; educate on self-awareness of recurrence. Recurrence is **rare** but reported. (PMC)



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B. Training & tools

- **Ultrasound skills:** Adopt recent **standardized transperineal vulvar ultrasound methodology**; short hands-on modules for MBBS/CHOs/ob-gyns at district hubs. (<u>PMC</u>)
- Checklists & job-aids: A one-page "solid vs cystic vulvar lump" algorithm at AAMs; incorporate in NACO/NRHM training materials. (National Health Mission)
- **Vulvar clinics**: Encourage tertiary centers to run **multidisciplinary vulvar clinics** (gynecology-dermatology-pathology), following **BSSVD/ISSVD** standards, and to offer **tele-proctoring** to district surgeons. (bssvd.org)

C. Communication innovation

- Launch **Hindi/regional language** patient sheets clarifying that excision of a benign vulvar mass **does not threaten fertility** and is commonly day-care.
- Promote **ISSVD** "Vulva Diaries" and Indian professional content (FOGSI) to normalize discussion of vulvar health among clinicians and the public. (Apple Podcasts, YouTube)

D. Financing & pathways

- Map **AB-PM-JAY/state package codes** (e.g., "labial cyst excision") for benign vulvar mass excision; align pre-authorization checklists (ultrasound report, photos, consent). (<u>Jeevandayee</u>)
- Use **telemedicine** to pre-triage referrals—reducing travel and time costs that drive delay. (<u>Ministry of Health and Family Welfare</u>)

E. Research and registry

- Build a **national benign vulvar tumor registry** leveraging academic pathology departments and e-health records to capture Indian epidemiology and outcomes.
- Encourage **community-based audits** to quantify misdiagnosis rates (e.g., "Bartholin vs leiomyoma").

F. When to suspect something more sinister

• Rapid growth, pain, ulceration; imaging showing infiltrative margins; size ≥5 cm plus mitoses or atypia—apply vulvar SMT risk criteria and involve oncology early. (PMC)

4. Conclusion

Summary of key findings. Vulval fibroid (vulvar leiomyoma) is a **rare, benign** smooth-muscle tumor that India largely meets at late stages due to **misdiagnosis as Bartholin disease** and **cultural barriers to examination**. Imaging (especially **transperineal ultrasound**) can reliably flag solid masses, while **histology/IHC** secure the diagnosis and rule out sarcoma using established **vulvar SMT criteria**. **Surgical excision** is curative for most, with **low recurrence** but advisable follow-up. (PMC)



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Implications for stakeholders.

- Clinicians: Adopt a "solid vs cystic" mindset for vulvar lumps; use ultrasound first, avoid blind drainage of firm masses, and refer for excision with pathology.
- Health-system planners: Embed a vulvar-mass pathway in AAMs and eSanjeevani; ensure availability of female providers, privacy, and ultrasound at district level; facilitate IHC access. (Ministry of Health and Family Welfare, Ministry of Health and Family Welfare)
- **Policymakers:** Use **AB-PM-JAY** and state schemes to cover day-care excision (e.g., labial cyst packages) and incentivize **transperineal ultrasound** at primary care. (<u>Jeevandayee</u>)
- **Communities:** Normalize respectful, chaperoned examinations; counter myths (e.g., surgery harms virginity); encourage early care-seeking.

Future research directions.

- 1. **Prospective Indian cohorts** of vulvar masses with standardized ultrasound descriptors. (PMC)
- 2. **Molecular profiling** (e.g., MED12 status) of Indian vulvar leiomyomas to clarify pathogenesis and recurrence risk. (PubMed)
- 3. **Implementation studies** testing the triage-via-telemedicine model for benign vulvar surgery, including patient-reported outcomes. (Ministry of Health and Family Welfare)

Policy recommendations (India-specific).

- Issue an MoHFW clinical practice note within AAM operational guidelines: "Evaluation of Vulvar Lumps—when to ultrasound, when to refer, how to code under PM-JAY."
- Incorporate basic vulvar ultrasound competencies in CHO/MBBS skilling.
- Establish at least one **multidisciplinary vulvar clinic** per medical college (gynecology/dermatology/psycho-sexual counseling), referencing **ISSVD/BSSVD** standards. (bssvd.org)

Bottom line for India: Respectful examinations, accessible ultrasound, and timely excision can transform the experience of women with vulval fibroids—turning a source of private anxiety into a brief day-care procedure with excellent outcomes.

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Note: Many additional India-specific case reports exist; those cited here (Items 14–21, 26–27, 50) satisfy the \geq 30% India-specific criterion and are recent where possible.