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This Doctoral Project, *Naming the Wound, Rewriting the Record: Uterine Fibroids and the Cost of Silence in Sierra Leone,* presented by *Fatou Wurie* and Submitted to the Faculty of The Harvard T.H. Chan School of Public Health in Partial Fulfillment of the Requirements for the Degree of Doctor of *Public Health*, has been read and approved by:

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NAMING THE WOUND, REWRITING THE RECORD: UTERINE FIBROIDS AND THE COST OF SILENCE IN SIERRA LEONE

FATOU WURIE

A Doctoral Thesis Submitted to the Faculty of

The Harvard T.H. Chan School of Public Health

in Partial Fulfillment of the Requirements

for the Degree of *Doctor of Public Health*

Harvard University

Boston, Massachusetts.

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Doctoral Thesis Advisor: Jesse B. Bump

Fatou Wurie

Naming the Wound, Rewriting the Record:

Uterine Fibroids and the Cost of Silence in Sierra Leone

Abstract

Uterine fibroids affect up to eighty percent of women of African descent and account for 34 percent of gynecologic admissions at Sierra Leone's national referral hospital. They appear in no national policy document, receive no dedicated financing, and generate no national data. This thesis asks how that happens and at what cost, not as a failure of any single actor, but as the outcome of how reproductive health systems across the region have been built, what they were designed to measure, and whose suffering they were structured to see.

Women living with fibroids navigate delayed diagnosis, social stigma, and catastrophic out-of-pocket costs with no public support. This thesis traces how that exclusion is produced and what it means for women, households, and the health system.

The study uses a convergent mixed-methods design. A retrospective chart review of 262 gynecologic admissions at Princess Christian Maternity Hospital documents clinical burden, diagnostic pathways, and treatment costs. Fifteen in-depth interviews, five focus group discussions, and seven key informant interviews explore how women interpret symptoms, seek care, and sustain their families while managing chronic illness.

Fibroids accounted for 34 percent of gynecologic admissions. Most diagnoses relied on clinical examination alone because imaging was unavailable or unaffordable. Surgical care required out-of-pocket payments equivalent to several months of household income, with no cases receiving subsidy or insurance coverage. The thesis develops the Cycle of Suffering and Resilience

(COSAR), an original analytic framework that traces six mechanisms, diagnostic invisibility, clinical disregard, epistemic negotiation, financial exclusion, moral surveillance, and survival labor, through which women absorb the costs of a system not designed to see them.

Reproductive health frameworks across the region are built around maternity and are not structured to respond to chronic gynecologic suffering. This thesis provides the evidence and the conceptual foundation for integrating uterine health into national data systems, financing, and service delivery. Naming the wound is the precondition for rewriting the record.

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DEDICATION

To be entrusted is sacred. And to you, my daughter, **Amanah Seray**, whose name means trust. You are both my beginning and my becoming. May you grow in a world that listens when women speak, believes their pain, honors their knowledge, and invests in their healing. This work is for you, my greatest gift, and for the future we are shaping together.

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Alhamdulillah to God for mercy, grace, and the strength to complete this work.

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To my brother-friends, Esias and Salif, thank you for grounding me and showing up without hesitation.

To my cousin Zulaika, and to my friends Aminata, Carlos, Karen, Rania, and Randa, thank you for your care, your constancy, and the quiet ways you kept me moving forward.

To the Youterus Health team and to everyone who has walked with us, thank you. Youterus is more than an organization. It represents what becomes possible when women's experiences are treated as evidence and when collective care is turned into action.

And finally, to every woman still bleeding unseen or unheard, this work is written in witness to you. May it stand as one step in rewriting the record of your lives, your pain, and your power.

CHAPTER 1 INTRODUCTION

Across global health systems, some forms of women's suffering receive policy attention and financing, while others are absorbed into silence. This thesis begins in that silence. It examines how uterine leiomyomas (fibroids), a condition affecting millions of African women and one in three women seeking gynecologic care at Sierra Leone's largest referral hospital, remain largely uncounted and unprioritized within the systems responsible for women's health. The central question is not why women suffer, but why their suffering is not recognized as a measurable burden or a policy concern.

This research shows that uterine leiomyomas, tumors that develop in or around the uterus and can cause heavy bleeding, pelvic pressure, chronic pain, infertility and significant disruption to daily life, accounted for 34 percent of gynecologic admissions at Princess Christian Maternity Hospital in 2025. Eighty nine of the 262 women seen for gynecologic care were treated for fibroid-related complications. Yet fibroids appear in no national policy document, are absent from the Health Management Information System, and are not covered under the Free Health Care Initiative, which supports services for pregnant women, lactating mothers and children under five. There is no allocation for diagnostics, medications, surgery or reimbursement for fibroid-related care.

The absence of fibroids from policy, financing and information systems follows the way reproductive health has been organized in Sierra Leone and across the region. Over the past two decades, particularly under the maternal mortality focus of the Millennium Development Goals, health system design has centered pregnancy and childbirth. This approach has reduced deaths during delivery but has also limited the scope of reproductive health to maternity and left chronic gynecologic conditions outside routine planning and investment.

National health information systems in Sierra Leone, as in many African countries, record pregnancy-related indicators but do not capture chronic gynecologic conditions. Routine reporting tracks antenatal attendance, deliveries, cesarean sections and maternal deaths. There are no fields for fibroids or other non-pregnancy related uterine conditions. Regional and global monitoring frameworks follow the same pattern. WHO reproductive health indicators focus on skilled birth attendance, contraceptive prevalence and antenatal care coverage. The African Union's continental scorecard monitors maternal mortality and adolescent birth rates but includes no measures for chronic gynecologic morbidity. Sierra Leone's annual health sector reviews devote substantial space to maternal and child health and mention fibroids only when they complicate pregnancy. The Maputo Plan of Action and the Sustainable Development Goals affirm reproductive health, yet their indicators remain centered on maternal outcomes. Within this measurement framework, chronic uterine conditions such as fibroids, endometriosis and adenomyosis fall outside routine data collection and therefore outside policy and financing priorities.

1.1 Continental Context: Aspiration and Implementation

The African Union's Agenda 2063: The Africa We Want, and the Maputo Plan of Action (2023-2033) call for universal health coverage that guarantees sexual and reproductive health across the life course. Goal 3 of Agenda 2063 envisions healthy and well-nourished citizens; Aspiration 6 situates gender equality as a foundation of Africa's transformation (African Union, 2015). The AU Strategy for Gender Equality and Women's Empowerment (2018-2028) identifies health autonomy as a prerequisite for women's economic participation. Yet across the continent, reproductive health policy remains dominated by maternity indicators. Only a few African countries (South Africa, Botswana, and Mauritius) include chronic gynecologic conditions in national insurance benefit packages (WHO AFRO, 2023).

Sierra Leone's FHCI exemplifies this continental pattern: a program that proves state capacity to deliver maternal care but not yet its commitment to extend protection across women's reproductive lives. Nigeria's 2025 Uterine Health Roundtable documented that fibroids account for 30 percent of national gynecologic admissions yet remain absent from the National Health Management Information System and from insurance coverage (FMOH & SW, 2025). This continental pattern, where high clinical burden is coupled with structural exclusion, suggests that invisibility is not driven primarily by scarcity but by the design of what health systems choose to count and prioritize.

It is not the absence of funding, facilities, or clinical expertise that determines this gap. It is the architecture of indicators and investment. Metrics follow money, and money follows mortality. Agenda 2063 and the Maputo Plan commit member states to generating disaggregated reproductive health data, yet national Health Management Information System templates, including those used in Sierra Leone, continue to reproduce donor shaped indicators focused on maternal outcomes. The distance between continental commitments and national instrumentation reveals a central challenge of African health governance. Until reproductive morbidity is measured with the same investment and urgency as maternal mortality, the aspiration of healthy and empowered women will remain constrained. Sierra Leone’s Free Health Care Initiative exemplifies this disjuncture. It demonstrates the state’s capacity to deliver maternal care but not yet its willingness to extend that protection across the full arc of women’s lives.

The FHCI Paradox: Proof of Capacity, Evidence of Design

Launched in 2010, the Free Health Care Initiative abolished user fees for essential services for pregnant women, lactating mothers, and children under five. It increased facility deliveries and contributed to a reduction in maternal mortality from 1,165 deaths per 100,000 live births in 2010

to 443 in 2019 (Statistics Sierra Leone and ICF, 2019 The FHCI's design establishes categorical boundaries: eligibility is defined as "free health care services for pregnant women, lactating mothers, and children under five years" (Government of Sierra Leone, 2010, Section 2.1). A woman hemorrhaging during childbirth receives emergency surgery at state expense; the same woman hemorrhaging from fibroids six months later must pay privately.

Diagnostic equipment procured through FHCI sits in maternity wards; HMIS tracks deliveries but not uterine morbidity; provider training prioritizes obstetric emergencies; performance metrics reward births attended, not women's wellness. As one clinician explained, "Fibroid operation is not in the health care category. This is a surgery you pay for." The FHCI demonstrates state capacity to mobilize resources when policy defines a need. Its success on maternal mortality is evidence of capacity; its neglect of fibroids is evidence of design boundaries.

1.2 The Problem of Silence

Three interlocking silences sustain this invisibility. Social silence operates through stigma: women hide bleeding, avoid disclosure, and internalize suffering as private duty. Cultural silence arises when biomedical systems offer inadequate explanations, leaving communities to interpret symptoms as witchcraft, punishment, or "rise and fall" (a local term describing the sensation of internal movement from fibroids). Systemic silence is bureaucratic: the absence of fibroids in HMIS data fields, FHCI eligibility criteria, and national plans constructs invisibility through omission. Each silence reinforces the others. Social concealment enables policy neglect; policy neglect creates interpretive gaps that cultural frameworks fill; cultural interpretation discourages formal care. Breaking the silence in one area requires confronting all three.

These patterns recur across African contexts. In Kenya, 68 percent of women delayed seeking care for fibroid symptoms for more than a year, citing shame and fear of bewitchment (Gichuhi et

al., 2021). In Nigeria, diagnostic delays of one to three years persist because symptoms are normalized as "ordinary female problems" (Nigeria Uterine Health Roundtable, 2025). In South Africa, Black women face longer diagnostic delays and higher surgical costs than white women, showing how race compounds gendered neglect (Wise et al., 2020).

The pattern extends to high-income settings where racial and economic inequities intersect with gendered neglect. In the United States and United Kingdom, Black women are two to three times more likely than white women to undergo hysterectomy for fibroids, yet the condition receives a fraction of the research investment devoted to comparable male reproductive disorders (Stewart et al., 2017). Internationally, less than one percent of annual global health funding targets non-maternal gynecologic morbidity (IHME, 2023). This cross-continental neglect reproduces the same hierarchy of visibility: what threatens fertility or life commands resources; what diminishes daily living does not. The mechanisms of silence operate similarly across both low-income and high-income contexts.

1.3 Rationale and Significance

No research in Sierra Leone has documented the clinical burden faced by women with fibroids at the national referral level, has mapped diagnostic pathways, or connected clinical data to economic and social outcomes. The 34 percent clinical burden documented at PCMH establishes fibroids as a dominant gynecologic condition yet unmeasured in national systems. When systems record only maternal deaths, they define women's health through reproduction alone. When the FHCI covers cesarean sections but not fibroid surgery, policy design determines which suffering is recognized. These distinctions are products of design. Policy design operates through ordinary technical decisions that accumulate into exclusion. When HMIS developers omit uterine conditions from reporting templates, when authorities classify fibroid surgery as "elective," when

procurement officers assign ultrasound machines exclusively to maternity wards, each decision appears administrative but collectively defines whose suffering counts.

Redesigning systems requires locating those decision points and demonstrating that alternative designs are possible. This study contributes in three ways. First, it establishes baseline evidence of fibroid clinical burden at Sierra Leone's referral level, providing the foundation for policy action. Second, it develops the Cycle of Suffering and Resilience (COSAR) as a grounded framework for understanding how exclusion operates. COSAR identifies six interconnected mechanisms through which system-level design choices produce individual suffering and points to intervention opportunities where reforms can disrupt exclusion cycles. Third, it reinterprets "resilience" as an indicator of structural violence rather than a cultural virtue. Women's adaptation under constraint is proof of systemic neglect. Documenting that adaptation is an act of indictment, not praise.

1.4 Research Aim and Questions

The overarching aim of this research project is to examine how health system design produces and sustains fibroid invisibility despite documented clinical burden and to generate evidence for integrating uterine health into Sierra Leone's national and continental priorities.

This research addresses four questions:

1. What is the clinical burden and diagnostic profile of fibroids at PCMH?
2. How do women, families, and providers experience fibroid care within contexts of policy exclusion?
3. Through which mechanisms do infrastructure gaps, financing exclusions, and data invisibility produce the documented patterns?
4. What reforms would integrate fibroid care into national and continental priorities? What policy, financing, and information system reforms would integrate fibroid care

into national priorities while advancing continental frameworks under Agenda 2063 and the Maputo Plan of Action?

1.5 Methodological Approach

The study employs a convergent mixed methods design integrating quantitative description with an inductive qualitative component guided by grounded theory techniques. The quantitative strand provides scale: clinical burden, diagnostic methods, and treatment decisions. The qualitative strand generates conceptual insight into how women, families, and providers experience and interpret system design. Integration occurs at analysis and interpretation, allowing numerical patterns to be explained through lived experience and narratives to be situated within measurable realities. The qualitative component follows grounded theory methodology (Charmaz, 2014; Corbin & Strauss, 2015).

It privileges inductive reasoning, allowing categories and relationships to emerge from participants' accounts rather than from prior theory. In Sierra Leone, where national surveillance systems lack variables on uterine morbidity, grounded theory provides both philosophical stance and pragmatic fit. Women's testimonies, provider reflections, and community narratives are treated as generative data capable of producing explanatory categories about how system design interacts with social and economic life.

Grounded theory techniques were applied through open, focused, and selective coding accompanied by analytic memos. Initial line-by-line coding captured key actions and meanings; focused coding clustered these into categories describing wider patterns such as diagnostic invisibility, clinical disregard, and moral surveillance. Constant comparison across transcripts refined categories and revealed their relationships. Theoretical saturation was assessed continuously; coding ceased when no new analytic insights emerged. Memos created an audit trail

linking data to interpretation, and member checking with four participants confirmed interpretive resonance.

Through this iterative process, the research developed the Cycle of Suffering and Resilience (COSAR), a mid-range analytic framework identifying six recurrent mechanisms by which system design converts women's reproductive pain into institutional stability: diagnostic invisibility, clinical disregard, epistemic negotiation, financial exclusion, moral surveillance, and survival labor. COSAR did not precede data collection; it emerged inductively from sustained analysis and reflexive discussion. While the qualitative strand is grounded theory driven, the overall design is mixed methods rather than classic grounded theory.

The quantitative chart review provided descriptive context and corroboration rather than theoretical sampling. Quantitative and qualitative data were collected convergently rather than sequentially. For this reason, the study employed grounded theory techniques within its qualitative process, not pure grounded theory methodology. This transparency ensures methodological rigor while recognizing that inductive logic (iterative coding, memos, and constant comparison) shaped all stages of analysis and interpretation. Combining quantitative measurement with qualitative generation achieves both rigor and depth.

Quantitative data establish the scope of burden for policy engagement; qualitative data reveal the mechanisms that produce it. Together they realize the DrPH mandate for applied systems research: evidence that is empirically credible, conceptually grounded, and immediately relevant to reform.

1.7 The Scope

The study examines structures, not surgical techniques. It explores how social norms, economic realities, and policy design determine access to diagnosis and treatment. Fieldwork

occurred in Freetown and peri-urban Western Area communities in Sierra Leone between January and August 2025. The quantitative strand analyzed 262 gynecologic charts from PCMH, identifying 89 confirmed fibroid cases (34 percent).

The qualitative strand comprised fifteen in-depth interviews with women, five focus group discussions with women, men, and families, and seven key informant interviews with clinicians, nurses, healers, and community leaders. The research does not evaluate surgical skill or procedural outcomes; it interrogates the architecture that determines which suffering receives collective recognition.

1.6 Positionality and Research Practice

The researcher approached this work as a Sierra Leonean woman examining a condition that shapes the lives of Sierra Leonean women. Insider status enabled depth of trust and cultural fluency while requiring reflexive vigilance against over-familiarity. Reflexivity was maintained through analytic memos, participant feedback, and research team review. Approval was obtained from the Sierra Leone Ethics and Scientific Review Committee (SLERC-2024-0312).

Research practice extended beyond protocol compliance to reciprocity, ensuring that participants' stories inform reform. Confidentiality was maintained without erasing voice; quotations remain intact but anonymized. Participants explicitly asked that their testimonies be used to help other women who are suffering. This work honors that request.

1.7 Structure of the Thesis

Chapter 2 reviews scholarship on fibroids, reproductive health systems, and gendered financing. Chapter 3 elaborates the theoretical and methodological orientation, situating grounded theory techniques within structural violence, reproductive justice, and African feminist traditions, and details research design, sampling, instruments, and analysis. Chapter 4 presents quantitative

clinical burden and diagnostic patterns followed by qualitative analysis organized through COSAR's six mechanisms. Chapter 5 interprets these findings within social, cultural, and economic dimensions and proposes policy reforms. Chapter 6 synthesizes recommendations and concludes with implications for comprehensive reproductive health.

This thesis was conducted as an independent doctoral research project. Fieldwork and analysis were funded through the Frederick Sheldon Traveling Fellowship. The researcher is also the founder of Youterus Health, an organization working to advance uterine health across Africa, but the study was conceptualized, implemented, and analyzed independently of the organization's programs. Professional experience informed familiarity with the reproductive health landscape yet did not shape the data collection, findings, or interpretive claims of the research.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews scholarship on reproductive health systems, chronic gynecologic conditions, and health financing in sub-Saharan Africa. It establishes what is known about fibroid burden and health system responses, identifies what remains undocumented, and positions this research within existing evidence.

The review addresses three questions: What is known about fibroid prevalence and health system responses? How have scholars explained the gap between clinical burden and policy attention? What frameworks exist for understanding how policy exclusion shapes lived experience? This review synthesizes scholarship across health systems research, medical anthropology, and scholarship on gendered economic systems.

Chronic reproductive conditions occupy what Kruk et al. (2018) term the "blind spot" of health systems designed for mortality reduction. In Africa, this orientation has been

institutionalized through financing and data systems that equate women's reproductive health with pregnancy outcomes. The following sections trace how existing literature explains this pattern and identify what remains undocumented.

2.2 Global and Regional Fibroid Epidemiology

Uterine fibroids are among the most common tumors affecting women of reproductive age. They can cause heavy menstrual bleeding, chronic pelvic pain, anemia, pressure symptoms affecting bladder and bowel function, infertility, and pregnancy complications. Their chronic nature shapes every facet of daily life, from mobility and work to intimacy, caregiving, and participation in community and economic life. Although fibroids are rarely framed as life threatening, their cumulative effects can be debilitating and sustained, producing cycles of exhaustion, financial strain, and delayed care. By age fifty, approximately seventy percent of women have fibroids, with imaging studies reporting between sixty-nine and eighty three percent overall and eighty percent or higher among Black women (Stewart et al. 2017; Munro and Critchley 2021). Women of African descent experience higher prevalence, earlier onset, more severe symptoms, and a greater likelihood of surgical intervention compared to women of European or Asian descent (Wise et al. 2020; Marsh et al. 2018).

In sub-Saharan Africa, epidemiological data remain sparse and facility-based rather than population-derived. Hospital studies from Nigeria, Ghana, Kenya, and South Africa document fibroid prevalence rates between 20 and 40 percent among women presenting for gynecologic care (Okolo, 2008; Morhason-Bello et al., 2022; Macharia et al., 2019). These figures likely underestimate true population burden given substantial barriers to care seeking and diagnostic infrastructure limitations. No population-based prevalence studies exist for most African countries,

including Sierra Leone, because national health surveys do not include questions about chronic gynecologic symptoms and health management information systems lack relevant data fields.

This measurement gap reflects policy priorities that define women's reproductive health narrowly around pregnancy outcomes rather than across the life course. Gullo et al. (2017) analyzed reproductive health policies across 18 sub-Saharan African countries and found that fewer than 20 percent mentioned chronic gynecologic morbidity; none allocated dedicated financing or established service delivery standards. Conditions that remain unmeasured cannot generate budget allocations, performance metrics, or accountability mechanisms. The absence of prevalence data thus perpetuates policy invisibility.

2.3 The Maternal Paradigm and Health System Design

2.3 The Maternal Paradigm and Health System Design

The critique of pregnancy-centered measurement architecture presented in the preceding section must be situated within the policy reasoning that shaped this design. Categorical targeting of pregnant women and children under five did not emerge through arbitrary exclusion. It reflected a public health logic that warrants careful engagement before outlining its limitations.

The maternal health emergency in sub-Saharan Africa presented governments and development partners with a measurable and urgent crisis. Sierra Leone's maternal mortality ratio reached 1,682 deaths per 100,000 live births in 2000, among the highest in the world (WHO, 2023). Concentrating resources on pregnancy-related care, where each additional facility delivery and emergency obstetric intervention translated into identifiable lives saved, represented rational priority-setting. Categorical eligibility simplified administration, focused accountability, and enabled the political mobilization that Shiffman and Smith (2007) identify as central to generating

commitment for maternal survival. The subsequent reduction to 443 deaths per 100,000 by 2020 demonstrates that targeted investment produced measurable impact.

The efficiency rationale reinforced this approach. Under severe resource constraints, categorical targeting can be more equitable than universal coverage stretched too thin to achieve meaningful clinical effect. The Free Health Care Initiative (FHCI) enabled depth of coverage for a defined population rather than shallow coverage that wealthier groups might disproportionately capture. The Oxford Policy Management evaluation (2013) confirmed that the FHCI successfully removed financial barriers for its target populations and improved service utilization where coverage applied.

These justifications retain force when examining 2010 policy choices. They become harder to sustain when examining 2025 realities. The reduction from 1,682 to 443 deaths per 100,000 demonstrates institutional capacity that could extend protection across women's reproductive lives. Sierra Leone's health expenditure has grown, and chronic gynecologic conditions could integrate into existing FHCI infrastructure at marginal cost. The question is no longer whether resources exist but how they are allocated.

2.4 Diagnostic Infrastructure and Clinical Practice Patterns

Diagnostic gaps reflect both infrastructure limitations and financing architecture. Across West African facilities, fewer than 10 percent of women received ultrasound confirmation before surgery, relying instead on clinical palpation with limited sensitivity (Okolo, 2008). Where ultrasound equipment exists, it is frequently non-functional due to maintenance challenges, lack of replacement parts, or electricity supply interruptions. The WHO Service Availability and Readiness Assessment for Sierra Leone (2021) reported that fewer than 30 percent of primary health facilities and 60 percent of hospitals had functional ultrasound machines. Machines that do

function are often allocated exclusively to obstetric services, positioned in maternity wards, scheduled for antenatal scanning, and unavailable for general gynecologic imaging without special arrangement and private payment.

Women seeking gynecologic imaging must therefore pay out-of-pocket for private scans. In Freetown, ultrasound costs range from Le 200,000 to Le 500,000 ($20–$50 USD)—substantial sums for households where median monthly income for informal-sector workers approximates Le 800,000 (Statistics Sierra Leone, 2022). The financial barrier to diagnostic imaging thus compounds the infrastructure gap, producing diagnostic delays extending months or years despite repeated clinical presentations.

Overburdened clinicians compress clinical encounters to manage volume, providing minimal explanation (Tunçalp et al., 2015; Freedman et al., 2014). Women leave without understanding their condition—a communication gap reflecting system constraints rather than provider indifference.

2.5 Financial Architecture and Household Economic Consequences

Chronic gynecologic conditions often impose catastrophic household expenditure when public financing excludes coverage. Xu et al. (2018) demonstrated through an 89-country analysis that reproductive-age women in low-income households face the highest risk of impoverishing health expenditure for surgical care, a finding they attribute to the gap between high surgical costs and limited insurance coverage for non-obstetric reproductive procedures.

Country-specific studies from Africa provide detail on these patterns. In Ghana, the National Health Insurance Scheme covers maternal complications including cesarean delivery but explicitly excludes fibroid surgery unless the condition directly threatens pregnancy (NHIS Ghana, 2024). Women requiring myomectomy or hysterectomy for symptomatic fibroids must pay

privately or forgo surgery. In Nigeria, all fibroid treatment requires out-of-pocket payment; studies document surgery costs equivalent to six to twelve months of household income for informal sector workers (Morhason-Bello et al., 2022). In Kenya, even when accessing public hospitals, women must purchase surgical consumables, medications, blood products, and imaging privately (Gichuhi et al., 2021).

Lassi et al. (2021) found similar patterns across Uganda, Tanzania, and Malawi, with households responding to surgical costs through asset sales (livestock, land, household goods), loans from informal networks at high interest rates, or treatment delays that allow symptoms to progress while families attempt to accumulate necessary funds. A substantial proportion of women ultimately forgo surgery entirely when costs prove insurmountable.

Economic consequences extend beyond direct expenditure to productivity losses: women cannot maintain market trading during bleeding, reduce agricultural labor during pain, or sustain wage employment (Kabia et al., 2019). These indirect costs often exceed treatment expenditures while remaining invisible to policymakers.

Economists studying how costs distribute by gender have shown that these patterns reflect the gendered distribution of health system costs. When public financing excludes conditions primarily affecting women, households (and within households, women themselves) absorb costs through multiple mechanisms: direct out-of-pocket payment, foregone income due to symptom-related productivity loss, unpaid care work to manage illness without formal health services, and asset depletion that compromises long-term economic security (Elson, 2017; Folbre, 2021; Razavi, 2016). This cost-shifting from public to private, from state to household, from collective to individual represents what Standing (2014) terms the feminization of precarity: the systematic transfer of risk and responsibility that falls disproportionately on women.

This cost-shifting is invisible in national health accounts, which record only public expenditure. The full economic burden of excluding chronic gynecologic conditions from public financing thus remains unmeasured and therefore absent from policy discourse about affordability, sustainability, or equity.

2.6 Social and Cultural Dimensions of Reproductive Illness

Medical anthropologists have long documented how communities generate alternative explanatory models when health systems offer inadequate explanation (Amadiume 1997; Lock and Nguyen 2010). In West Africa, women pragmatically engage multiple healing systems, using biomedical facilities for diagnosis, turning to traditional healers for causal narratives, and seeking guidance from religious leaders for spiritual counsel. Rather than relying on a single system, they combine these pathways strategically in response to the limits of any one source of care (Janzen 1978; Feierman and Janzen 1992).

This form of medical pluralism reflects neither superstition nor ignorance. It is a rational response to the limits of biomedical care. When repeated clinic visits yield no diagnosis despite persistent symptoms, when providers offer no explanation of causes, and when the cost of surgery exceeds what a household can bear, turning to traditional healers or seeking prayer becomes a strategic effort to secure relief. Studies across West Africa show that women do not reject biomedical care. They seek alternative pathways because biomedical facilities often have limited diagnostic capacity, no affordable treatment options, and communication practices that leave symptoms unexplained and suffering unacknowledged (Janzen 1978; Feierman and Janzen 1992; Lock and Nguyen 2010).

Infertility associated with fibroids attracts social scrutiny: childlessness invites accusations of spiritual impurity or divine punishment (Inhorn & Patrizio, 2015). In Sierra Leone, where

women's social value is tied to reproductive capacity, childlessness becomes moral failing or spiritual contamination (Bledsoe, 2002). These interpretations emerge not from "cultural backwardness" but from biomedical systems' failure to provide timely diagnosis.

2.7 Gendered Labor and Health System Sustainability

Feminist economists demonstrate how women's unpaid labor subsidizes inadequate social provisioning. When countries reduce health spending, women absorb the fiscal gap through unpaid household care (Elson, 2017). This "uncompensated positive externality" enables health systems to function while the true costs remain invisible in planning and budgets (Folbre, 2021).

Razavi (2016) applied these insights specifically to health systems, arguing that women's work compensates for structural underinvestment in three overlapping ways: direct care provision for ill family members when health facilities are inaccessible or unaffordable; income generation to purchase private services when public coverage is inadequate; and management of their own chronic conditions while simultaneously maintaining productive and reproductive responsibilities. Standing (2014) synthesized these patterns under the concept of "feminization of precarity"—the systematic transfer of risk and cost from collective to individual, from public to private, from male to female that characterizes neoliberal health sector reforms.

Empirical studies from African settings validate these theoretical claims. Research from Uganda, Tanzania, and Kenya documents women continuing income-generating activities during acute illness because household survival depends on their earnings (Kabia et al., 2019; Adongo et al., 2013). Studies of post-surgical recovery show women returning to market trading, agricultural labor, and domestic responsibilities within days of major abdominal procedures because no alternative income or care arrangements exist (Moyer et al., 2014). Providers report that women

leave hospitals "against medical advice" not from poor understanding but from economic necessity.

This labor is invisible, necessary, and exploited—what Farmer et al. (2006) term structural violence: systematic injury embedded in social arrangements that appear normal.

2.8 The Sierra Leone Policy and Research Context

National policy documents corroborate the structural patterns identified across the region. The Free Health Care Initiative (FHCI) (Government of Sierra Leone, 2010) defines beneficiaries as "pregnant and lactating women and children under five years," thereby excluding chronic gynecologic conditions from public coverage. The Health Sector Strategic Plan 2021–2025 (MoHS, 2021) emphasizes maternal and child health, communicable disease control, and emergency obstetric care but omits fibroids, endometriosis, chronic pelvic pain, and other non-pregnancy gynecologic conditions.

Sierra Leone's Health Management Information System (HMIS) tracks antenatal attendance, facility deliveries, cesarean-section rates, and maternal deaths, yet contains no data fields for gynecologic diagnoses unrelated to pregnancy (MoHS, 2022). As a result, the system cannot generate statistics on fibroid prevalence, treatment volume, or outcomes—an omission that reflects policy design rather than data-entry failure.

The World Bank (2020) public-expenditure review found that less than 5% of reproductive-health spending supports non-obstetric care. The WHO Service Availability and Readiness Assessment (2021) reported that fewer than 30 percent of primary facilities had functional ultrasound equipment, most reserved for antenatal use.

Existing research in Sierra Leone focuses appropriately on maternal mortality, antenatal care, and emergency obstetric services, where investment through the Free Health Care Initiative

has produced measurable improvement (Wurie et al. 2016; Witter et al. 2016; Mayhew et al. 2016). A smaller body of work on women's health seeking behavior highlights barriers such as cost, distance, and stigma (Bayray et al. 2015; Wilkinson et al. 2016). Yet this scholarship does not examine chronic gynecologic morbidity or the policy architecture that produces these constraints.

This study contributes the first systematic documentation of fibroid prevalence at Sierra Leone's national referral hospital and the first analysis connecting clinical patterns with household economic strategies. It addresses two central gaps in the evidence base: establishing the scale of the burden and illuminating the mechanisms through which policy exclusion intensifies it.

2.9 Conceptual Gaps and Study Contributions

The literature shows that fibroids impose substantial burden globally, with higher prevalence among women of African descent, yet receive minimal research investment. The maternal health paradigm achieves mortality reduction while excluding chronic gynecologic conditions from measurement, financing, and service delivery. Diagnostic infrastructure gaps and financing exclusions produce diagnostic delays and catastrophic household costs across African settings. When biomedical systems provide inadequate explanation or inaccessible treatment, communities generate spiritual and traditional interpretive frameworks as rational responses. Women's unpaid labor compensates for systemic underinvestment, enabling household survival and health system function while remaining invisible in policy accounts.

These findings come from disparate literatures. Existing research documents outcomes (diagnostic delays, financial barriers, treatment gaps, household economic crises) that do not always trace the mechanisms through which policy design choices produce individual suffering and household adaptation.

Studies typically examine single dimensions (clinical access, financial barriers, or cultural interpretations) without analyzing their interdependence. Research on diagnostic delays do not often connect to specific policy choices (HMIS exclusions, equipment allocation, insurance rules). Studies of household coping strategies seldom link back to the policy architecture that necessitates them. Analyses of cultural interpretations treat such frameworks as independent variables rather than as responses to biomedical inadequacy.

This research examines clinical patterns, lived experiences, household strategies, and policy architecture simultaneously. It documents prevalence at Sierra Leone's national referral facility, investigates women's experiences through narrative inquiry, analyzes policy documents and financing structures, and examines how providers and communities respond to structural constraints.

The framework that emerged from this analysis identifies mechanisms linking policy design to individual suffering and household adaptation. It shows how systemic exclusion functions and where interventions can disrupt these patterns.

2.10 Conclusion

The literature establishes that chronic gynecologic conditions remain invisible within health systems that privilege maternal mortality reduction (Kruk et al., 2018; Yamin & Boulanger, 2013). Policy defines reproductive health through pregnancy, excluding chronic conditions from financing and data systems (Gullo et al., 2017). Economic analyses reveal cost transfers to households and women's unpaid labor (Elson, 2017; Folbre, 2021). Sierra Leone's FHCI illustrates both state capacity for maternal health gains and persistent design boundaries excluding chronic gynecologic care. This study quantifies fibroid burden, maps care pathways, and analyzes how women confront structural exclusion.

CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

This chapter describes the research design, data collection procedures, and analytical approach.

3.2 Epistemological Stance and Research Orientation

3.2.1 Constructivist–Pragmatist Approach

The research adopts constructivist and pragmatist approaches. Women's accounts of symptoms, care-seeking, financing strategies, and treatment decisions are treated as valid sources of knowledge about how health systems operate in practice. The analysis prioritizes frameworks that identify system-level problems and inform feasible reform.

Three assumptions guided the analysis. First, women's narratives reveal how institutions function, not only how individuals experience them. Second, health systems reflect priorities and values rather than neutral or natural arrangements. Third, women's unpaid labor plays a central role in sustaining households and health systems and must therefore be analytically visible. The Cycle of Suffering and Resilience (COSAR) emerged from systematic engagement with the Sierra Leone data rather than from pre-existing theoretical models.

3.2.2 Grounded-Theory Techniques and Inductive Analysis

The study uses grounded theory techniques, including iterative coding, constant comparison, and theoretical sampling, to develop concepts from data rather than test predetermined hypotheses (Charmaz 2014; Corbin and Strauss 2015). Existing frameworks offered important insights but did not account for how policy design, household economics and care-seeking practices combine to produce the patterns observed in Sierra Leone. The exclusion of fibroids from routine data systems required an inductive approach based on available evidence.

Women's accounts revealed patterns not captured in existing literature, including the timing of traditional healer consultations, household economic strategies across social positions and the gendered distribution of care work. Analysis proceeded through open, axial and selective coding, supported by continuous memo writing documenting analytic decisions and emerging interpretations.

3.3 Research Design

The study uses a convergent mixed-methods design (Creswell & Plano Clark, 2018). Quantitative and qualitative data were collected simultaneously and integrated during interpretation.

Quantitative chart review analyzed all 262 gynecologic admissions at Princess Christian Maternity Hospital during the study period, documenting fibroid prevalence, diagnostic methods, treatment decisions, and recorded costs. These data established the empirical foundation of this study.

Qualitative inquiry comprised 15 in-depth interviews with women diagnosed with fibroids, five focus group discussions with women and family members, and seven key informant interviews with health care providers, traditional healers, and community leaders. These data revealed the mechanisms behind quantitative patterns. Chart reviews documented diagnostic delays; interviews explained why (equipment breakdowns, unaffordable imaging costs, inadequate counseling). Chart reviews recorded high surgical costs; focus groups detailed how households mobilized resources (asset sales, borrowing, postponing treatment).

Quantitative findings provide descriptive context. Qualitative analyses explain mechanisms and generate the COSAR framework.

3.3.1 Study Setting

Research occurred in Freetown and peri-urban Western Area of Sierra Leone between January and August 2025. Princess Christian Maternity Hospital (PCMH), Sierra Leone's sole tertiary facility for complex gynecologic cases, served as the quantitative site. Chart reviews examined all 262 gynecologic admissions during April-May 2025.

Qualitative fieldwork extended to Wilberforce, Mountain Cut, Kissy, Waterloo, and Tombo, sites selected for variation in proximity to PCMH (urban to 45km peri-urban), economic profiles (informal settlements to middle-income areas), and referral pathways (secondary facilities vs. primary health units).

Additional data collection occurred at Jui Government Hospital and King Harman Road Hospital, secondary-level facilities that serve as referral points for primary care facilities and refer complex gynecologic cases to PCMH. Engaging these sites enabled understanding of the full referral continuum and provider perspectives at different system levels, revealing how diagnostic delays and referral gaps accumulate as women move from community health units through secondary facilities to tertiary care.

3.3.2 Sampling and Participants

3.3.2.1 Quantitative Sample

The quantitative component reviewed all gynecologic admissions at PCMH during April 1–May 15, 2025—a timeframe balancing prevalence estimation needs with doctoral research feasibility. The review identified 262 gynecologic admissions during this period, of which 89 cases (34.0 percent) involved confirmed fibroid diagnoses. This fibroid-confirmed subset constituted the primary analytic sample for detailed quantitative analysis.

As Sierra Leone's sole national referral facility for complex gynecologic cases, PCMH receives patients from across the country's health system hierarchy, district hospitals, community

health centers, and private clinics. While this facility-based census approach cannot establish population-level prevalence, it provides the best available evidence of fibroid burden within Sierra Leone's formal health system and enables investigation of diagnostic pathways, treatment patterns, and documented costs among women who reach tertiary care.

Inclusion criteria: gynecologic admission during the study period, complete records, and fibroid diagnosis confirmed by clinical palpation, imaging, or surgical pathology. Exclusion criteria: obstetric admissions, charts with >50% missing data, and suspected but unconfirmed cases.

Data abstraction used standardized Epicollect5 forms capturing demographics, reproductive history, presenting symptoms, diagnostic methods, fibroid characteristics, treatment decisions, documented costs, and outcomes—variables enabling both descriptive epidemiology and care pathway analysis.

Data quality assurance procedures included: review of Epicollect5 forms for completeness before leaving the hospital chart room each day, verification of data consistency through spot-checks of entered data against source documents, and systematic documentation of missing data patterns. Charts meeting exclusion criteria were systematically logged with reasons documented to maintain transparency and enable assessment of potential selection bias.

3.3.2.2 Qualitative Sample

Qualitative sampling used purposive and snowball methods capturing variation across reproductive status (nulliparous vs. parous), economic capacity (informal traders vs. salaried employees), treatment status (pre-diagnosis, awaiting surgery, post-surgical), and geography (urban vs. peri-urban).

Target ranges (12-15 interviews, 4-6 focus groups, 6-8 key informants) balanced data richness needs with eight-month fieldwork constraints. Recruitment continued until analytical adequacy, when additional data elaborated rather than generated new categories.

Fifteen in-depth interviews were conducted with women diagnosed with fibroids: age 28-52 (median 38), parity 0-5, varied marital status and education, diverse economic activities (traders, teachers, domestic workers, small business owners), and treatment stages (pre-diagnosis, awaiting surgery, post-surgical).

Five focus groups included three with women who experienced fibroids (6-8 participants each, n=21), one with male partners (n=6), and one mixed-gender family group (n=7). Groups lasted 75-120 minutes in community spaces selected by participants.

Seven key-informant interviews were conducted with two gynecologists at PCMH, one general practitioner at Jui Government Hospital, two nurses/midwives at PCMH and King Harman Road Hospital, one traditional healer in Kissy, and one female community leader in Waterloo.

Recruitment used multiple channels. Women were identified through PCMH gynecology clinic staff who provided study cards during consultations. Interested women contacted the researcher directly. Snowball sampling expanded recruitment through participants' social networks, churches, and community groups, reaching women who might not access PCMH due to financial constraints. This multi-channel approach included women successfully navigating the system and women excluded by barriers.

Data collection and analysis proceeded convergently, enabling iterative assessment of thematic development. By the twelfth interview, major analytical categories were established, with subsequent interviews yielding elaboration rather than new insights. The final three interviews ensured representation of key subgroups: an older nulliparous woman, a highly educated

professional woman, and a post-hysterectomy patient. Focus groups validated patterns from individual interviews and revealed social dimensions around stigma, household negotiations, and community interpretations.

Qualitative Data Collection Procedures

Semi-structured guides were developed collaboratively and refined iteratively. Interview guides addressed: symptom recognition, care-seeking pathways, diagnostic delays, financial strategies, social responses, traditional healer consultations, treatment outcomes, and system improvement recommendations.

Focus group discussion guides explored similar thematic terrain but emphasized social dynamics, household decision-making processes, community norms regarding women's reproductive health, collective experiences of navigating the health system, and group perspectives on what enables or constrains fibroid care access.

Key informant interview guides addressed: clinical perspectives on fibroid prevalence and management (how common providers perceive fibroids to be, typical clinical presentations, standard management approaches), diagnostic and treatment capacity and constraints (what equipment and services are available or not available, what limits providers face), referral pathways and coordination (how cases move through the system, what works and what breaks down in referral processes), provider communication practices and challenges (how providers explain diagnoses and options to patients, what makes communication difficult), policy and financing barriers observed in practice (how FHCI exclusion manifests in clinical work, what financial barriers providers witness), and recommendations for system improvement (what changes would enable providers to better serve women with fibroids).

All interviews and focus group discussions were conducted by the principal investigator in English or Krio based on participant preference and comfort. Most individual interviews occurred in participants' homes or private spaces they selected (homes, church offices, quiet corners of community centers); some occurred at health facilities when participants preferred this for convenience or privacy. Focus group discussions were held in community spaces (church halls, community center meeting rooms) selected by participant groups for accessibility and comfort.

Interviews lasted 45–90 minutes; focus group discussions lasted 75–120 minutes. Timing was flexible, allowing conversations to unfold naturally rather than enforcing rigid time limits that might truncate important discussions.

All sessions were audio-recorded with consent. Field notes documented setting, nonverbal communication, group dynamics, and emerging themes. When recording was declined (two instances), detailed handwritten notes were immediately expanded into typed field notes.

Audio recordings were transcribed verbatim by the principal investigator and a trained transcription assistant. Quality assurance involved the principal investigator reviewing all transcripts against audio files to ensure accuracy. Krio-language portions were first transcribed in Krio to preserve original language, then translated to English by bilingual team members (the principal investigator and transcription assistant, both native Krio speakers with professional English fluency). Translation prioritized conceptual equivalence rather than word-for-word rendering, preserving idioms, metaphors, and culturally specific expressions with explanatory notes where direct translation would lose meaning.

Weekly analytical debriefs occurred throughout the data collection period. These sessions brought together the principal investigator and transcription research assistants to review emerging themes, discuss analytical insights, refine interview and focus group guides based on what was

being learned, identify gaps in sampling requiring additional recruitment, and document key methodological decisions. This iterative process enabled responsive data collection guided by developing analytical understanding while maintaining systematic procedures across all interviews and focus groups.

3.4 Analytical Procedures

3.4.1 Quantitative Analysis

Quantitative data were exported from Epicollect5 to Microsoft Excel for initial cleaning and preparation, then imported to Stata 17 statistical software for analysis. Analysis remained descriptive rather than inferential, appropriate for the facility-based census sampling approach and the study's primary purpose of documenting patterns rather than testing pre-specified hypotheses.

Descriptive statistical procedures included: frequencies and percentages for categorical variables (diagnostic methods employed, presenting symptoms, treatment types, education levels, occupations), means, medians, and ranges for continuous variables (age, parity, documented costs where available), and cross-tabulations exploring potential associations between demographic characteristics (age, education, parity) and diagnostic pathways or treatment access patterns.

Missing data were handled transparently. Percentages and statistics were calculated from non-missing observations, with sample sizes clearly reported for each variable analyzed. Patterns of missingness were systematically examined to assess whether data were missing completely at random or systematically related to other variables. Where systematic patterns appeared - for instance, surgical costs were more frequently missing for women who did not proceed to surgery or education level was often more undocumented for women from rural referral areas - this was explicitly noted in results interpretation to avoid misleading inferences.

Statistical outputs were cross-checked against raw data entries for internal consistency. Any unexpected values (outliers, inconsistent patterns) triggered return to original charts for verification before inclusion in analysis.

3.4.2 Qualitative Analysis

Qualitative analysis employed grounded-theory techniques to enable patterns and explanatory frameworks to emerge from systematic data engagement. The analytical process proceeded through four iterative phases, with constant comparison and memo-writing throughout.

Phase 1: Initial coding involved line-by-line analysis of interview and focus group transcripts, generating over 300 initial codes. Codes used participants' own language where possible (in vivo codes such as "bad blood," "selling property," "people say witchcraft," "rise and fall") and remained close to data rather than imposing abstract analytical categories prematurely. Each transcript was coded multiple times as analytical understanding deepened through constant comparison.

Phase 2: Focused coding grouped initial codes into broader analytical categories describing processes, relationships, and patterns recurring across multiple transcripts. Discrete codes like "waited months for scan," "could not afford imaging," "provider said come back if worse" clustered into broader categories such as "diagnostic delays despite repeated presentations," "financial barriers to imaging," "symptomatic management without definitive diagnosis." Categories captured recurring phenomena: diagnostic invisibility, household financial mobilization, navigation between multiple healing systems, provider communication constraints under resource scarcity, community moral judgments about childlessness, women's continued labor during illness and recovery.

Phase 3: Selective coding identified relationships among focused-code categories, revealing how categories connected to form larger analytical patterns rather than existing as isolated phenomena. For instance, analysis revealed that diagnostic delays created temporal and epistemic space for alternative spiritual and moral explanations to take hold; that financial exclusion from imaging and surgery necessitated elaborate household economic strategies distributing burden in gendered ways; that women's ability to continue market trading, farming, and domestic labor despite chronic symptoms enabled both household survival and health system function by reducing pressure for system reform.

Phase 4: Integration synthesized categories and their relationships into a coherent analytical framework to organize findings. Constant comparison continued throughout this phase, systematically testing emerging patterns against the full qualitative corpus. Negative cases—instances that did not fit emerging patterns—prompted either pattern refinement (specifying boundary conditions under which patterns did or did not apply) or recognition of meaningful variation requiring explanation rather than dismissal as outliers.

Throughout all phases, systematic memo-writing documented the analytical process. Early memos described rich data excerpts and initial impressions. Mid-stage memos explored relationships between categories, posed analytical questions requiring additional data or alternative interpretations, and connected empirical patterns to relevant scholarly literatures. Late-stage memos articulated the emerging analytical framework in increasingly abstract terms, synthesizing understanding and identifying implications for policy and practice.

Analytical adequacy was assessed through ongoing monitoring using three criteria: Were new interviews generating new analytical categories, or only providing additional instances of established categories? Were relationships between categories stable and well-specified, or still

evolving with each new case? Were boundary conditions (circumstances under which patterns did and did not apply) sufficiently identified and explained? When all three criteria indicated stability—no new categories emerging, relationships stable and specified, boundaries clear—adequacy was deemed achieved.

3.4.3 Integration and Triangulation

Findings were integrated through joint displays (Creswell & Plano Clark, 2018) matrices organizing quantitative patterns with corresponding qualitative evidence. For example, when diagnostic delays occurred, this systematic integration enabled identification of areas where quantitative and qualitative findings converged (strengthening confidence in documented patterns), diverged (prompting investigation of why different data sources told different stories), or addressed complementary aspects (enabling construction of fuller understanding than either data source alone could provide).

Triangulation operated across three dimensions: (1) methodological—combining quantitative measurement with qualitative exploration of meanings and mechanisms; (2) data sources—women, families, providers, healers, community leaders, policy documents, and charts; (3) investigators—primary researcher, transcription assistant, and independent reviewers.

Member checking with four participants (two who had completed fibroid surgery, two who remained unable to afford treatment despite years of effort) provided additional validation. Preliminary analytical findings were shared in accessible language, and participants were asked whether the identified categories and patterns resonated with their lived experiences or required revision to accurately represent what they had shared. Participant feedback refined understanding particularly regarding variation in family support availability (correcting preliminary over-emphasis on family financial mobilization by highlighting women's experiences of limited family

assistance) and timing of traditional healer consultations (clarifying that such consultations typically followed rather than preceded biomedical encounters that failed to produce satisfactory diagnosis or relief).

3.5 Reflexivity and Positionality

The researcher, a Sierra Leonean woman, public health professional, and fibroid survivor held insider knowledge that enhanced rapport and cultural understanding while requiring sustained reflexive vigilance throughout the research process. This multifaceted positionality shaped what data were accessible, how participants responded, and how data were interpreted.

Insider status advantages: Women shared intimate details about bleeding patterns, sexual relations, infertility struggles, financial hardships, and marital tensions that they might withhold from foreign researchers. Cultural fluency enabled immediate understanding of practices (osusu rotating savings groups, native doctor consultations, church prayer interventions). Speaking Krio eliminated language barriers. Personal networks facilitated research access. Health care providers spoke frankly about system failures rather than presenting sanitized accounts.

Insider status challenges: Familiarity risks over-assuming shared understanding. When participants mentioned practices, the researcher's cultural knowledge provided immediate comprehension but potentially short-circuited deeper exploration. Insider status creates pressure to represent the community positively, potentially tempering critical analysis. The researcher's professional background risked imposing policy-oriented frameworks rather than allowing women's own meaning-making to emerge.

The researcher's personal experience as a fibroid survivor added additional complexity. While this shared experience facilitated deep empathetic understanding and rapport-building, it also risked over-identification, assuming that others' experiences mirrored the researcher's own, or

projecting the researcher's emotional responses onto participants. Conversely, the researcher's successful navigation to diagnosis and treatment (facilitated by educational credentials, professional networks, and financial resources unavailable to many participants) created social distance that required explicit acknowledgment.

Reflexive practices addressing these tensions included: Sustained analytical journaling (memos) that recorded not only analytical decisions but also researcher emotional and intellectual responses throughout the research process, moments of surprise (the frequency and pragmatic sophistication of women's medical pluralism), discomfort (community leaders' harsh moral judgments of childless women), resonance (shared frustration with FHCI exclusion policies), and confusion (why some women delayed treatment despite apparent financial capacity). Memos systematically tracked how these responses potentially shaped interpretation and what additional data collection or analytical strategies might test or challenge researcher assumptions.

Regular peer debriefing with research assistants and research team provided external critical perspective on emerging analyses, questioning interpretations that seemed self-evident to the researcher but might reflect unexamined cultural assumptions or analytical blind spots. For instance, the researcher initially coded women's return to market trading and domestic labor within days of abdominal surgery as straightforward "economic necessity," but research assistant discussions prompted investigation of whether women themselves framed their rapid resumption of work primarily in economic terms or whether the researcher had imposed an economic-determinist interpretation onto more complex motivations involving family duty, work identity, and household power dynamics.

Member checking with selected participants tested whether analytical categories and interpretive frameworks resonated with participants' own understandings of their experiences.

These follow-up conversations surfaced places where preliminary analysis mischaracterized lived experience or overlooked important variation. One woman forcefully challenged the framework's emphasis on family financial support and collective household mobilization, noting that women like herself received minimal family assistance and managed fibroid costs primarily through their own economic strategies, a corrective that prompted more careful attention to variation in family support rather than presenting collective mobilization as a universal pattern.

Theoretical sensitivity developed through systematic engagement with scholarly literature helped the researcher recognize when analytical categories aligned with, diverged from, or extended established frameworks. For example, the pattern of women navigating between biomedical facilities and traditional healers initially seemed novel until literature review revealed anthropological scholarship on medical pluralism. What was distinctive in Sierra Leone: traditional healing consultations occurred predominantly after biomedical consultations failed, suggesting medical pluralism as adaptive response to biomedical inadequacy.

Explicit documentation of starting assumptions occurred at the study's inception through structured memos. The researcher recorded the analytical position brought to this work: that the limited visibility of chronic gynecologic conditions in Sierra Leone's health system reflects the ways reproductive priorities have been historically constructed and operationalized. This assumption recognized the country's broader fiscal context, in which public health spending remains constrained and heavily shaped by external financing. Global frameworks, including the Sustainable Development Goals, further direct political attention and donor investment toward maternal mortality reduction, reinforcing a metric culture in which what is counted becomes what is funded. At the same time, the memos acknowledged that scarcity is never merely a technical fact. Even within a narrow fiscal envelope, governments make distributive decisions about which

burdens to measure, which conditions to integrate into essential packages, and which populations to protect. The consistent omission of chronic reproductive morbidity—despite its clinical burden and its economic and social costs—therefore suggested a policy design logic that extends beyond limited resources alone. The memoing process was used to surface these starting points so they could be interrogated and refined as the research revealed the interplay between resource constraint, global agenda setting, and national policy architecture.

Reflexive practice cannot eliminate researcher influence on data collection, interpretation, or analytic framing, nor can it produce an objective account detached from positionality. Some dimensions of identity, assumption, and interpretive predisposition operate below conscious awareness and remain inaccessible regardless of how deliberate the reflexive effort. Reflexivity itself can also slip into performance, becoming a methodological ritual that signals sophistication without substantively shaping analytical choices or improving interpretation. Acknowledging these limits, the study approached reflexivity not as a guarantor of neutrality but as a disciplined attempt to recognize how positionality interacts with inquiry.

In this study, reflexivity functioned as an iterative tool for analytic refinement. Insights surfaced through memoing, self-interrogation, and discussion with peers were treated as prompts for deeper engagement with the data rather than as one-time validations of rigor. When member checking revealed that an initial interpretation mischaracterized participants' experiences, the analysis was revised. When peer debriefing illuminated assumptions that had gone unexamined, additional data were collected to test alternative explanations. Reflexivity therefore operated as a continuous mechanism for improving analytical clarity, acknowledging influence, and sharpening interpretation, rather than as a fixed checkpoint or procedural safeguard.

3.6 Ethical Considerations

Formal ethical approval was obtained from the Sierra Leone Ethics and Scientific Review Committee (SLERC-2024-0312) prior to initiating any data collection activities. The approval process required submission of detailed research protocol specifying study purpose and significance, research design and methods, participant recruitment procedures, informed consent processes, confidentiality and data security measures, potential risks and mitigation strategies, and plans for research dissemination and community benefit.

All participants provided written informed consent after receiving a thorough explanation (in English or Krio per participant preference) of: study purpose and procedures, voluntary nature of participation and right to decline or withdraw at any time without consequences, confidentiality protections and their limits, absence of direct therapeutic benefits from participation, compensation offered (transport reimbursement for individual interviews, refreshments for focus group participants), and how research findings would be used and disseminated.

Confidentiality and data protection procedures included:

All transcripts use pseudonyms. Digital recordings were encrypted and destroyed after transcription. Only the research team accessed identifiable data.

Secure data retention and destruction: Per SLERC requirements, identifiable research data (audio recordings, consent forms with signatures, the linking key) will be retained in secure storage for five years following study completion to enable verification of findings if questions arise, then permanently and irreversibly destroyed. De-identified data (anonymized transcripts, coded data files) may be retained longer for potential secondary analysis or archiving for future research use if participants explicitly consented to such uses during the informed consent process.

Reciprocity and research benefits: Ethical research practice extends beyond minimizing harm to actively considering how research might benefit participating individuals and communities.

Direct individual benefits: While study participation offered no direct therapeutic benefit, women participants expressed that the opportunity to share their stories felt personally meaningful. Several explicitly stated that they wanted their experiences documented "so it can help other women who are suffering" or "so the government will know what women are going through." These framing positions research participation as contribution to collective good rather than as extraction of knowledge for researcher benefit without benefit to participants or their communities.

Potential collective benefits: The research aims explicitly to inform policy reform and system redesign that could benefit future women experiencing fibroids and other chronic gynecologic conditions. Whether this potential materializes depends on factors beyond the research itself (political will, advocacy campaign effectiveness, resource availability, competing policy priorities), but the study was designed from inception to generate actionable evidence rather than only academic knowledge.

Financial recognition: Interview participants who traveled to meet the researcher received transport reimbursement of 50,000 Leones covering estimated round-trip costs. Focus group participants received light refreshments during sessions. These practices recognize the real economic burden of research participation (lost work time, transportation costs) while intentionally avoiding compensation payments large enough to constitute undue inducement that might compromise voluntary consent.

Research dissemination: Academic publications, policy briefs to Ministry of Health officials and donor agencies, community radio programs in Krio, and presentations at community meetings. The thesis will be submitted to Ministry of Health and PCMH leadership.

Advocacy commitment: The researcher's involvement in policy advocacy for women's health equity in Sierra Leone preceded this doctoral research and will continue after degree completion through ongoing work with Youterus Health, Africa's first uterine health company committed to driving research informed policy, availing the findings of this work to policymakers and community stakeholders alike.

3.7 Study Limitations

This research has limitations:

Facility-based quantitative sampling: The quantitative component analyzed medical charts from PCMH, Sierra Leone's sole tertiary referral facility for complex gynecologic care. Women who reached PCMH represent those who successfully experience multiple barriers: recognizing symptoms as requiring medical attention, accessing transportation and consultation fees for initial facility visits, receiving referral recommendations from lower-level providers, and having sufficient resources to travel to Freetown for tertiary care. Population-level fibroid prevalence remains unknown because national health surveys do not include questions about chronic gynecologic symptoms and HMIS does not track non-pregnancy gynecologic conditions. The study therefore documents patterns among women who accessed specialized gynecologic care, not population-wide burden or experiences of women who never reach formal health services.

Geographic concentration of qualitative data: Qualitative data collection occurred in Freetown and peri-urban Western Area communities within approximately 45 kilometers of PCMH. Rural women's experiences, particularly those living in provinces distant from Freetown

where access to even basic diagnostic capacity is more limited, transportation costs and time required to reach referral facilities are substantially greater, and social norms regarding women's reproductive health may differ, these experiences may differ substantially from patterns documented in this urban and peri-urban sample. The analytical framework's applicability and explanatory power beyond urban contexts requires empirical verification through future research in rural settings.

Cross-sectional design: Eight months of convergent data collection captured patterns observable within that timeframe but could not document longer-term trajectories of living with fibroids, multi-year care seeking journeys, extended recovery periods following surgery, or long-term consequences of foregoing treatment. Women's experiences unfold over time periods substantially exceeding the study duration. Longitudinal research following women over years would provide complementary insights not accessible through cross-sectional investigation.

Recall limitations: Individual interviews asked women to retrospectively describe care-seeking pathways, symptoms, clinical encounters, household financial negotiations, and community responses that extended over months or years prior to interview. Human memory is inevitably incomplete and reconstructive rather than perfectly accurate. Women may not precisely recall timing of consultations, exact costs paid years earlier, or specific content of provider communication from consultations occurring in the distant past. The study triangulated self-reported information with medical record documentation and provider interview accounts to partially address recall limitations, but some degree of imprecision is inevitable in retrospective qualitative research.

Language and translation: While most interviews were conducted in Krio (participants' preferred language) with some in English (when participants preferred), translation between

languages inevitably involves interpretation that may subtly shift meanings. Krio idioms and culturally specific expressions do not always translate straightforwardly into English without losing nuance. While bilingual research team members prioritized conceptual equivalence and preserved idioms with explanatory annotations, some meaning may be lost or transformed in translation.

Researcher positionality: As detailed in Section 3.5, the researcher's identity as Sierra Leonean woman with public health professional expertise and personal fibroid experience shaped what participants chose to share, how the researcher understood and interpreted their accounts, what patterns seemed analytically salient, and what questions seemed worth pursuing. Other researchers with different backgrounds, training, and experiences might construct different analytical frameworks from similar data. The framework presented represents one plausible, systematically developed, empirically grounded interpretation, not the singular objective truth about fibroid care in Sierra Leone.

These limitations define the study's scope and the boundaries within which findings can be generalized.

3.8 Conclusion

This chapter explained the research design. The study used constructivist-pragmatist approaches, mixed methods, and grounded theory techniques to document clinical burden and investigate how women, families, and providers experience fibroid care. Chapter 4 presents the findings.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter presents findings from chart review of 262 gynecologic admissions at Princess Christian Maternity Hospital and qualitative interviews with 27 participants.

4.2 Prevalence and Demographic Profile

4.2.1 Clinical Burden

Of 262 gynecologic admissions reviewed at PCMH during April–May 2025, 89 contained confirmed fibroid diagnoses, a prevalence of 34 percent. One in three women admitted to Sierra Leone's national referral hospital for gynecologic care had fibroids, the highest proportion for any single condition. Percentages derived from the 89-case chart review describe patterns among women who reached PCMH with confirmed fibroid diagnoses, a group that successfully navigated multiple barriers to access tertiary care. Percentages from the 27-participant qualitative sample describe patterns among purposively selected individuals whose experiences illuminate mechanisms but are not intended to be statistically generalizable. Quantitative findings document clinical and service use patterns. Qualitative findings explain the institutional, social, and economic processes underlying those patterns. Their integration informs the analysis that follows.

4.2.2 Demographic Characteristics

Table 4.1: Sociodemographic Characteristics of Women Diagnosed with Fibroids (n = 89)

Characteristic	Category	n	%
Age (years)	Mean (SD)	39.4 (6.8)	—
	25–34	18	20.2
	35–44	51	57.3
	45–52	20	22.5
Marital status	Married	62	69.7
	Single	22	24.7

Table 4.1 (Continued)

	Divorced/widowed	5	5.6
Education	None	8	9.0
	Primary	18	20.2
	Secondary	10	11.2
	Tertiary	53	59.6
Parity	Nulliparous	34	38.2
	1–2 children	31	34.8
	3+ children	24	27.0
Economic activity	Employed/self-employed	69	77.5
	Unemployed/homemaker	20	22.5

Source: PCMH chart review, 2025.

Mean age of 39 years reflects the reproductive peak when fibroids become symptomatic. The 38 percent nulliparity rate is more than ten times the three percent national rate among women aged 35 to 44 (Statistics Sierra Leone, 2019), while 70 percent married, and 60 percent tertiary educated indicates fibroids affect women across social strata.

4.2.3 Clinical Presentation and Diagnostic Pathways

Table 4.2: Presenting Symptoms and Diagnostic Methods (n = 89)

Category	**Item**	**n**	**%**
Presenting symptoms*	Abnormal uterine bleeding	67	75.3
	Pelvic pain/dysmenorrhea	52	58.4
	Abdominal swelling/mass	41	46.1
	Infertility/subfertility	29	32.6

Table 4.2 (Continued)

	Anemia symptoms	37	41.6
Diagnostic methods	Clinical examination only	37	41.6
	Ultrasound alone	12	13.5
	Clinical exam + ultrasound	28	31.5
	Diagnosed at surgery	12	13.5
Diagnostic delays (n=55)	<1 month	8	14.5
	1–3 months	13	23.6
	>3 months	34	61.8

*Multiple symptoms per patient; percentages do not sum to 100.

Source: PCMH chart review, 2025.

Abnormal bleeding (75%), pelvic pain (58%), and abdominal swelling (46%) were most common. One third presented with infertility. Diagnostic pathways revealed reliance on clinical examination alone (42%), with only 13.5 percent receiving ultrasound before admission. Among cases with documented symptom duration, 62 percent experienced delays exceeding three months.

4.3 Integrated Findings: Six Recurring Patterns

Six recurring patterns emerged from constant comparative analysis, integrating quantitative indicators with qualitative evidence to reveal how policy exclusion shapes care experiences.

4.3.1 Pattern One: Diagnostic Invisibility

Sixty two percent experienced diagnostic delays exceeding three months despite repeated presentations. Only 13.5 percent received ultrasound before admission, with 42 percent diagnosed by clinical examination alone and 65 percent of imaging occurring at private facilities requiring payment. Women described cycles of presentation without diagnosis: "I was bleeding for months;

they said infection. After two years, when my stomach grew big, they did a scan" (Woman, 37, Waterloo). "I went to clinic many times. They gave me iron tablets. Nobody told me fibroid until I reach PCMH" (Woman, 41, Kissy). Providers explained structural constraints: "Sometimes the ultrasound is broken for weeks; we make diagnoses based on what we can feel" (Gynecologist, PCMH). "The machine is in maternity for pregnancy scans. When gynecology patients need imaging, they must pay private" (Nurse, Jui Hospital).

4.3.2 Pattern Two: Clinical Disregard

Counseling was documented in only 4 percent of records (n = 4 of 89). Absence of documentation does not necessarily indicate absence of counseling, as providers may counsel without recording the interaction. The near-universal lack of documentation, combined with qualitative accounts from women and providers describing minimal explanation, suggests that the documentation gap reflects communication constraints rather than recording failures alone. No records documented discussion of risk factors or treatment options. Women described limited explanation: “The doctor said I have fibroid. I asked what causes it. He said, ‘It just happens.’ That was all” (Woman, 28, Brookfields). “They told me I need operation, but nobody explained what they will do or how much time to recover” (Woman, 35, Mountain Cut). Providers contextualized these gaps: “Sometimes we see 40 women in a morning. We cannot counsel everyone the way we would like” (Gynecologist, PCMH). Clinic volumes of forty to fifty patients per session leave approximately five minutes per patient, limiting the possibility of detailed counseling.

This produces mutual frustration where women feel dismissed and providers feel overwhelmed, a dynamic neither creates individually but emerges from system design.

4.3.3 Pattern Three: Epistemic Negotiation

Among the fifteen women interviewed, all but one reported no prior awareness of fibroids before diagnosis, and none had received written information materials. Women constructed understanding through multiple sources. “When the hospital did not explain, I asked my mother. She said it is from not having children early” (Woman, 33, Brookfields). “What the hospital did not explain, I learned from others, my friend, my church members, people who had surgery before” (Woman, 28, Brookfields). Traditional healers described their role in filling information gaps: “Women come to me after the hospital. They say the doctor found something but did not explain. They want to know what it means, what caused it” (Traditional Healer, Kissy). These patterns illustrate epistemic negotiation, the process through which women generate practical knowledge when biomedical systems provide limited guidance. Women combine biomedical diagnosis with explanatory frameworks offered by family members, community networks, religious leaders, and traditional healers to make sense of their condition.

This pattern challenges narratives that position cultural beliefs as barriers to care. Women's plural knowledge construction follows from rather than precedes inadequate biomedical communication.

4.3.4 Pattern Four: Financial Exclusion

Documented surgical costs ranged from Le 2 to 9 million ($100 to $450 USD). Zero cases showed FHCI subsidy or insurance coverage. Fifty seven percent required blood transfusion, adding Le 300,000 to 600,000 per unit. Women described catastrophic household impacts: "I sold my sewing machine and my phone to pay for surgery. After the operation, I had nothing left to restart my business" (Woman, 41, Lumley). "My husband borrowed from his boss. We are still paying back two years later" (Woman, 36, Kissy). "I have been saving for three years. Every month I put small money aside. I am still not enough" (Woman, 39, Mountain Cut). Families described

distributed burden: "Everyone contributed. We sold palm oil, borrowed from osusu. It took six months to gather the money" (Sister, Waterloo). Financial exclusion emerges directly from policy design. The Free Health Care Initiative covers pregnancy related conditions but excludes chronic gynecologic conditions (Government of Sierra Leone, 2010).

This categorical exclusion renders fibroid treatment entirely private expense. Women and families respond through asset liquidation, informal borrowing, extended household mobilization, and prolonged saving while symptoms worsen.

4.3.5 Pattern Five: Moral Surveillance

Among women with fibroids, 38.2 percent were nulliparous, more than ten times the national rate. One third presented with infertility. The mean age of 39 years places women at reproductive peak when childlessness attracts scrutiny. Women described how fibroid-related infertility becomes moralized: "People ask me every day: 'When you go born?' They think I am waiting, that I don't want children. They don't know I cannot" (Woman, 33, Brookfields). "My mother-in-law said I am cursed, that God is punishing me for something I did" (Woman, 31, Waterloo). Community members articulated expectations: "A woman without children is seen as incomplete. People say she is selfish, or something is wrong with her spiritually" (Community Leader, Tombo). Moral surveillance describes how infertility resulting from fibroids transforms a clinical outcome into social accusation. Women experience double suffering: physical symptoms and reproductive loss compounded with community judgment interpreting childlessness as personal or spiritual failing.

Delayed diagnosis intensifies this dynamic; the longer infertility remains unexplained biomedically, the more space exists for moral interpretations.

4.3.6 Pattern Six: Survival Labor

Seventy-seven and a half percent remained economically active despite chronic symptoms. Seventy five percent presented with abnormal bleeding. Seventy one percent had anemia (mean hemoglobin 8.3 g/dL). Women described continuing work through debilitating illness: "Even when I bleed heavily, I must go to market. If I don't sell, my children don't eat. No work, no food, it is simple" (Woman, 39, Lumley). "After surgery, doctor said rest one month. I rested one week. I had to go back to my shop, nobody else can run it" (Woman, 36, Kissy). Providers observed premature return to labor: "We tell women to rest after surgery, but they come back too soon because they have no income, no sick leave, no support" (Nurse, PCMH). Survival labor captures how women's continued economic activity through chronic illness enables household survival while concealing system failure. When women successfully work through severe symptoms, manage financial barriers through extended saving, and resume labor days after surgery, this appears as resilience rather than evidence of inadequate social protection. Resilience becomes structural dependency: systems function because women's labor compensates for gaps.

4.4 Synthesizing the Patterns: The Cycle of Suffering and Resilience (COSAR)

The six patterns interconnect to form a cyclical dynamic—the Cycle of Suffering and Resilience (COSAR)—an analytical framework organizing how policy exclusion, infrastructure constraints, and household adaptation interact to produce care experiences.

4.4.1 How the Cycle Operates

The six patterns interconnect to form a cyclical dynamic: diagnostic invisibility enables clinical disregard, which necessitates epistemic negotiation; financial exclusion requires survival labor; diagnostic delays create temporal space for moral surveillance. Women cycle through stages repeatedly rather than progressing linearly. Seeking diagnosis multiple times before confirmation,

engaging multiple healing modalities simultaneously, experiencing moral judgment throughout, and continuing survival labor across all stages.

These stages do not proceed linearly. Women may cycle through stages repeatedly: seeking diagnosis multiple times before confirmation, engaging multiple healing modalities simultaneously, experiencing moral judgment throughout. Survival labor continues across all stages rather than occurring only at the end.

4.4.2 What COSAR Explains

COSAR reveals three dynamics. First, policy exclusion produces embodied consequences: FHCI's categorical design interacts with equipment allocation to produce diagnostic delays, inadequate communication, and financial catastrophe that women experience as chronic pain, bleeding, infertility, and stigma. Second, women's adaptations sustain system dysfunction. Household resource mobilization and continued labor through illness enable eventual care access despite inadequacy. These successful adaptations obscure that women traverse barriers that should not exist. Third, the cycle regenerates unless interrupted at multiple points simultaneously. Adding ultrasound without addressing FHCI exclusion means women still cannot afford imaging. Subsidizing surgery without ensuring respectful communication means women still lack understanding. Single interventions prove insufficient.

4.4.3 Exit Points

COSAR describes a cyclical dynamic, but cycles are not indefinite. Women exit through multiple pathways, each with distinct implications for health systems and policy.

Successful treatment represents the intended exit. Women who access surgery, complete recovery, and resume daily life without ongoing suffering have moved through the cycle. This study documented such cases: women who mobilized resources, navigated diagnostic delays, and

ultimately received care. Their exit required substantial effort. The policy question is not whether treatment is possible but whether it should demand such struggle.

Accommodation without resolution describes women who live with symptoms indefinitely. They continue survival labor, adjust daily routines, seek periodic care, or rely on symptom management rather than definitive treatment. This represents stabilization within the cycle rather than exit. For policy purposes, these women remain affected even when they no longer seek care.

Withdrawal from care-seeking occurs when women conclude that formal health services offer limited benefit. Repeated failed presentations, cumulative costs, and dismissive encounters lead women to disengage. They shift toward traditional healing, prayer, or endurance. These women are no longer captured in facility-based data but continue to suffer. Their exit reflects system failure rather than improvement.

Death is also an exit. Severe anemia can be fatal. Fibroid-related complications during pregnancy contribute to maternal deaths recorded in HMIS without attribution to underlying chronic disease. The full mortality burden of fibroids in Sierra Leone is unknown because the condition is not tracked.

Emigration enables access to care outside national constraints. Women who travel to Ghana, Senegal, or other countries exit the limitations of the local system. Their departure represents an individual solution and a collective loss.

Identifying exit points ensures the framework does not imply that all women cycle indefinitely. It highlights that most exits do not represent effective system performance. Only exit through accessible, affordable, and respectful care reflects a functioning reproductive health system.

4.4.4 Integrated Evidence Summary

Table 4.3: COSAR Stages with Integrated Evidence

COSAR Stage	Quantitative Evidence	Qualitative Evidence	Mechanism
Diagnostic Invisibility	62% delays >3 months; 42% clinical exam only	"Nobody told me fibroid until PCMH" (Woman, 41, Kissy)	Equipment concentrated in maternity; private payment required for imaging
Clinical Disregard	96% no counseling documented; 0% discussion of options	"He said 'it just happens.' That was all" (Woman, 28, Brookfields)	Patient volumes of 40 to 50 per session preclude adequate communication
Epistemic Negotiation	97% no prior fibroid awareness; 0% written materials	"When hospital did not explain, I asked my mother" (Woman, 33, Brookfields)	Women construct understanding from multiple sources when biomedical systems provide none

Table 4.3 (Continued)

Financial Exclusion	Le 2 to 9M surgical costs; 0% FHCI coverage	"I sold my sewing machine and my phone" (Woman, 41, Lumley)	FHCI categorically excludes chronic gynecologic conditions
Moral Surveillance	38% nulliparous (10x national rate); 33% presented with infertility	"My mother-in-law said I am cursed" (Woman, 31, Waterloo)	Diagnostic delays create temporal space for stigmatizing explanations of childlessness
Survival Labor	77.5% economically active despite symptoms; 71% anemic	"If I don't sell, my children don't eat" (Woman, 39, Lumley)	No social protection: household survival depends on women's continued work

Source: Integrated analysis, PCMH data (n=89) and qualitative data (27 participants), 2025.

4.5 Summary of Findings

Four key findings emerged from this integrated analysis:

Fibroids represent a substantial clinical burden yet remain systematically invisible. The 34 percent prevalence among gynecologic admissions at PCMH establishes fibroids as the single most common condition affecting women seeking gynecologic care at Sierra Leone's national referral hospital. Yet the condition remains absent from national health information systems, unlisted in FHCI coverage, and rarely mentioned in reproductive health policy documents. This invisibility is not incidental—it reflects specific policy choices that define reproductive health as pregnancy care.

Women face systematic diagnostic delays produced by infrastructure allocation and financing mechanisms. Sixty-two percent of cases with documented symptom duration experienced diagnostic delays exceeding three months. These delays result from three intersecting constraints: equipment concentrated in maternity services rather than gynecology; imaging costs that create financial barriers; and provider adaptations to resource scarcity. Women presented early and repeatedly; diagnosis was delayed by system design, not patient behavior.

Financial exclusion structures care access through categorical policy design. Complete absence of FHCI coverage or insurance subsidies renders fibroid treatment an entirely private, out-of-pocket expense. Documented surgical costs of Le 2–9 million ($100–450 USD) represent catastrophic expenditure for households. Women and families respond through asset liquidation, informal borrowing networks, extended household mobilization, and prolonged saving while symptoms worsen—strategies that enable eventual access while imposing severe economic burden.

Six interconnected patterns organize how policy exclusion produces lived experience. Diagnostic invisibility, clinical disregard, epistemic negotiation, financial exclusion, moral surveillance, and survival labor form the Cycle of Suffering and Resilience (COSAR)—an analytical framework revealing how women endure a cyclical dynamic that systematically disadvantages them through institutional design. Each stage creates conditions for the next; together they form a self-reinforcing cycle that regenerates unless interrupted at multiple points simultaneously.

Chapter 5 interprets these findings.

CHAPTER 5: DISCUSSION

5.1 Overview

Chapter 4 documented that fibroids affect one in three women admitted for gynecologic care at PCMH yet remain systematically excluded from health information systems, FHCI eligibility, and policy documents. Six patterns emerged: diagnostic invisibility, clinical disregard, epistemic negotiation, financial exclusion, moral surveillance, and survival labor. These interconnect to form the Cycle of Suffering and Resilience (COSAR). This chapter interprets what these patterns reveal about health system design. Each stage represents system level choices rather than individual failures. Women navigate extraordinary barriers with sophistication, but this navigation should not be celebrated without interrogating why such barriers exist.

5.2 Interpreting Findings Through COSAR: System-Level Analysis

5.2.1 Stage 1: Diagnostic Invisibility: Recognition as Infrastructure, Not Knowledge Gap

Equipment allocation reflects policy priorities, but also the realities of a chronically underfunded health system. Ultrasound machines concentrate in antenatal clinics where pregnancy monitoring is reimbursed under the Free Health Care Initiative. Gynecologic services caring for women with chronic conditions outside pregnancy operate within the same constrained resource envelope yet lack reliable access to imaging. Even when ultrasound units exist in gynecology departments, they often malfunction without timely repair. As one provider explained, “Sometimes the ultrasound is broken for weeks; we make diagnoses based on what we can feel.” Resource constraints shape this landscape, but they do so through the filter of policy design. When budgets are tight, the definition of reproductive health embedded in FHCI, focused narrowly on pregnancy, creates powerful institutional incentives to direct equipment procurement, maintenance, and infrastructure investment toward antenatal spaces. Gynecologic departments serving non-pregnant women become residual rather than priority sites. In this context, scarcity does not produce

invisibility on its own. It is scarcity interpreted through policy eligibility that organizes diagnostic capacity around who is counted, rather than around clinical need.

Cost barriers impact diagnostic access. When gynecologic imaging requires private payment while pregnancy-related imaging is subsidized, women face financial constraints that delay or prevent diagnosis. The documented pattern (65 percent of imaging occurring at private centers) reflects this financing mechanism. Women with financial resources access timely diagnosis; women without resources experience prolonged uncertainty while symptoms worsen.

This is not incidental market sorting but policy-produced stratification. FHCI's categorical approach to subsidy eligibility creates parallel care pathways: subsidized, relatively well-equipped services for pregnant women; unsubsidized, poorly equipped services for women with chronic gynecologic conditions. Women navigate these pathways based on financial capacity rather than clinical need.

Providers adapt to resource constraints through triage strategies that normalize delay. Facing overwhelming patient volumes, limited imaging access, and inadequate counseling time, providers develop practical heuristics: offer symptomatic management first, observe symptom progression, and wait for conditions to become clinically obvious through palpation. As one gynecologist explained, seeing "40 women in a morning" leaves approximately five minutes per patient (insufficient for thorough history, physical examination, counseling, and diagnostic planning). These provider adaptations are rational responses to impossible working conditions. The problem is not individual provider negligence but system design that generates untenable patient-to-provider ratios, concentrates diagnostic equipment away from gynecologic services, and provides no financing mechanism for non-pregnancy reproductive care. Providers do what they can within structural constraints they did not create and cannot individually overcome.

Diagnostic invisibility emerges from policy architecture, not knowledge gaps. Providers know fibroids exist. Women present with classic symptoms. The barrier is not recognition but infrastructure: where equipment is allocated, how imaging is financed, what patient volumes providers must manage. Addressing diagnostic invisibility requires changing infrastructure allocation and financing policy, not training providers to "recognize" a condition they already know exists.

Standard capacity-building approaches misidentify the problem. Providers already recognize fibroid symptoms. The constraint is system-level: equipment allocation policies that deprioritize gynecologic services, financing structures that make imaging unaffordable for many women, and staffing ratios that preclude adequate clinical encounters.

Health systems scholarship distinguishes between "supply-side" and "demand-side" barriers (Peters et al., 2008). Supply-side barriers (inadequate infrastructure, workforce shortages, equipment deficits) limit what health systems can offer. Demand-side barriers (cost, distance, cultural beliefs) limit what populations can access. COSAR demonstrates how policy design produces supply-side barriers that appear as demand-side failures. When women cannot afford imaging, this looks like demand-side financial barrier. But the underlying cause is supply-side policy choice: FHCI's categorical exclusion makes imaging unaffordable by design.

Furthermore, diagnostic invisibility is not a stable endpoint but entry into a cycle. Delayed diagnosis creates temporal space for the patterns documented in Stages 2-5: inadequate communication leaves women seeking alternative explanations, financial constraints necessitate prolonged saving while symptoms worsen, unexplained infertility attracts moral scrutiny, and women continue working through illness because no social protection exists. Each stage feeds the next, producing the cyclical reinforcement COSAR documents.

5.2.2 Stage 2: Clinical Disregard: Communication Failure as Structural Constraint

Overwhelming patient volumes preclude adequate communication. Providers seeing 40 to 50 women per clinic session spend approximately five minutes per patient. This duration suffices for brief history, focused examination, and prescription but not for explanation, counseling, answering questions, or documenting discussions. As one gynecologist acknowledged: "We cannot counsel everyone the way we would like." This is not individual provider failure but system capacity constraint. Sierra Leone's physician to population ratio of 0.3 per 10,000 people, compared to WHO's minimum recommended 10 per 10,000, creates clinic conditions where adequate communication becomes structurally impossible (WHO, 2016).

Providers are not choosing to withhold information; they are adapting to conditions where thoroughness with each patient means seeing fewer patients overall, leaving others unserved. Women experience biomedical encounters as dismissive: "He said 'it just happens' that was all." This experience of disregard is real, even when providers believe they are doing their best under impossible constraints. The structural inadequacy translates into interpersonal experience women interpret as lack of care. This creates mutual frustration. Women feel dismissed; providers feel overwhelmed.

Neither creates this dynamic individually. It emerges from workforce shortages, facility under-resourcing, and health system design that concentrates resources in tertiary centers while leaving peripheral and secondary facilities chronically understaffed. Clinical disregard is not attitudinal problem amenable to sensitivity training. It is capacity problem requiring workforce expansion, infrastructure investment, and service delivery redesign. Providers who want to communicate adequately cannot do so within five-minute encounters managing 50 patients per morning.

Addressing clinical disregard requires changing the conditions under which providers work, not changing provider attitudes. This stage connects directly to Stage 3. When biomedical systems provide diagnosis without explanation, women seek understanding elsewhere (family, community, spiritual leaders, traditional healers). This epistemic negotiation is rational response to biomedical opacity, not cultural preference for non-biomedical knowledge.

5.2.3 Stage 3: Epistemic Negotiation: Knowledge Construction as Rational Response

When biomedical systems offer diagnosis without explanation, women pragmatically seek understanding from available knowledge sources. This is not rejection of biomedical knowledge but a supplement to biomedical opacity. Women accept the biomedical diagnosis (fibroid) while seeking explanatory frameworks biomedical encounters failed to provide (what caused it, why me, what does it mean). Family members offer reproductive history interpretations: "from not having children early." Community networks share experiential knowledge: "people who had surgery before." Religious leaders provide spiritual frameworks: divine will, tests of faith. Traditional healers offer alternative causation theories and therapeutic interventions. Women synthesize these sources pragmatically, combining biomedical diagnosis with plural explanatory frameworks.

Global health literature frequently frames cultural beliefs as barriers to care: women delay treatment because traditional healing systems offer alternative explanations (WHO, 2013). COSAR reveals that women's epistemic negotiation follows from, rather than precedes, biomedical inadequacy. When biomedical systems provide diagnosis without explanation, women rationally seek explanation elsewhere. The barrier is not cultural belief but biomedical opacity. Comprehensive reproductive health requires different approaches. Rather than correcting cultural beliefs, biomedical systems must explain conditions to patients. When women receive thorough

biomedical explanation (what fibroids are, what causes them, how they develop, what treatment options exist), they can integrate this knowledge with other frameworks as they choose.

The problem is not that women consult multiple knowledge sources; the problem is that biomedical systems fail to provide adequate information, making consultation of other sources necessary rather than supplementary. Epistemic negotiation demonstrates women's agency and sophisticated knowledge management. It is not evidence of medical ignorance but evidence of system failure to communicate. Addressing this stage requires improving biomedical communication (Stage 2 interventions) rather than correcting beliefs. This stage has implications for Stage 5. When diagnostic delays (Stage 1) and communication failures (Stage 2) leave infertility unexplained biomedically, the temporal and epistemic gap invites moral interpretations: childlessness as divine punishment, curse, spiritual problem. Timely diagnosis and adequate explanation reduce the space for stigmatizing explanations to emerge.

5.2.4 Stage 4: Financial Exclusion: Catastrophe by Design

FHCI's categorical design excludes chronic gynecologic conditions from subsidy eligibility. The policy covers pregnant women, lactating mothers, and children under five (Government of Sierra Leone, 2010). Fibroids affecting non-pregnant, non-lactating women fall outside these categories. This is not implementation failure or resource constraint preventing coverage expansion. It is policy architecture: FHCI deliberately defines reproductive health as pregnancy care, categorically excluding chronic gynecologic conditions. The result is predictable: fibroid treatment becomes entirely private expense.

Women and families respond through asset liquidation, informal borrowing from employers, relatives or rotating credit groups, extended household mobilization and prolonged saving while symptoms worsen. Financial exclusion reflects how reproductive priorities are set

within Sierra Leone's health system. Since its launch, the Free Health Care Initiative has attracted significant government and donor investment, yet its design directs these resources toward maternal and child health. Global frameworks such as the Sustainable Development Goals reinforce this focus by aligning measurement and financing with maternal mortality reduction.

Conditions that fall outside SDG indicators, including fibroids, remain peripheral to public spending. FHCI's success for pregnant women shows that when a condition is defined as a national and global priority, financing, service delivery and measurable improvement follow. Facility-based deliveries increased from 54 percent in 2008 to 87 percent in 2019, and maternal mortality declined from 1,165 to 717 per 100,000 live births (Statistics Sierra Leone 2019). These gains illustrate what becomes possible when political will and measurement frameworks align. The exclusion of fibroids shows how policy design rather than fiscal inevitability determines which conditions receive visibility and public investment.

Current policy frameworks could include chronic gynecologic conditions, yet they do not. This exclusion contributes to the financial strain that women experience when seeking care. Addressing this requires examining how eligibility criteria within FHCI organize financing and shape access. Increasing resources without revisiting these criteria would strengthen services for pregnant women while leaving the structural neglect of chronic conditions unchanged. A more comprehensive approach to reproductive health financing would consider how to extend financial protection across the full spectrum of conditions affecting reproductive organs and capacity, including those unrelated to pregnancy.

This stage directly enables Stage 6. When surgery costs six to twelve months of income and no social protection exists, women must continue working through illness and return to income generating activity prematurely post-surgery. Financial exclusion necessitates survival labor.

5.2.5 Stage 5: Moral Surveillance: Infertility as Social Accusation

In pronatalist cultural contexts where motherhood defines women's social value, involuntary childlessness attracts scrutiny and judgment. When biomedical systems delay diagnosis (Stages 1 and 2), the temporal gap between symptom onset and explanation invites moral interpretations: childlessness as punishment, curse, selfish choice, spiritual problem. This is not simply cultural belief operating independently of health systems. It is a dynamic produced by the interaction between cultural norms and system failures. Pronatalist norms exist as background condition. Health system failures activate these norms by leaving infertility unexplained for extended periods. The longer the diagnostic delay, the more space exists for non-biomedical explanations (including stigmatizing ones) to circulate and solidify. Health system inadequacies do not affect all populations equally.

Diagnostic delays affect women seeking gynecologic care; moral surveillance affects women experiencing infertility within pronatalist cultures. The interaction between health system failure and gendered social norms produces suffering that women experience as both physical (symptoms, reproductive loss) and social (stigma, relationship strain, community judgment). Feminist health systems scholarship emphasizes that health systems operate within and reproduce gendered power relations (Morgan et al., 2016). System failures that might appear gender neutral (diagnostic delays, equipment shortages) produce gendered consequences when they interact with social norms that penalize women for reproductive outcomes. Addressing moral surveillance requires both biomedical and social interventions.

Biomedically, timely diagnosis and adequate explanation reduce the temporal gap during which stigmatizing interpretations emerge. Socially, public education normalizing infertility as

medical condition rather than moral failing challenges community level stigma. Neither intervention alone suffices; both are necessary. This stage connects to all previous stages.

Diagnostic delays (Stage 1) create temporal space for stigma. Communication failures (Stage 2) leave women without biomedical explanation to counter stigmatizing narratives. Epistemic negotiation (Stage 3) may incorporate stigmatizing frameworks when biomedical explanations are absent. Financial exclusion (Stage 4) delays treatment, prolonging the period of infertility and stigma exposure.

5.2.6 Stage 6: Survival Labor: Resilience as System Dependency

Survival labor emerges from intersection of three system failures. Lack of social protection means women have no income during illness or recovery (no sick leave, no disability benefits, no household support). Financial exclusion (Stage 4) means women must self-finance treatment, requiring continued income generation even through illness. Household economic structures depend on women's labor. For many households, women's market selling, petty trading, or agricultural work provides essential income that cannot be replaced if they stop working. The result: women work through severe anemia, continue trading during menstrual bleeding so heavy it requires changing cloths hourly, and return to income generating activities one-week post-surgery when medical guidance recommends one month rest. Global health discourse frequently celebrates women's resilience (their capacity to overcome barriers, adapt to hardship, persist despite obstacles) (Ungar, 2008). When women successfully navigate diagnostic barriers, mobilize household resources for catastrophic expenditure, and maintain income generation through severe illness, this demonstrates competence and agency. But it also demonstrates inadequate system design. Women should not need such extraordinary effort to access basic reproductive health care.

Their resilience enables system gaps to persist because women compensate for failures through their own labor. When women mobilize resources, absorb costs, and continue working through illness, the system receives little pressure to change. This is survival labor, work undertaken to maintain daily life under constrained conditions rather than to improve opportunity. Survival labor allows women to cope but also obscures the need for structural reform. Women's unpaid care work, household economic strategies, and continued labor during illness fill gaps that policy should address.

The structural analysis developed here risks overlooking what women accomplish. Women in this study demonstrated considerable competence: identifying symptoms with limited information, navigating health facilities across multiple levels, assembling financial resources, negotiating with family members and providers, and sustaining productive and reproductive labor while managing chronic illness. These are achievements. The challenge is to recognize agency without romanticizing burden. A woman who sells her sewing machine to finance surgery demonstrates resourcefulness, but she also demonstrates that the system required her to choose between livelihood and health. Both are true. Agency operates within constraints that policy could remove.

How findings are communicated matters for policy design. Framing women solely as victims misrepresents their capabilities and may produce paternalistic interventions. Framing them solely as resilient agents obscures the conditions that make such effort necessary and can enable systems to avoid accountability. Women navigate constraints effectively, but the goal of policy should be to make such extraordinary labor unnecessary.

Comprehensive reproductive health requires system design that supports women rather than relying on them to compensate for gaps. In Sierra Leone, such protections—sick leave during

illness, income support, and coverage for chronic gynecologic conditions—do not yet exist. Nor do systems routinely provide timely diagnosis, consistent counseling, or clear referral pathways without requiring substantial effort from patients. In the absence of these supports, women's unpaid care work, household resource mobilization and continued labor during illness sustain both families and facilities. These adaptations demonstrate capability, but they also indicate that the system depends on women's uncompensated labor to function.

5.3 The Cycle

The six stages interconnect through four feedback loops rather than proceeding linearly: Invisibility enables disregard. Diagnostic delays normalize prolonged uncertainty (Stage 1), so providers adapt by offering symptomatic management and deferring investigation. This produces communication patterns women experience as disregard (Stage 2). When providers lack time for adequate explanation, they cannot contextualize why imaging is delayed, reinforcing diagnostic opacity.

Disregard necessitates negotiation. When biomedical systems fail to explain conditions (Stage 2), women pragmatically seek understanding from other sources (Stage 3). This plural knowledge construction then gets interpreted by biomedical systems as "cultural beliefs" preventing care, even though women's epistemic negotiation resulted from biomedical communication failure, not cultural preference for traditional knowledge.

Exclusion requires labor. Financial exclusion (Stage 4) creates catastrophic expenditure that necessitates household economic strategies. Women must continue working through illness to save for treatment (Stage 6). This survival labor enables eventual treatment access, creating appearance that systems work, obscuring the extraordinary effort women expended and suffering they endured.

Delays expose women to prolonged scrutiny, allowing others to fill the explanatory void with moral interpretations long before a biomedical diagnosis arrives. Diagnostic delays (Stage 1) extend the period during which infertility remains unexplained biomedically. This temporal gap allows moral interpretations to circulate and solidify (Stage 5). When women finally receive biomedical diagnosis years after symptom onset, they have often already internalized stigmatizing explanations or endured relationship strain from family pressure.

These interconnections produce cyclical reinforcement. Each stage creates conditions enabling others; together they form self-perpetuating dynamic. Interventions targeting single stages prove insufficient because other stages regenerate the barriers addressed. Adding ultrasound machines without expanding FHCI means women still cannot afford imaging. Subsidizing surgery without addressing workforce shortages means women still experience communication failures. Providing education about fibroids without social protection means women still must work through illness.

Systems change must address policy architecture (FHCI reform), infrastructure allocation (equipment distribution), workforce capacity (provider-to-patient ratios), financial protection (subsidy expansion), social norms (stigma reduction), and economic security (social protection). No single reform suffices.

5.4 Continental Patterns: Sierra Leone Within Regional Context

Sierra Leone's patterns reflect broader dynamics across sub-Saharan Africa.

Pattern 1: Maternal health success and chronic condition neglect exist side by side. Across multiple African countries, focused programs have driven substantial reductions in maternal mortality (Rwanda, Ethiopia, Kenya, Ghana). Yet chronic gynecologic conditions remain systematically excluded from national health priorities (Heaton et al. 2016). This pattern is not

specific to Sierra Leone but reflects a continental reproductive health policy architecture that equates reproductive health with maternal health.

Pattern 2: Gaps in health information systems make chronic reproductive conditions invisible. Most African countries use the District Health Information System 2 (DHIS2), yet its standard data fields do not include fibroids, endometriosis, gynecologic cancers or other chronic reproductive conditions (HISP 2020). When national systems cannot capture a condition, they cannot monitor its burden, allocate resources or evaluate interventions. Invisibility in data systems often precedes invisibility in policy.

Pattern 3: Diagnostic equipment is concentrated in tertiary centers. Across sub-Saharan Africa, imaging capacity is predominantly located in urban referral hospitals, while peripheral health centers where most women first seek care lack basic diagnostic tools (WHO 2015). This distribution reflects financing mechanisms that prioritize tertiary infrastructure rather than primary care capacity.

Pattern 4: Household expenditure for gynecologic care is often catastrophic. Studies from Kenya, Nigeria, Uganda and Tanzania document similar patterns of asset liquidation, informal borrowing and household economic strain to finance gynecologic treatment (Kruk et al. 2009). When national health financing excludes chronic conditions, households bear the full cost.

Pattern 5: Women's unpaid care work masks gaps in the health system. Research across African health systems shows that women's labor, including caring for ill household members, managing household economics during health shocks and sustaining income generation through their own illness, enables health systems to function despite underinvestment (Grown et al. 2006). COSAR's "survival labor" stage provides a specific analytical frame for these dynamics.

Sierra Leone represents a case study of broader continental patterns. COSAR provides analytical framework potentially applicable across contexts where maternal health programs succeed while chronic gynecologic conditions remain neglected. The framework's portability depends on similar structural conditions: categorical health financing excluding chronic conditions, HMIS lacking relevant data fields, equipment allocation following maternal program priorities, inadequate social protection, and pronatalist cultural contexts.

5.5 Policy Architecture as Structural Determinant

Three features of national policy architecture function as structural determinants shaping women's fibroid care experiences: FHCI design, Health Management Information System (HMIS) exclusions, and equipment allocation mechanisms.

5.5.1 FHCI Design and Eligibility Logic

The FHCI's categorical eligibility (pregnant women, lactating mothers, and children under five) deliberately excludes chronic gynecologic conditions. This is not a matter of oversight or limited resources preventing coverage expansion. It is a foundational policy choice that defines reproductive health primarily as pregnancy care. Reforming this structure requires expanding eligibility toward a condition-neutral model in which all reproductive-age people receive financial protection for any condition affecting reproductive organs or reproductive capacity.

5.5.2 HMIS Exclusions and Data Invisibility

National health information systems lack standardized data fields for fibroids and most chronic gynecologic conditions. When systems cannot capture conditions, they cannot monitor burden or evaluate interventions. Data invisibility produces policy invisibility. Reform requires integrating gynecologic conditions into the DHIS2 framework and ensuring facility-level reporting systems capture non-maternal reproductive health encounters.

5.5.3 Equipment Allocation and Resource Prioritization

Current allocation mechanisms concentrate ultrasound and diagnostic equipment within antenatal clinics, reflecting FHCI priorities. As a result, gynecologic services become residual sites for equipment investment. Reform demands allocation policies that recognize gynecologic diagnostic capacity as core reproductive health infrastructure, not a supplementary addition after maternal services are equipped.

5.5.4 Interactions Across Policy Architecture

These three architectural features reinforce one another. FHCI exclusion removes the financing incentive to invest in gynecologic capacity; HMIS gaps prevent monitoring of unfunded conditions; and equipment allocation follows financing priorities. Together, they produce the diagnostic invisibility, financial exclusion, and service inadequacy that COSAR documents.

Reform must therefore address all three simultaneously. Expanding FHCI coverage without HMIS integration results in conditions that remain invisible in data. Integrating conditions into HMIS without financing mechanisms leads to monitoring of unmet needs without resources to address them. Redistributing equipment without workforce expansion creates better-equipped facilities still overwhelmed by patient volumes.

5.6 Political Economy of Reform

Understanding why fibroids remain excluded from health policy requires examining the incentives shaping current arrangements. As Walt and Gilson (1994) argue, policy outcomes reflect the interplay of actors, processes and context; evidence alone does not generate reform.

Interests Sustaining the Status Quo: The current configuration persists less because actors actively defend fibroid exclusion and more because no concentrated interest mobilizes for change while diffuse interests benefit from stability. This reflects a challenge common to neglected

health issues: the absence of cohesive policy communities capable of generating political priority (Shiffman and Smith, 2007).

Donor priorities influence national agendas. Development partners supporting Sierra Leone's health sector focus on indicators they monitor internally, including maternal mortality, child mortality and infectious disease burden. Expanding the FHCI to include chronic gynecologic conditions would require either additional financing or reallocation from existing priorities, both of which are constrained by donor accountability structures tied to established metrics.

Within the Ministry of Health and Sanitation, capacity constraints create incentives to maintain existing programs. Officials managing the FHCI already navigate drug stockouts, reimbursement challenges and facility readiness issues. Adding new conditions increases administrative demands without corresponding political reward. Reductions in maternal mortality generate international recognition; improvements in fibroid care do not.

Professional associations could advocate for gynecologic service expansion, but competing priorities—training, compensation and workload—limit the feasibility of expanding service scope without workforce investment. Private sector providers benefit modestly from current exclusions: imaging and surgical revenue from patients who seek care outside the public system. These actors do not face incentives to lobby for FHCI coverage expansion.

Potential Coalitions for Reform: Women's organizations represent the most plausible advocacy constituency. Groups focused on reproductive rights could incorporate chronic gynecologic conditions into existing mandates. The challenge is that fibroids lack the political salience of maternal mortality or gender-based violence. Effective coalition-building would require framing fibroid care as essential to women's economic participation and bodily autonomy.

First Lady offices in several African countries have elevated under-recognized health issues. Sierra Leone's First Lady has engaged with uterine health initiatives linked to this research, suggesting a potential pathway for high-profile leadership. Professional associations may also provide technical advocacy, especially if expansion is framed as a clinical necessity rather than a political demand.

Continental policy processes offer additional leverage. Incorporating chronic gynecologic conditions into the Maputo Plan of Action review or African Union health strategies creates normative expectations that national systems often follow (African Union, 2016; African Union Commission, 2015).

Strategic Leverage: Reform does not require confrontation with opposing interests. It requires mobilizing latent supporters and reducing barriers for policymakers who are sympathetic but constrained. This thesis provides evidence that did not previously exist. Documented prevalence, diagnostic delays and financial burdens shift the burden of justification from advocates seeking change to officials defending exclusion.

Framing FHCI expansion as completing its original mandate rather than enlarging it may reduce resistance. Extending reproductive health protection across the life course aligns with the underlying logic of the policy. Demonstrating that untreated chronic conditions generate downstream costs appeals to fiscal considerations: emergency interventions, productivity losses and complications during pregnancy all impose system-level burdens.

Pilot programs implemented in defined geographies offer opportunities to demonstrate feasibility and build momentum for national adoption. The Western Area, where this research was conducted, provides an initial testing ground.

Evidence is a necessary but insufficient condition for reform. Translation requires strategic engagement with interests, coalition-building and sustained advocacy beyond doctoral completion. The political work begins where the academic work concludes.

5.7 Recommendations: From Evidence to Policy Action

5.7.1 National Policy Reforms

Recommendation 1: Expand FHCI eligibility to include chronic gynecologic conditions.

Current FHCI covers pregnancy-related care. Coverage should be expanded to condition-neutral reproductive health coverage: all reproductive-age people merit financial protection for conditions affecting reproductive organs (fibroids, endometriosis, gynecologic cancers, pelvic inflammatory disease, menstrual disorders). This eliminates categorical exclusion producing financial barriers.

Implementation pathway: Ministry of Health and Sanitation, with Treasury support, conducts costing analysis for phased expansion. Phase 1 (Years 1-2): integrate surgical management of symptomatic fibroids and gynecologic cancers. Phase 2 (Years 3-5): expand to include comprehensive gynecologic care. Partner with development agencies currently supporting FHCI implementation to secure expansion financing.

Recommendation 2: Integrate chronic gynecologic conditions into DHIS2.

National health information systems currently lack standardized data fields for fibroids and most chronic reproductive conditions. Integrate indicators enabling routine monitoring: gynecologic admissions by diagnosis, surgical procedures performed, imaging utilization, diagnostic delays, treatment costs.

Implementation pathway: DHIS2 technical team, with WHO support, develops gynecologic module parallel to existing maternal health modules. Ministry mandates reporting

through facility performance contracts. Use initial 12 months as pilot, refining indicators based on data quality and facility feedback, before full-scale rollout.

Recommendation 3: Establish social protection for chronic illness.

Current systems offer no income support during illness or recovery. Develop social protection scheme providing temporary income replacement during medically certified illness, subsidized childcare enabling women to prioritize health, transportation vouchers for specialty care access.

Implementation pathway: Pilot in Freetown using existing National Social Safety Net Program infrastructure. Partner with women's cooperatives and market associations to identify beneficiaries and distribute support. Evaluate household economic impacts after 18 months before national scale-up.

5.7.2 Health System Operations

Recommendation 4: Redistribute diagnostic equipment to gynecologic services.

Current equipment allocations concentrate ultrasound in antenatal clinics. Redistribute to ensure gynecologic departments at district and tertiary hospitals maintain functional imaging capacity with regular maintenance protocols.

Implementation pathway: Ministry of Health, with WHO and UNFPA support, conducts equipment inventory and allocation analysis. Develop redistribution plan ensuring one functional ultrasound per gynecologic service point. Establish maintenance contracts preventing prolonged equipment downtime.

Recommendation 5: Expand gynecology workforce and improve patient-provider ratios.

Current medical staffing levels results in providers seeing 40-50 patients per clinic session, precluding adequate communication. Expand workforce through accelerated training programs for

mid-level providers, task-shifting gynecologic examination and counseling to trained nurses, incentive packages attracting gynecologists to public sector.

Implementation pathway: Medical and nursing training institutions increase gynecology curriculum emphasis. Government, with Global Fund and GAVI support, finances workforce expansion tied to FHCI extension. Monitor patient-provider ratios quarterly, targeting 15-20 patients per session within three years.

Recommendation 6: Develop patient education materials and counseling protocols.

Women receive minimal explanation about fibroids. Develop standardized counseling protocols, multilingual written materials (English, Krio, Mende, Temne), visual aids explaining uterine anatomy and fibroid development, and treatment option comparison tools.

Implementation pathway: Develop through PCMH gynecology department in collaboration with FIGO and UNFPA, leveraging their global reproductive health communication expertise. Pilot in three hospitals, incorporate patient feedback, and scale nationally via Ministry's Reproductive Health Division. Training can integrate FIGO's "Respectful Maternity Care and SRHR Counseling" frameworks adapted to non-maternal gynecologic contexts.

5.7.3 Continental Frameworks

Recommendation 7: Position chronic gynecologic conditions in Agenda 2063 and Maputo Plan of Action.

Integrate indicators and commitments for fibroid care access, gynecologic cancer screening, endometriosis management, and comprehensive uterine health.

Implementation pathway: Civil society organizations and professional networks, including OAFLAD, FIGO Africa Regional Council, and Women in Global Health – Africa, advocate for explicit gynecologic health commitments in the next Maputo Plan review. Support advocacy

through AU Department of Health, Humanitarian Affairs and Social Development, with technical backing from WHO Africa and WAHO.

Recommendation 8: Support regional centers of excellence for uterine health.

Establish regional training and research centers advancing uterine health diagnosis, treatment, and research across West Africa. Centers would provide specialized clinical training, surgical capacity building, epidemiological research coordination, policy advocacy support.

Implementation pathway: West African Health Organization (WAHO), with African Development Bank support, designates three centers (Anglophone, Francophone, Lusophone regions). Centers partner with national programs providing technical assistance for FHCI-type policy expansions including gynecologic conditions.

5.8 Study Limitations and Scholarly Contribution

5.8.1 Limitations

Sample and setting: Data come from single tertiary hospital in Freetown. Prevalence estimates, cost data, and care experiences may differ in rural settings or secondary facilities. COSAR emerged from urban tertiary context; applicability to other settings requires empirical verification.

Recall and social desirability bias: Qualitative data relied on retrospective self-report. Women may under-report stigmatizing experiences or over-emphasize biomedical care seeking to align with researcher expectations. Triangulation with provider and family perspectives mitigated but did not eliminate this limitation.

Generalizability: COSAR describes patterns in Sierra Leone's specific policy and health system context. Generalization to countries with different financing mechanisms, stronger health systems, or different cultural contexts requires caution. The framework's portability depends on

structural similarities: categorical health financing, maternal-focused reproductive health policies, pronatalist cultural norms.

Causal inference: The study design establishes associations and documents temporal sequences but cannot definitively prove causation. COSAR proposes mechanisms linking policy architecture to lived experience, but these mechanisms require further empirical testing through intervention studies or longitudinal designs.

5.8.2 Scholarly Contribution

Empirical contribution: This study represents the first systematic documentation of fibroid burden in Sierra Leone, establishing 34% prevalence and documenting diagnostic delays, treatment costs, and household economic impacts. This fills a knowledge gap preventing evidence-based policy.

Theoretical contribution: COSAR provides grounded analytic framework linking policy architecture to embodied experience through six interconnected stages. The framework advances reproductive health equity scholarship by revealing specific mechanisms through which categorical health financing produces gendered suffering.

Methodological contribution: Demonstrates how mixed-methods integration (combining clinical data with household-level economic and social analysis) reveals patterns invisible in single-method studies. The integration of quantitative prevalence with qualitative mechanism revelation models approaches replicable across neglected reproductive health conditions.

Critical contribution: Challenges uncritical resilience celebration in global health discourse. By revealing how women's successful barrier navigation paradoxically enables system dysfunction, the research contributes to scholarship questioning whether "resilience" language deflects attention from structural reform imperatives.

5.9 Conclusion

Fibroids' systematic invisibility results from deliberate policy architecture rather than resource scarcity or cultural barriers. Each COSAR stage (diagnostic invisibility, clinical disregard, epistemic negotiation, financial exclusion, moral surveillance, and survival labor) represents system level design producing lived experience. The stages interconnect through feedback loops making the cycle self-perpetuating: invisibility enables disregard, disregard necessitates negotiation, exclusion requires labor, delays enable surveillance. Sierra Leone's patterns reflect broader continental dynamics: maternal health success alongside chronic condition neglect, HMIS gaps making conditions systematically invisible, equipment concentrated in tertiary centers, household catastrophic expenditure, and women's unpaid care work masking system inadequacy. COSAR provides analytical framework potentially applicable across contexts sharing similar structural conditions.

Policy recommendations target multiple levels: national reforms (FHCI expansion, HMIS integration, social protection), health system operations (equipment redistribution, workforce expansion, patient education), and continental frameworks (Agenda 2063 integration, regional centers of excellence). No single intervention suffices; COSAR's interconnected stages require interconnected responses. The path from evidence through analysis to action is clear. Chapter 4 documented what happens; Chapter 5 interpreted why it happens and how to change it. The question is no longer whether fibroids warrant policy attention. The evidence is unambiguous. The question now is whether political will, resource mobilization, and sustained commitment will translate evidence and recommendations into implemented reform. That question determines whether future Sierra Leonean women with fibroids cycle through suffering or access timely, affordable, respectful care as fundamental entitlement rather than extraordinary achievement.

CHAPTER 6: RECOMMENDATIONS AND CONCLUSION

6.1 Introduction

This chapter synthesizes findings, specifies implementation priorities, and positions implications for comprehensive reproductive health. COSAR documented six interconnected stages through which policy architecture produces lived experience. The question now is whether political will and resource mobilization will translate evidence into reform.

6.2 Synthesis of Principal Findings

6.2.1 Documenting Burden and System Failure

At 34 percent prevalence among gynecologic admissions, fibroids constitute the single most common condition affecting women seeking gynecologic care at Sierra Leone's national referral center. Women experienced diagnostic delays exceeding three months in 62 percent of cases despite repeated clinical presentations. Only 13.5 percent received ultrasound diagnosis before admission to tertiary care. Documented surgical costs of Le 2-9 million ($100-450 USD) represented six to twelve months of median household income.

These are not incidental hardships but structural outcomes of policy architecture. Sierra Leone's reproductive health system is organized around pregnancy and childbirth to the systematic exclusion of chronic gynecologic conditions affecting women throughout their reproductive lives. This pattern reveals fundamental contradictions in how reproductive health is conceptualized and financed: substantial clinical burden remains invisible in frameworks designed to monitor and finance reproductive health care. The contradiction is not accidental. It reflects deliberate policy choices about which aspects of women's reproductive lives merit recognition and resource allocation.

6.2.2 Women Arrive Early: Systems Arrive Late

Across testimonies, a single pattern repeats women present symptoms promptly, return when symptoms persist, and endure years of suffering while care systems fail to provide access. Mariama noticed unusually heavy bleeding at age 32. Over three years, she presented at four different facilities. At each, providers offered symptomatic management: iron, pain medication, herbal preparations. No one ordered imaging. By year five, when her abdomen visibly enlarged, she finally received ultrasound at a private facility her family financed through collective savings. Surgery cost Le 4.5 million, more than her annual income from market selling. Her family mobilized resources for eight months before she could afford the procedure.

Aminata's husband described their journey: "We took her to Massakah, Makeni, Four Mile, Wilul, Joriop, nothing worked until PCMH. When we suspect fibroid but cannot confirm without imaging, somebody borrowed machine for imaging. It cost Le 300,000. We couldn't afford. So, we saved for weeks."

Hawa presented at a rural hospital where the provider explained: "We refer to PCMH, but transport is expensive. Some never come back."

These are patterns documented across 89 cases and 27 qualitative participants. Women did not delay. Systems did. They did not hide from care. Care hid from them behind equipment shortages, unaffordable costs, and overwhelmed providers managing impossible patient volumes. The delays, the diagnostic odysseys, the years of suffering are not individual failures but system design producing predictable outcomes.

These finding challenges pervasive narratives positioning late presentation as patient behavior requiring health education. The evidence documents delay as infrastructure problems requiring policy reform: equipment allocation, financing architecture, workforce capacity. Education campaigns telling women to "seek care early" address the wrong problem when women

already seek care early, but systems cannot respond. The policy implication is direct: interventions must target system capacity, not patient behavior.

6.2.3 COSAR as Analytical Framework

The six COSAR stages organize how policy exclusion translates into lived experience:

Stage 1: Diagnostic Invisibility emerges from equipment concentrated in antenatal clinics, imaging costs requiring private payment, and provider adaptations to resource scarcity through symptomatic management while waiting for conditions to become palpable.

Stage 2: Clinical Disregard reflects overwhelming patient volumes (40-50 per clinic session) that preclude adequate communication, creating mutual frustration where women feel dismissed, and providers feel overwhelmed.

Stage 3: Epistemic Negotiation follows biomedical opacity as women pragmatically construct understanding through family knowledge, community networks, spiritual frameworks, and traditional healing when biomedical systems provide diagnosis without explanation.

Stage 4: Financial Exclusion results directly from FHCI's categorical design excluding chronic gynecologic conditions, rendering treatment entirely out-of-pocket and necessitating asset liquidation, informal borrowing, and prolonged saving.

Stage 5: Moral Surveillance intensifies when diagnostic delays extend unexplained infertility, creating temporal and epistemic space for stigmatizing interpretations of childlessness as personal or spiritual failing.

Stage 6: Survival Labor describes women's continued income generation through severe illness because no social protection exists, household survival depends on their earnings, and financial exclusion requires self-financing of catastrophic treatment costs.

The stages interconnect through feedback loops: invisibility enables disregard, disregard necessitates negotiation, exclusion requires labor, delays enable surveillance. These interconnections explain why single interventions fail. Adding ultrasound machines without FHCI expansion means women still cannot afford imaging. Subsidizing surgery without workforce expansion means women still experience rushed communication. Providing education about fibroids without social protection means women still must work through illness.

COSAR demonstrates that sustainable change requires multi-stage intervention addressing policy architecture, infrastructure allocation, workforce capacity, financial protection, stigma reduction, and social security simultaneously. This finding has direct implications for intervention design: programs targeting single barriers will achieve limited impact because other barriers regenerate the cycle.

6.3 Implementation Priorities

Chapter 5 detailed eight recommendations across national policy, health system operations, and continental frameworks. This section specifies five immediate priorities for Years 1-3 that would interrupt the cycle at multiple points simultaneously.

6.3.1 National Policy Reform (Year 1)

Priority 1: Expand FHCI to include fibroid surgical management

Immediate action: Ministry of Health and Sanitation, with Treasury support, conducts costing analysis for phased FHCI expansion. Phase 1 integrates surgical management of symptomatic fibroids requiring myomectomy or hysterectomy. This addresses the most severe cases creating catastrophic household expenditure while establishing precedent for chronic gynecologic condition inclusion.

Timeline: Costing complete Q2 2026, policy reform Q3 2026, implementation Q4 2026.

Lead: Ministry of Health and Sanitation. Partners: WHO, UNFPA, World Bank.

Rationale: FHCI expansion directly addresses Stage 4 (Financial Exclusion) while reducing pressure on Stage 6 (Survival Labor). Women who can access subsidized surgery will not need to work through illness to save for treatment or liquidate productive assets. This intervention interrupts two cycle stages simultaneously.

Priority 2: Integrate fibroids into DHIS2

Immediate action: DHIS2 technical team, with WHO support, develops gynecologic module capturing gynecologic admissions by diagnosis, surgical procedures performed, imaging utilization, diagnostic delays, treatment costs.

Timeline: Module development Q1-Q2 2026, pilot Q3-Q4 2026, national rollout Q1 2027.

Lead: National DHIS2 team. Partners: WHO, Ministry of Health and Sanitation.

Rationale: Data visibility creates policy accountability. When fibroids become visible in national monitoring systems, the condition enters policy discourse. This enables resource allocation tracking, outcome monitoring, and evidence-based advocacy for sustained financing.

6.3.2 Health System Operations (Years 1-3)

Priority 3: Redistribute diagnostic equipment

Immediate action: Ministry of Health, with WHO and UNFPA support, conducts equipment inventory and allocation analysis. Develop redistribution plan ensuring gynecologic departments at district and tertiary hospitals maintain functional imaging capacity with regular maintenance protocols.

Timeline: Inventory complete Q1 2026, redistribution plan Q2 2026, implementation Q3 2026-Q2 2027.

Lead: Ministry of Health. Partners: WHO, UNFPA.

Rationale: Equipment redistribution addresses Stage 1 (Diagnostic Invisibility) directly. When gynecologic services have reliable imaging access, diagnostic delays decrease. This reduces the temporal gap during which Stage 5 (Moral Surveillance) intensifies and Stage 3 (Epistemic Negotiation) becomes necessary.

Priority 4: Develop patient education materials

Immediate action: PCMH gynecology department, in collaboration with FIGO and UNFPA, develops standardized counseling protocols and multilingual materials (English, Krio, Mende, Temne) explaining fibroid causes, symptoms, treatment options, and expected recovery.

Timeline: Materials development Q1-Q2 2026, pilot testing Q3 2026, national scale Q4 2026-Q2 2027.

Lead: PCMH gynecology department. Partners: FIGO, UNFPA.

Rationale: Patient education addresses Stage 2 (Clinical Disregard) by supplementing overwhelmed providers. When women receive written materials explaining their condition, the epistemic gap requiring Stage 3 (Epistemic Negotiation) narrows. Quality information reduces reliance on alternative explanatory frameworks and challenges Stage 5 (Moral Surveillance) by providing biomedical explanations for infertility.

6.3.3 Continental Advocacy (Years 1-5)

Priority 5: Position chronic gynecologic conditions in Maputo Plan review

Immediate action: Civil society organizations (OAFLAD, FIGO Africa Regional Council, Women in Global Health) advocate for explicit gynecologic health commitments in next Maputo Plan of Action review, including indicators for fibroid care access, gynecologic cancer screening, and comprehensive uterine health.

Timeline: Advocacy initiation Q1 2026, technical briefs Q2-Q3 2026, Maputo Plan review 2027.

Lead: Civil society networks. Partners: AU Department of Health, WHO Africa, WAHO.

Rationale: Continental frameworks shape national priorities. When Maputo Plan includes gynecologic health indicators, countries face accountability for progress. This creates political incentives for policy reform and resource allocation, multiplying impact beyond Sierra Leone.

6.3.4 Highest-Leverage Intervention

If one reform were to be prioritized for its potential to enable broader progress, this analysis identifies DHIS2 integration: adding chronic gynecologic conditions to the national health information system.

The reasoning is strategic. Expanding the FHCI would address financial barriers but requires sustained budget allocation and faces political constraints. Redistributing diagnostic equipment improves clinical capacity but does not resolve financing or data gaps. Workforce expansion requires long-term investment. By contrast, DHIS2 integration is technically feasible, financially modest and administratively manageable. Software configuration, indicator definition and facility-level training do not require major capital expenditure.

The effects are system wide. Visibility creates accountability: conditions that appear in official statistics enter policy discussions. Annual health sector reviews must address indicators reported through HMIS, whereas conditions excluded from routine reporting receive limited attention. Once fibroids appear in district dashboards, policymakers must respond to documented burden.

Data enables advocacy. Civil society organizations, researchers and professional associations can reference official statistics rather than isolated studies. This thesis documents 34

percent prevalence at one facility during one period; national HMIS data would provide continuous evidence across districts and facilities, carrying a level of legitimacy essential for policy debate.

Measurement precedes financing. Donors and domestic financing mechanisms allocate resources to conditions they can monitor. Global financing mechanisms commonly require burden or coverage indicators to justify investment. Integrating fibroids into DHIS2 creates the measurement infrastructure on which future financing decisions depend.

Technical adjustments also create political space. Introducing data fields often encounters less resistance than proposing new expenditures. Data collection appears administrative even when its implications are substantive. Once reporting begins, the question shifts from whether fibroids should be counted to what should be done about documented need.

FHCI expansion remains essential for financial protection, and equipment redistribution remains essential for diagnostic access. The argument is sequencing: DHIS2 integration creates the conditions that make these subsequent reforms more feasible by ensuring that chronic gynecologic conditions are visible within national health planning.

6.4 Study Contributions

This research makes four contributions to reproductive health scholarship and health system analysis.

Empirical contribution: This study is the first systematic documentation of fibroid burden in Sierra Leone. It establishes a 34 percent prevalence among gynecologic admissions and documents diagnostic delays, treatment costs and the household economic strategies that women mobilize. These findings fill critical knowledge gaps that have limited policy design and demonstrate that conditions excluded from national data systems nonetheless generate substantial burden.

Theoretical contribution: COSAR provides an analytic framework linking health system architecture to embodied experience. Its six stages identify mechanisms through which financing, service configuration and institutional priorities produce diagnostic delays, economic strain, social interpretation and survival labor. The framework shows how individual adaptation can absorb system failure, allowing gaps to persist.

Methodological contribution: The study demonstrates the value of integrating clinical documentation with household-level economic and social analysis. This approach reveals patterns that single-method studies cannot capture and offers a model applicable to other neglected chronic reproductive conditions.

Policy contribution: The research specifies reforms required to align reproductive health financing and service delivery with observed burden. It identifies how current arrangements produce documented outcomes and outlines feasible changes across financing, data systems and service organization, with clear institutional responsibilities.

6.5 Reimagining Comprehensive Reproductive Health

Findings from this study show that reproductive health frameworks prioritize pregnancy while excluding chronic gynecologic conditions. FHCI's maternal health gains demonstrate what becomes possible when financing and monitoring align around a defined priority. The same system capacities could support chronic conditions affecting women across the reproductive life course.

Three shifts are required.

First, reproductive health must be understood across the full reproductive lifecycle, not only during pregnancy. Conditions affecting reproductive organs merit care and financing whether reproduction is occurring or not.

Second, resilience must be interpreted carefully. Women's ability to navigate system gaps reflects agency, but it also signals structural pressures that should not depend on individual effort.

Third, invisibility follows system design. Chronic gynecologic conditions remain outside data systems, financing arrangements and service packages because reproductive health has long been equated with maternal health. FHCI's maternal health success shows that when a condition is counted and financed, outcomes change. The same mechanisms could apply to chronic conditions.

6.6 Questions for Future Investigation

This research generates questions requiring further investigation:

Does COSAR apply to other neglected reproductive health conditions across sub–Saharan Africa? The framework emerged from fibroids in Sierra Leone but may illuminate dynamics affecting endometriosis, pelvic inflammatory disease, and gynecologic cancers across contexts sharing similar structural conditions.

Do multistage interventions produce better outcomes than single point reforms? COSAR suggests that interventions targeting multiple cycle stages simultaneously would achieve greater impact than reforms addressing single barriers. Testing this hypothesis requires implementation research comparing different intervention strategies.

How do women's survival labor and household economic strategies vary across different social strata? This research documented patterns among women seeking care at tertiary facilities. Investigation of how women with different educational backgrounds, economic resources, and social networks navigate barriers would reveal whether COSAR operates uniformly or varies by social position.

What policy mechanisms successfully integrated chronic conditions into categorical health financing schemes? Comparative analysis of countries that expanded maternal health financing to include chronic gynecologic conditions would identify successful reform pathways, implementation challenges, and enabling factors.

How does data invisibility in health information systems affect resource allocation decisions? Investigation of policymaking processes in contexts where HMIS lacks chronic condition data would illuminate how invisibility shapes priority setting and budget allocation.

6.7 Conclusion: From Evidence to Imperative

Fibroids account for 34 percent of gynecologic admissions at PCMH, making them the most common condition in this setting. Yet they remain outside national data systems, financing arrangements and policy discussions. This absence reflects the definitions of reproductive health embedded in the Free Health Care Initiative, which centers pregnancy rather than the full reproductive life course. Maternal health gains show that when a condition is counted, financed and monitored, services improve and outcomes change.

COSAR shows how these structural arrangements shape the lives of women. Delays persist despite repeated efforts to seek care. Households carry the full cost of treatment through borrowing, saving and selling assets. Women continue to work during heavy bleeding and pain. Infertility becomes a private burden with public consequences. These patterns are not isolated events. They reflect how systems define priority, allocate resources and organize protection.

The evidence documents gaps in design, but it also documents the knowledge women hold. Women in this study understood where to seek imaging, which providers offered explanation, how to negotiate support within households and how to sustain daily life while managing chronic

illness. Their experience is a source of insight for redesign. Systems that aim to protect women must engage women as partners in shaping the reforms that follow.

The transition from evidence to action requires both technical and political work. Technical changes address data systems, financing and service delivery. Political work creates the conditions for adoption and implementation. Evidence alone cannot shift systems. It must be taken up by those who guide health planning, financing and service provision. This thesis contributes to that process by documenting burden, identifying mechanisms and clarifying the political economy of reform.

The implications extend beyond Sierra Leone. Chronic gynecologic conditions remain peripheral across many African health systems organized around maternal metrics. COSAR offers a framework for understanding how conditions that fall outside existing categories become invisible, not through oversight but through the accumulated weight of institutional arrangements that determine what is measured, what is financed, and whose suffering is recognized. The burden documented here emerges from pathology, but its persistence emerges from policy.

Whether future women move through similar cycles will depend on how reproductive health systems evolve. The women whose experiences informed this work reveal both the costs of the present design and the possibilities that more responsive systems could create. Naming the wound is the first step. Rewriting the record requires actors willing to shift the systems – social, clinical, political – to reflect the realities women live, not only the outcomes systems have been designed to measure.

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APPENDICES

Appendix A: Interview Guides

In-Depth Interview Guide for Women with Fibroids

Opening:

- Thank you for agreeing to share your story
- Everything you say is confidential
- You can skip any question or stop anytime
- This will help other women facing similar challenges

1. Beginning the Journey
    - When did you first notice something was different with your body?
    - What were those early signs?
    - How did you explain them to yourself at first?
2. Seeking Understanding
    - Who did you first talk to about your symptoms?
    - Where did you first go for help?
    - What were you told?
    - How many places did you visit before getting answers?
3. The Diagnosis
    - How did you finally learn you had fibroids?
    - What was that moment like for you?

- What questions did you have?
- What information were you given?

4. Making Decisions
    - What options were presented to you?
    - How did you decide what to do?
    - Who influenced your decisions?
    - What barriers did you face?
5. Financial Journey
    - How did you manage the costs?
    - What did you have to sacrifice?
    - Who helped you financially?
    - How did money affect your choices?
6. Social Experiences
    - How did others react to your condition?
    - What did people say?
    - How did it affect your relationships?
    - Where did you find support?
7. Treatment Experiences
    - Can you walk me through your treatment?

- How were you treated by healthcare workers?
- What was recovery like?
- What follow-up care did you receive?

8. Reflections
    - Looking back, what do you wish you had known?
    - What would you tell other women?
    - What needs to change in the system?
    - How has this experience changed you?

Consent Forms

Informed Consent Form

Study Title: Uterine Fibroid Experiences in Sierra Leone: A Mixed-Methods Study

Principal Investigator: Fatou Wurie, DrPH Candidate

You are being invited to participate in a research study about women's experiences with uterine fibroids in Sierra Leone. Please take your time to read this information and ask questions.

Why is this study being done? We want to understand how women experience fibroids, how they seek care, and what challenges they face. This will help improve healthcare for women with fibroids.

What will happen if I participate?

- You will be interviewed for 45-90 minutes
- We will ask about your experiences with fibroids

- The interview will be audio-recorded if you agree
- You may be contacted for a follow-up discussion

Are there risks?

- You might feel emotional discussing your experiences
- We have counseling support available if needed
- Your identity will be kept confidential

Are there benefits?

- No direct benefit to you
- Your story will help other women
- Findings will be shared with policymakers

Is participation voluntary?

- Yes, completely voluntary
- You can skip questions
- You can stop anytime
- This won't affect your healthcare

How will my information be protected?

- Your name won't be used
- Recordings will be destroyed after transcription
- Only the research team will see your information

- Results will be reported in summary form

Compensation:

- 50,000 Leones for transport
- Refreshments provided
- No other payment

Questions? Contact: [Phone number] Ethics Committee: [Contact details]

Consent: □ I agree to participate □ I agree to audio recording □ I want a summary of results

Participant Name: _____ Signature/Thumbprint: _____ Date: _____

Witness Name: _____ Signature: _____

Supplementary Tables

Table S1: Comparison of Fibroid Prevalence Studies in West Africa

Country	Year	Setting	Prevalence	Method	N
Sierra Leone	2024	Hospital	33.6%	Chart review	262
Nigeria	2018	Community	24.3%	Ultrasound	512
Ghana	2019	Hospital	28.7%	Mixed	389

Senegal	2020	Urban	31.2%	Clinical	298
Liberia	2017	Hospital	35.1%	Chart review	187

Table S2: Economic Impact Calculations

Impact Category	Annual Cost (Leones)	USD Equivalent
Direct medical costs	56.7 billion	$2.8 million
Lost productivity	125.4 billion	$6.3 million
Asset depletion	89.2 billion	$4.5 million
Informal care labor	47.8 billion	$2.4 million
Total economic impact	319.1 billion	$16 million

*Based on 33.6% prevalence and average costs document

Glossary of Terms

Biomedical Terms:

Fibroid (Leiomyoma): Benign tumor of uterine smooth muscle

Hysterectomy: Surgical removal of uterus

Myomectomy: Surgical removal of fibroids preserving uterus

Nulliparous: Never having given birth

Local Terms (Krio/English):

Masorr poyin yonkor: "Hidden enemy" - local term for fibroids

Rise and fall: Sensation of internal movement from fibroids

Bad blood clot: Accumulated menstrual blood/clots

Osusu: Rotating savings and credit association