CHARACTERISTICS, OUTCOMES AND EXPERIENCES OF PREGNANT WOMEN WITH CARDIAC DISEASE AT JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL IN KISUMU, KENYA

BY

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DECLARATION

This thesis is the result of original work, completed under the guidance of supervisors. Further, this project has not been submitted for any academic award or degree program elsewhere.

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DEDICATION

To my sister, Joy Otadoh-Morgan, I celebrate your strength, resilience, and boldness as you navigate this life. Thank you for inspiring this project.

ABSTRACT

Cardiac disease in pregnancy is a cause of indirect maternal morbidity and death worldwide. It places an excessive burden on low- and middle-income regions. In Western Kenya, there is a high prevalence of clinically significant heart lesions. However, many women remain undiagnosed until decompensation occurs. At JOOTRH, a lack of integrated regional data on disease burden, sociodemographic profiles, and patients' lived experiences hinders the development of evidence-based cardio-obstetric protocols. The broad objective of this study was to investigate the characteristics, outcomes, and lived experiences of pregnant women with cardiac disease managed at JOOTRH between 2022 and 2026. Specifically, the study aimed to describe the sociodemographic and clinical profiles and determine maternal, cardiac, and neonatal outcomes. Concurrently, the study explored the biological, psychological, and social experiences of these patients. The research adopted a convergent parallel mixed-methods design to understand the disease burden. A retrospective, analytical cross-sectional review of 27 patient files was conducted. The files had been identified through census sampling. Simultaneously, a cross-sectional phenomenological design was used, comprising nine in-depth interviews selected through purposive sampling. Quantitative data comprising patients' characteristics (sociodemographic factors, obstetric history, and clinical features) and outcomes (cardiac, obstetric, and foetal) were extracted using a pre-tested data abstraction form and analysed in R. Fisher's exact tests were used to assess bivariate associations between categorical clinical markers and binary materno-foetal outcomes. Firth's penalised logistic regression was employed for multivariable analysis to calculate stable, adjusted odds ratios despite small-sample data separation. The quantitative analysis revealed rheumatic heart disease as the main cause of morbidity. The composite cardio-obstetric Major Adverse Cardiovascular Event rate was 63.0%, driven predominantly by heart failure and pulmonary oedema, with a maternal mortality rate of 14.8%. Bivariate and multivariable analyses identified New York Heart Association functional class III/IV at entry as the sole significant adjusted predictor of MACE. Qualitative data were managed using NVivo. The narratives contextualised the results by describing biological experiences, including "diagnostic odysseys", symptom normalisation, and traumatic peripartum crises. The Psychological Experiences included fear of death, ambivalence about pregnancy termination, and maladaptive coping strategies. The Socio-Structural Experience included stigma, financial stress, and institutional failures. The study determined that poor outcomes are not solely attributable to the biological severity of cardiac lesions but result from cumulative failures in systemic recognition and access to health services. It is recommended that JOOTRH develop and institutionalise cardio-obstetric protocols and establish a Pregnancy Heart Team. Additionally, early first-trimester NYHA functional status screening, shared decision-making, and a maternal health financial subsidy should be implemented to reduce barriers to specialist care.

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LIST OF ABBREVIATIONS

ANC - Antenatal Care

BP- Blood Pressure

CARPREG - Cardiac Disease in Pregnancy Study I and II

CHD- congenital heart disease

CS - Caesarean Section

GOPC - Gynaecological (and Obstetrics) Outpatient Clinic

HIC - High-income Countries

IHD- ischemic heart disease

JOOTRH - Jaramogi Oginga Odinga Teaching and Referral Hospital

LBW- Low Birth Weight

LMIC - Low-and-middle income Countries

MOPC - Medical Outpatient Clinic

MTRH - Moi Teaching and Referral Hospital

mWHO score - Modified World Health Organisation Score

NCD - Non-communicable Diseases

NVIVO - Qualitative Data Analysis Software

NYHA - New York Heart Association Functional Classification

OBSGYN- Obstetrician and Gynaecologist

PII- Personally Identifiable Information

PPCM - Postpartum Cardiomyopathy

RHD- Rheumatic Heart Disease

ROPAC- Registry of Pregnancy and Cardiac Disease

SVD - Spontaneous Vertex Delivery

WHO - World Health Organisation

OPERATIONAL DEFINITION OF TERMS

Adverse Neonatal Outcome: A composite of perinatal mortality, LBW or preterm birth before 34 weeks

Adverse Outcomes: Any negative, suboptimal, or harmful result or effect from cardiac disease during pregnancy; a detrimental biological change in the cardiac disease patient that begins in pregnancy; the occurrence of a cardiac, maternal, or foetal event.

Antenatal period: The entire duration from conception to the onset of labour.

Cardiac condition: The specific type of heart disease or lesion diagnosed in the woman, e.g., RHD, CHD

Cardiac disease: Any diagnosed (or objectively confirmed) structural or functional abnormality of the heart that impairs its ability to pump blood effectively. This includes congenital, genetic, and acquired disorders but excludes hypertensive disease. When radiographic or sonographic evidence is unavailable, there must be objective documentation from a physician's conclusion based on established criteria, such as the Modified Duke Criteria, Jones Criteria, or Framingham Criteria, among others.

Characteristics: This includes the unique social and biodemographic aspects of patients, as well as clinical features and obstetric history.

Clinically unstable patient: A woman with a cardiac condition exhibiting significant deviations from normal vital signs, an acute worsening of cardiac symptoms, or requiring immediate intervention to stabilise her.

Complication: A secondary disease or condition that worsens the cardiac disease during pregnancy.

Functional Status: The woman's ability to perform daily responsibilities is affected by her cardiac condition and pregnancy, particularly as classified by the New York Heart Association.

Incomplete Records: Any patient file or registry entry where the critical data points required to meet the study objectives are missing, illegible, or unrecorded. Specifically: missing core clinical data (missing diagnosis, missing severity indicators- NYHA); or missing outcome data (maternal and neonatal outcomes); and structural and clerical incompleteness (missing files, illegibility, inconsistent data that is fundamentally contradictory).

Intrapartum: The period from the beginning of true labour to the delivery of the foetus, baby, and expulsion of the placenta.

Cardio-obstetric Major Adverse Cardiovascular Event (MACE): A composite of maternal death, cardiac arrest, heart failure or arrhythmia requiring treatment. This aligns with the cardio-obstetrics population where landmark cardio-obstetric risk models (e.g., CARPREG I, CARPREG II, and the mWHO classification) formally include heart failure, severe arrhythmias, stroke, and maternal death in their composite primary outcomes. It differs from the standard cardiology definition, in which the "3-point MACE" typically refers to non-fatal myocardial infarction (heart attack), non-fatal stroke, and cardiovascular death.

Outcomes: The clinical, health, or biological end-states and events occurring in a woman or her foetus/neonate during pregnancy, childbirth, or up to 42 days post-delivery (or 28 days for the neonate), resulting from the physiological impact or management of cardiac disease. In this study, outcomes were categorised into cardiac, obstetric and foetal/neonatal events.

Post-delivery: The period following childbirth until contact with the researcher.

Pregnancy complications: Any adverse outcomes or events during the pregnancy directly attributable to the cardiac disease

Pregnancy experiences: Encompass the biological, psychological, and socio-structural aspects of pregnancy in the context of cardiac disease.

Pregnancy: The condition of carrying a developing embryo or foetus in the uterus from conception to delivery, regardless of gestation length or birth outcome.

VARIABLES

Acute Heart Failure: New-onset or worsening of symptoms (dyspnoea, orthopnoea) and signs (oedema, rhonchi) of heart failure requiring intravenous therapy or intensification of oral therapy, or progressively worsening (NYHA) functional status.

Age: The cumulative years the woman has lived, rounded up, at the time of her first encounter at JOOTRH.

Arrhythmia: This is part of the Major Adverse Cardiovascular Events (MACE) and is defined as any abnormal heart rhythm that requires medical treatment. It includes new onset or worsening atrial fibrillation, supraventricular tachycardia (SVT), or ventricular arrhythmias requiring pharmacological intervention and cardioversion.

Biological experiences: This refers to the physical and health-related aspects experienced by women with cardiac disease during pregnancy, including changes in bodily functions resulting from the condition.

Birth Weight (Low Birth Weight): This was defined as a birth weight of < or = 2,500g, at whatever gestational age at delivery.

Cardiac Outcomes: adverse cardiovascular events occurring as a direct or indirect complication of cardiac disease during pregnancy or the puerperium. In this study, this was evaluated as a composite occurrence of acute heart failure/pulmonary oedema, thromboembolic events (deep vein thrombosis, pulmonary embolism, stroke), arrhythmias requiring pharmacological or electronic intervention, and maternal cardiac arrest or mortality.

Comorbidities: The simultaneous presence of another disease or medical condition besides cardiac disease

Foetal and Neonatal Outcomes: The status of the conceptus or neonate from delivery, regardless of gestational age at delivery, through the first 28 days of life. In this study, these include birth weight (low birth weight defined as < 2500 g) and vital status at birth/early life (live birth, stillbirth, miscarriage/abortion, or neonatal death within 28 days).

ICU/HDU Admission: Escalation to a critical care unit for organ support (e.g., mechanical ventilation, inotropic support) or invasive monitoring for more than 24 hours.

Maternal Mortality: When a woman dies while pregnant or within 42 days of termination of pregnancy. This is regardless of the duration and site of pregnancy. The death could be from any cause related to or provoked by the pregnancy and/or cardiac disease or its management.

Neonatal Death: When a live-born infant dies within the first 28 completed days of life

New York Heart Association (NYHA) Functional Classification: A standardised clinical grading system used to classify the severity of cardiac disease based on the patient's physical activity limitations and symptom onset at first hospital contact

NYHA Class I: Asymptomatic; ordinary physical activity does not cause undue fatigue, palpitations or dyspnoea

NYHA Class II: Mild limitation of physical activity; comfortable at rest, but ordinary physical activity results in fatigue, palpitations or dyspnoea.

NYHA Class III: Marked limitation of physical activity; comfortable at rest, but less than ordinary physical activity causes fatigue, palpitations or dyspnoea.

NYHA Class IV: Inability to carry out any physical activity without discomfort; symptoms of cardiac insufficiency or heart failure are present even at rest.

Obstetric Outcomes: The maternal health events that happened during pregnancy, childbirth, or within 42 days of delivery as a result of the management or physiological impact of cardiac disease. In this study, these include the mode of delivery (Spontaneous Vertex Delivery, Assisted Vaginal Delivery or caesarean section), adverse maternal events (maternal mortality, ICU/HDU admission, referral to a higher-level specialised facility), and obstetric

complications (pre-eclampsia/eclampsia, antepartum haemorrhage, postpartum haemorrhage and preterm labour).

Perinatal Mortality: This includes stillbirth (a baby born with no signs of life at or after 28 weeks' gestation), neonatal death (the death of a live-born infant before or at 28 completed days of life), or loss of products of conception before viability (abortion).

Preterm Birth: All live births before 37 completed weeks.

Psychological experiences: This involves the specific mental and emotional processes related to cardiac disease during pregnancy, such as anxiety, fear, depression, and stigma. It also considers the woman's coping strategies and psychological health.

Referral to a Specialised Facility: This was defined as the transfer of a patient to a higher-level facility for management that exceeds JOOTRH's current capacity

Social and structural experiences: This covers the social interactions and relationships that pregnant women with cardiac disease encounter. It examined the external factors that affect a woman's health and care journey, including barriers to optimal care, ranging from community-level issues to hospital-level challenges, as well as economic factors and social support from partners or family.

Stillbirth: A baby born with no signs of life at or after 28weeks' gestation

Thromboembolic Events: Documented deep vein thrombosis (DVT), pulmonary embolism (PE), or systemic embolisation such as stroke and myocardial infarction.

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND

Cardiac diseases, whether congenital or acquired, are a group of disorders that directly affect the structure of the heart and, consequently, impair its function. Among women with this condition, pregnancy presents additional risks for severe complications and potential mortality (Diao et al., 2011; Miranda-Silva et al., 2021; Yang et al., 2024). The cardiovascular system experiences significant adaptation during pregnancy to support the developing foetus (Costantine, 2014). These changes may worsen existing cardiac conditions, increasing the risk of complications for women. Additionally, undiagnosed or subclinical heart disease may develop during pregnancy (Elkayam et al., 2016a). Despite the physiological risks, most cardiac patients, when properly managed, can experience relatively good outcomes during pregnancy, delivery, and the postpartum period (Elkayam et al., 2016b, 2016a).

Maternal and foetal morbidity and mortality from cardiac disease during pregnancy place a disproportionately high burden on LMIC (Diao et al., 2011; Lumsden et al., 2020; Paulo et al., 2023; Snelgrove et al., 2021; Wiradnyana et al., 2025). Recent studies in Western Kenya show a notably higher prevalence of cardiac disease among pregnant women than previously estimated (Poli et al., 2020; Snelgrove et al., 2021). Another study of women receiving routine antenatal care in the same region found that 21.6 out of every 1,000 women had a clinically significant cardiac lesion (Snelgrove et al., 2021). Information from a national referral hospital in Kenya shows that a pregnant woman with cardiac disease is ten times more likely to die during pregnancy than a woman without. The same study reported a 12.2% maternal death rate, with RHD accounting for 73% of all deaths (Diao et al., 2011; Lumsden et al., 2020). Although there is no specific data on the burden of cardiac disease in pregnancy at JOOTRH, the broader public health challenge of high maternal mortality is well documented at the facility, with a

reported rate of 630 deaths per 100,000 live births in 2019. While the facility has recently implemented measures to reduce these figures by 50%, specific, updated 2024-2025 numerical, audited rates for JOOTRH specifically are yet to be published. In the regional database, Kisumu records 343/100,000 live births as of early 2024.

In line with efforts to reduce maternal mortality, this study focused on cardiac disease in pregnancy. The difficulty of managing these high-risk pregnancies requires a specialised, multidisciplinary approach, often referred to as a "Pregnancy Heart Team" (Easter et al., 2020). This team-based care model has been shown to improve outcomes. It ensures seamless cooperation between cardiologists, obstetricians, anesthesiologists, and other specialists (Ernst et al., 2024; Mayer et al., 2018). Beyond the hospital, an all-encompassing approach is needed that addresses health disparities at every level. It stretches from the community to the hospital and is guided by health administrators (Elkayam et al., 2016a; Yang et al., 2024). Women with cardiac disease often encounter major barriers to care (Chang et al., 2018; Dawson et al., 2018; Hutchens et al., 2022b, 2022c, 2022a).

To define the regional burden, it is important to identify the characteristics and outcomes of pregnant patients with cardiac disease in the region. To demystify the sociodemographic confounders, narratives from cardiac patients should be examined and documented. This information would be valuable in strengthening current knowledge. It will help achieve better patient-centred solutions and more favourable outcomes.

1.2 STATEMENT OF THE PROBLEM

Cardiac disease in pregnancy has been recognised as a leading cause of non-obstetric maternal morbidity and mortality in the world (Elkayam et al., 2016a). Maternal deaths from direct obstetric causes like haemorrhage have declined. However, the proportion of deaths caused by indirect medical conditions, for example, heart disease, continues to rise. These conditions need

complex, multidisciplinary management that is often difficult to standardise among different resource settings (Yang et al., 2024).

In SSA, the burden is characterised by a different spectrum from that of the developed world (Diao et al., 2011; Yang et al., 2024). Pregnant women with cardiac disease face a double burden. There is the physiological strain of pregnancy on a diseased heart. This is in addition to significant system-wide barriers to care. In Kenya, the Ministry of Health has been working to reduce maternal mortality. There is, however, still an increasing trend of women presenting with advanced medical comorbidities during delivery (Lumsden et al., 2020). Specifically, routine antenatal screenings in Western Kenya have revealed a high prevalence of clinically significant cardiac lesions(Snelgrove et al., 2021). Many of these women, unfortunately, remain undiagnosed until they reach a state of critical decompensation during pregnancy (Lumsden et al., 2020; Poli et al., 2020; Snelgrove et al., 2021).

At JOOTRH, the primary referral hub for the Lake Victoria Basin, there is a critical lack of documented evidence on the disease burden and the specific sociodemographic and clinical profiles of this patient population. Risk stratification models that exist are largely derived from Western populations (Silversides et al., 2018; Van Hagen et al., 2016). They have however, shown limited usefulness in Western Kenya (Lumsden et al., 2020; Poli et al., 2020). Currently, there is a considerable scarcity of published data in Western Kenya that integrates clinical outcomes, sociodemographic characteristics, and the lived experiences of these women. Without region-specific data, the facility lacks a baseline to establish evidence-based, culturally sensitive cardio-obstetric protocols.

The persistence of this information gap potentially leads to several consequences. Clinically, it results in inadequate risk stratification and reactive rather than proactive management. This leads to preventable maternal and foetal complications. Socially and structurally, the lack of knowledge about patients' experiences means that barriers to care remain unattended. This

leads to poor healthcare-seeking behaviour and unsatisfactory patient journeys. This study assessed and defined the burden using documented facts and narratives and provided region-specific data. This information will aid in improving care practices among medical practitioners, developing protocols, and planning maternal health programs by policymakers.

1.3 JUSTIFICATION

There is an urgent need to assess and define the burden of women living in low-income countries who are in their reproductive years and navigating NCDs (Poli et al., 2020). Cardiac disease during pregnancy represents this vulnerable population that faces considerable risks throughout their obstetric journey (Chang et al., 2018; Diao et al., 2011; Soma-Pillay et al., 2018). By examining the experiences, characteristics, and outcomes of cardiac disease during pregnancy at JOOTRH, this study contributes to a field yet to be fully explored.

The study was planned to define the local burden by generating baseline data for JOOTRH to support the development of a patient-centred, region-specific approach to care. Additionally, the study will provide actionable insights to enhance community education, strengthen specialised support systems, and promote self-advocacy among high-risk pregnant women.

Importantly, this study provides essential data needed to transition from generalised global management strategies to a data-driven, patient-centred approach that addresses the specific needs of women in the region.

1.4 SIGNIFICANCE OF THE STUDY

This study investigates a high-risk, low-prevalence condition, which is recognised as a leading cause of non-obstetric maternal mortality globally, placing a disproportionately high burden on low- and middle-income countries. The findings may contribute to a scarce pool of region-specific data on cardiac disease in pregnancy, thereby addressing a gap in the literature. Through its mixed-methods approach, the study emphasises the importance of triangulation in identifying and understanding the disease burden. It may generate a valuable database to guide

healthcare practitioners and policymakers in developing evidence-based guidelines and maternal health programs, policies, and care protocols. Stakeholders, including high-risk pregnant women, clinicians in reproductive health and cardiology, and hospital administrators, will benefit from improved care practices and specialised support systems.

Additionally, using cardiac disease as a representative example, this study will provide insights into the specialised care needed for a vulnerable population- women navigating reproductive health challenges in the backdrop of various morbidities. Ultimately, beyond strengthening health systems, the findings aim to empower women with cardiac and other chronic diseases to make informed pregnancy choices by creating a platform for better education and self-advocacy. In conclusion, this study supports the global agenda towards achieving Sustainable Development Goal 3.

1.5 OBJECTIVES

1.5.1 BROAD OBJECTIVE

To investigate the characteristics, cardiac, obstetric and foetal outcomes, and the experiences of pregnant women with cardiac disease at JOOTRH from 2022 to 2026

1.5.2 SPECIFIC OBJECTIVES

1. To describe the sociodemographic and clinical profiles of pregnant women with cardiac disease
2. To assess the cardiac, obstetric and foetal outcomes of women with cardiac disease
3. To explore the lived experiences of pregnant women with cardiac disease

1.6 RESEARCH QUESTIONS

1) What sociodemographic and clinical characteristics define pregnant women with cardiac disease?
2) What are the cardiac, obstetric and foetal outcomes of women with cardiac disease?
3) What are the lived experiences of pregnant women with cardiac disease?

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Pregnancy is a life-changing experience for all women. It, however, creates unique challenges for women with cardiac disease. These women have a higher risk of severe complications, poor foetal outcomes, and even potential death. They also face various biological, psychological, and social challenges (Diao et al., 2011; Morton, 2021; Nakamura et al., 2018; Owens et al., 2018; Paulo et al., 2023; Wiradnyana et al., 2025).

The intersection of cardiac disease and pregnancy was relatively rare in the past. Many women with significant heart conditions did not survive to childbearing age. Over the last several decades, there have been advances in paediatric cardiology and cardiac surgery. These have significantly raised survival rates. There has consequently been a growing number of women with complex cardiac conditions, particularly CHD, who are now reaching reproductive age. This has led to a global increase in the prevalence of heart disease during pregnancy (Nakamura et al., 2018).

This increase is characterised by a transition in the types of cardiac diseases encountered globally. In HIC, there has been a shift from infectious causes to NCD and lifestyle-related conditions, with CHD and IHD (driven by advanced maternal age) now predominating. In LMIC regions like SSA, the transition is incomplete. NCDs are rising. However, infectious diseases, specifically RHD, remain the primary cause of maternal cardiac morbidity. This double burden creates a challenging clinical landscape. Health workers must manage both traditional infectious diseases and emerging NCD risks (Chang et al., 2018, 2020; Yang et al., 2024).

As cardiac disease became a leading indirect cause of maternal death, the need for standardised tools to predict adverse events led to the development of various risk stratification models.

Tools such as the CARPREG study and the mWHO classification were designed to categorise women based on the severity of their lesions and prior cardiac events (Silversides et al., 2018). While these models are globally recognised benchmarks, their usefulness in resource-scarce settings is still a point of debate. In these settings, sociodemographic barriers and late clinical presentation often limit their prospective (pre-pregnancy and early prenatal counselling) utilisation, and therefore cause these models to either underestimate or overestimate actual risk (Lumsden et al., 2020).

2.2 CHARACTERISTICS OF CARDIAC DISEASE IN PREGNANCY

The prevalence and spectrum of cardiac disease in pregnancy vary greatly depending on sociodemographic factors. Several studies highlight a disproportionately high burden of cardiac disease in pregnancy in Sub-Saharan Africa (Diao et al., 2011; Lumsden et al., 2020; Soma-Pillay et al., 2018). The leading cause of cardiac disease in pregnancy in developing countries is Rheumatic Heart Disease (RHD), which results from childhood Rheumatic Fever (RF) (Chang et al., 2018; Snelgrove et al., 2021; Soma-Pillay et al., 2018). A study conducted in Dakar, Senegal, reported that 92% of the cases reviewed were attributable to RHD (Diao et al., 2011). Another study in Western Kenya further confirmed this by showing that RHD caused 75% of cases and was often complicated by severe mitral stenosis and pulmonary hypertension. These conditions significantly impair a patient's NYHA functional class and ability to tolerate pregnancy (Lumsden et al., 2020).

Besides the type of cardiac lesion, other important characteristics that may influence the obstetric outcome include maternal age, parity, recreational tobacco use, multiple gestation, anticoagulation therapy, educational level, rural residence, and the patient's functional status (Diao et al., 2011; Elkayam et al., 2016b, 2016a; Lumsden et al., 2020; Poli et al., 2020; Soma-Pillay et al., 2018).

In a retrospective study conducted in SSA at MTRH in Kenya, which aimed to define the burden and spectrum of cardiac disease in pregnancy, the study noted an age range from 16 to 50 years, with a median age of 26 years. (Lumsden et al., 2020). In Senegal, a country in the same regional context, a study highlights older age as a risk factor for adverse outcomes(Diao et al., 2011). Older maternal age is associated with increased incidence of postpartum cardiomyopathy (Elkayam et al., 2016a, 2016b). A study from South Africa contradicts this by emphasising the Saving Mothers 2014-2016 report, which states that the majority of deaths from cardiac disease occur in the under-30-year age group (Soma-Pillay et al., 2018). Either way, the mWHO risk stratification and the CARPREG risk score both include maternal age as a significant factor, with extremes of age increasing the likelihood of severe cardiac complications and overall maternal mortality (Poli et al., 2020; Silversides et al., 2018). In the context of developing countries, age alone cannot explain the occurrence of an adverse outcomes (Lumsden et al., 2020).

Inferential evidence reveals that multiparous women, compared to nulliparous women, have a higher baseline cardiac output, stroke volume, and heart rate, suggesting a predisposition to adverse effects in the former (Costantine, 2014; Morton, 2021). Even though parity alone is not a reliable predictor of risk, according to a Southern California study, a history of uneventful pregnancy can be reassuring (Silversides et al., 2018). Furthermore, evidence indicates that beyond the immediate postpartum period, some women with cardiac disease face the risk of permanent deterioration of their condition, which could potentially affect future pregnancies, cause mortality, or severe long-lasting morbidity (Elkayam et al., 2016a, 2016b). Elkayam et al. (2016a) further suggest that the risk of death in post-partum cardiomyopathy is associated with multiparity. A western Kenyan study, in contrast to the U.S.A.-based study, showed that parity was a significant predictor of cardio-obstetric outcomes (Poli et al., 2020).

Comorbidities such as hypertension in pregnancy, infections, and autoimmunity have been implicated in postpartum cardiomyopathy (Elkayam et al., 2016b, 2016a).

2.3 OUTCOMES OF CARDIAC DISEASE IN PREGNANCY

Pregnancy in women with cardiac disease is important worldwide, causing maternal morbidity and death (Elkayam et al., 2016c, 2016a; Lumsden et al., 2020; Soma-Pillay et al., 2018). The physiological demands of pregnancy change cardiovascular dynamics. This worsens underlying cardiac conditions. A normal pregnancy involves significant changes in cardiovascular physiology. These changes begin in the first trimester, peak dramatically in the second, and continue through the third trimester. The compounded hemodynamic burden can worsen pre-existing heart conditions. It can also trigger symptoms in patients who were previously asymptomatic (Costantine, 2014; Diao et al., 2011; Owens et al., 2018). A study suggests that most women with cardiac disease tolerate pregnancy; however, certain conditions are linked to a higher risk (Soma-Pillay et al., 2018). Another local study indicates that maternal mortality in these patients is about ten times greater than in non-cardiac pregnant patients, emphasising the need for in-depth risk assessment (Lumsden et al., 2020).

Maternal and foetal outcomes in SSA are reported to be significantly worse compared to high-income countries, emphasising the global health disparity (Diao et al., 2011; Lumsden et al., 2020; Soma-Pillay et al., 2018; Van Hagen et al., 2016). Risk stratification models for adverse outcomes that have been successfully utilised in high-income countries have low utility in developing countries (Lumsden et al., 2020). Adverse outcomes in LMIC result from a complex interaction of various clinical and non-clinical factors specific to the region (Poli et al., 2020).

Most deaths, according to a South African study, occur after delivery (Soma-Pillay et al., 2018). This high-risk period is primarily due to the rapid backflow of blood from the uteroplacental unit back into the maternal circulation (Bright et al., 2021; Costantine, 2014). This redirection

results in a sudden volume load on an already compromised heart. Maternal mortality can, however, happen up to 44-150days post-delivery (Lumsden et al., 2020). In Kenya, a study conducted from 2016 to 2018 found that a significant proportion of patients died from cardiac disease, with RHD being the leading cause of maternal death (Poli et al., 2020).

A Kenyan hospital-based longitudinal case series rated maternal cardiac arrest as the least common adverse cardiac event, with complications such as HF and pulmonary oedema identified as the most common (Poli et al., 2020). Normal pregnancy symptoms may, to some extent, mimic heart failure symptoms; a high index of suspicion is therefore necessary (Elkayam et al., 2016b, 2016a). Other implicated cardiac complications include arrhythmia, pulmonary oedema, and pulmonary thromboembolism (Diao et al., 2011; Poli et al., 2020). Decompensation of heart failure and arrhythmias are common in the second trimester, while pulmonary oedema is most common postpartum (Poli et al., 2020).

A Dakar study recorded a median age at delivery of only 28 weeks, with high rates of preterm births and stillbirths. The study also noted that some patients underwent pregnancy termination (Diao et al., 2011). In Western Kenya, preterm delivery was identified as the most common obstetric event, followed by other maternal-foetal complications such as pre-eclampsia. Other identified events included postpartum haemorrhage, postpartum depression, miscarriage, and stillbirths (Poli et al., 2020).

Various studies suggest that the choice of the mode of delivery is significantly associated with adverse outcomes: Assisted vaginal delivery is generally preferred for most high-risk cardiac disease cases, with caesarean sections reserved for instances of maternal and/or foetal instability and significant aortopathy (Elkayam et al., 2016b, 2016a; Owens et al., 2018; Poli et al., 2020). A Sub-Saharan African study reported 63% of deliveries for cardiac disease patients as vaginal and 37% as caesarean section (Diao et al., 2011). Therapeutic abortions increase the odds of an adverse event 52-fold (Poli et al., 2020).

Favourable cardiac, obstetric, and foetal outcomes are linked to prior knowledge of the cardiac diagnosis, pregnancy preparedness, multidisciplinary specialist management, accurate risk prediction, and close monitoring throughout pregnancy. These results from a functional healthcare system that combines: collaboration among specialists, patient and community education, and policies that address socio-cultural barriers to care (Elkayam et al., 2016b, 2016a; Soma-Pillay et al., 2018; Yang et al., 2024)

2.4 EXPERIENCES OF CARDIAC DISEASE IN PREGNANCY

2.4.1 BIOLOGICAL EXPERIENCES

Women with heart disease face higher risks during pregnancy. The normal physiological changes that occur to support the developing foetus can have a compounded effect on pregnant women with cardiac conditions. There may be the onset of symptoms in women with previously undiagnosed or subclinical disease; similarly, there may be worsening of symptoms in those with known disease, leading to adverse outcomes for both mother and baby (Elkayam et al., 2016a, 2016b; Owens et al., 2018). The physiological adaptations begin in the first trimester, peak in the second, continue through the third, and persist into the postpartum period (Bright et al., 2021; Costantine, 2014). Consequently, these pregnant women may experience exaggerated limitation in their physical activity with restrictions and easy fatiguability due to their cardiac condition (Elkayam et al., 2016a, 2016b). They are also at higher risk of developing other pregnancy-related comorbidities, such as pre-eclampsia, which can be debilitating. This is in addition to their predisposition to pregnancy-induced complications like thromboembolism (Diao et al., 2011). The cardiac diagnosis, the severity of the disease, and the heart's ability to adapt to physical stressors heavily determine the functional status of pregnant cardiac patients. Having prior knowledge of the cardiac condition, making medication adjustments, and closely monitoring maternal and foetal health throughout pregnancy are essential for improving outcomes (Soma-Pillay et al., 2018).

Women with cardiac disease may need personalised birth plans that focus on maternal safety while also protecting the foetus. Continuous monitoring of the woman's hemodynamic status and foetal well-being during labour remains vital. Having a dedicated multidisciplinary team offers additional support and reassurance of supervision (Easter et al., 2020; Ernst et al., 2024). Recovery from childbirth can be slower and may need extra support for women with heart disease. They face the challenge of managing their heart condition while also handling postpartum recovery. Dealing with challenges of reduced heart function, while concurrently handling issues like infections or BP fluctuations, requires careful monitoring by healthcare providers. Even after the immediate postpartum period, some women with heart disease might experience a permanent decline in their health. The medical team should provide effective follow-up strategies, management plans, and family planning services (Easter et al., 2020; Elkayam et al., 2016a, 2016c; Ernst et al., 2024).

2.4.2 PSYCHOLOGICAL EXPERIENCES

Studies show increased levels of anxiety, depression, and fear during pregnancy in women with heart disease. Many women experience uncertainty, reporting months of cognitive and emotional dissociation (Hutchens et al., 2022a, 2022b, 2022c). Concerns regarding both their health and the well-being of their developing baby contribute to emotional stress (Hutchens et al., 2022a). A study showed that some patients may use harmful coping mechanisms like denial. This is risky because such mothers oversimplify their condition and tend to underestimate the risks associated with their condition. On the other hand, effective coping strategies are crucial in promoting positive mental health. These include relaxation techniques and social support networks (AL Obieat et al., 2023).

It is common for women with heart disease in pregnancy to experience anxiety and fear. This relates to the birthing process and anticipated complications. Effective communication and emotional support from healthcare providers has been shown to reduce anxiety and foster a

sense of control during delivery. Feeling prepared and informed about potential risks and interventions can boost confidence. It also facilitates shared decision-making during labour (Dawson et al., 2018).

Studies indicate an increased risk of postpartum depression and anxiety linked to effectiveness as a new mother and the progression of chronic illness. Women report disruptions in their thought processes and self-image, especially after a "near-miss" event. A study found that, in many cases, the anxiety lasted up to ten years after pregnancy and delivery. Some of these women are eventually diagnosed with significant mental health disorders after childbirth (Hutchens et al., 2022b).

2.4.3 SOCIAL AND STRUCTURAL EXPERIENCES

A study revealed that pregnant patients with cardiac disease experienced at least one isolated traumatic and challenging event during their pregnancy (Hutchens et al., 2022a). Another study conducted in Uganda revealed that many women felt stigmatised because of their perceived limitations in their physical and reproductive abilities, with some facing marital abandonment. Social support networks from partners and peers are essential for psychological health. Women with heart conditions need practical assistance (Chang et al., 2018). Regular counselling and debriefing for the patient and their partners or family members are recommended (Easter et al., 2020; Ernst et al., 2024). Women with cardiac disease often encounter major barriers to care. Research has shown issues, including restricted access to specialised services, a lack of consistent and coordinated care, and insufficient provider knowledge(Chang et al., 2018; Dawson et al., 2018; Hutchens et al., 2022c). This is especially experienced in resource-poor settings (Dawson et al., 2018; Hutchens et al., 2022c). Additionally, Negative interactions with medical providers can harm one's physical and mental health.

Women have reported feelings of being dismissed by health providers. This is frequently due to a lack of patient-centred care. These women usually have no access to clear information.

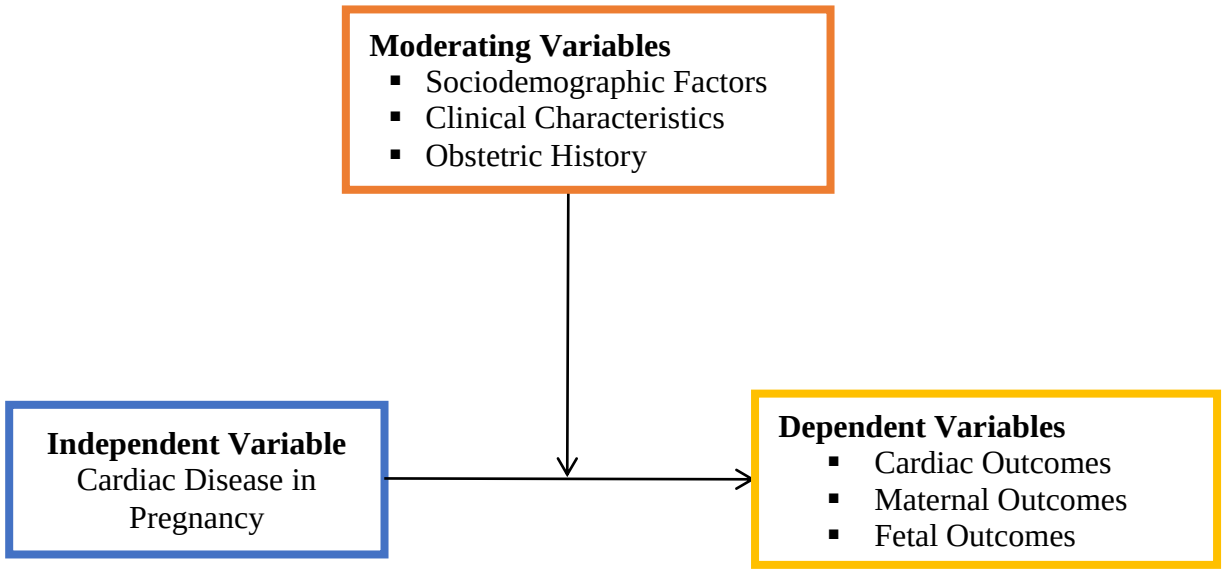
Good communication and joint decision-making are fundamental for creating trust and alleviating anxiety during pregnancy. A multidisciplinary approach to care bridges this gap (Easter et al., 2020; Ernst et al., 2024; Hutchens et al., 2022c). The presence of a trusted companion during delivery can reduce anxiety. Experiencing labour with a spouse or doula can improve the birth experience (AL Obieat et al., 2023).

Women in these settings may also face stigma related to their condition. This can influence family planning decisions and adherence to treatment (Chang et al., 2018). Reliable support networks and access to mental health services are necessary for preventing psychological issues. Connecting with other mothers who have cardiac disease can give a feeling of connection and common experiences. Financial support is also critical. Women have reported missing medical appointments due to unaffordable costs (Hutchens et al., 2022b). According to a study conducted in Uganda, many women with cardiac disease during pregnancy reported issues such as loss of employment due to their diagnosis, monetary problems, and abandonment by male partners after delivery (Chang et al., 2018).

Psychosocial support and comprehensive health education should be provided. Family planning education and support from medical professionals can help prevent unplanned pregnancies. This is. especially critical in patients with absolute contraindications. This class of patients may need to consider the possibility of permanent contraception (Soma-Pillay et al., 2018).

2.5 CONCEPTUAL FRAMEWORK

Figure 1: *Conceptual framework- Characteristics and outcomes of pregnant women with cardiac disease at JOOTRH*



CHAPTER THREE

METHODOLOGY

3.1 STUDY DESIGN

This study used a convergent parallel mixed-methods design. It combined qualitative and quantitative research methods. This approach was strategic and resulted in an in-depth understanding of the burden of cardiac disease during pregnancy. It showed not just what occurred (objectives one and two), but also why/how (objective three) it happened.

A retrospective, analytical, cross-sectional study strategy was employed to address the first and second objectives. A cross-sectional, phenomenological qualitative design was used to address the third objective. Through triangulation, this mixed-methods approach captured the complexity of cardio-obstetric care in a low-resource setting by enhancing complementarity and contextual validation (Habib, n.d.).

3.2 STUDY SITE AND SETTING

The study was conducted at JOOTRH in Kisumu, Kenya. JOOTRH is a public, tertiary-level health facility that has been operational for decades, gradually evolving to its current status as a Level 6A National Referral Hospital. It serves as a primary specialised healthcare hub for the Lake Region and Western Kenya, serving over 10 million people across 14 counties. Within Western Kenya, it is one of two national referral centres for specialised care, with Moi Teaching and Referral Hospital (MTRH) recognised as the more specialised cardio-obstetric centre.

JOOTRH is, however, a destination for cardiac patients in the region due to its strategic location. This is in addition to the advancing sub-speciality care services, including a dedicated newborn unit, an adult intensive care unit (ICU), specialised anaesthesia, cardiology, and OBSGYN teams, and diagnostic services such as echocardiography. JOOTRH's catchment population is predominantly peri-urban and rural, often representing limited previous access to

specialised cardio-obstetric services, with a few outliers. The facility is therefore representative of a resource-constrained but specialised environment. It was therefore a suitable location for the study, given the sociodemographic uniqueness of LMIC.

The specific study site was the obstetrics and gynaecology department's inpatient wards and outpatient clinics. The hospital registry from the aforementioned departments was utilised to recruit study participants for the quantitative wing of this study.

3.3 STUDY POPULATION

The study population was women who reside in a developing country setting and have a documented diagnosis of cardiac disease. The target population included high-risk individuals who have experienced pregnancy in the context of cardiac disease and have sought medical care at JOOTRH inpatient and outpatient facilities between May 2022 and April 2026, a period of forty-eight months. Additionally, these were typically women of reproductive age (15 to 49 years).

3.4 INCLUSION AND EXCLUSION CRITERIA

3.4.1 INCLUSION CRITERIA

For the quantitative arm (objectives one and two), the study included medical records of female patients with a confirmed diagnosis of cardiac disease, a history of pregnancy, and who had been managed at JOOTRH between May 2022 and April 2026 during any period of their pregnancy. For the qualitative arm (objective three), the study included patients with a confirmed diagnosis of cardiac disease, a history of pregnancy in the context of the cardiac disease and who were willing to provide informed consent.

3.4.2 EXCLUSION CRITERIA

For the quantitative arm (objectives one and two), the study excluded incomplete medical records. The key variables whose absence in a medical record would warrant exclusion include: cardiac diagnosis/type of cardiac lesion; baseline NYHA classification; and maternal outcome.

For the qualitative arm (objective three), the study excluded patients who were clinically unstable at the time of recruitment. Patients with an ongoing pregnancy were also excluded. Excluding ongoing pregnancies ensured that recruited participants could reflect on an entire journey from diagnosis through delivery and recovery. This ensured the provision of a holistic account that a patient still in the middle of the experience couldn't yet offer.

3.5 SAMPLING

3.5.1 SAMPLING METHOD

Quantitative Arm (Objectives one and two):

Census sampling was used for this study. This method ensures complete enumeration of the study population and has been used successfully in various health surveys (Colwill & Poullis, 2023). All records of patients with cardiac disease in pregnancy who had been managed at JOOTRH from May 2022 to April 2026 and met the inclusion criteria were included. This was the most appropriate methodology for a high-risk, high-impact, but low-prevalence condition. Hospital records, maternity registers, admission logbooks, and theatre records were reviewed to identify all patient files meeting the criteria. Rather than stopping after a set number, all available, eligible files were retrieved and reviewed. A complete enumeration yielded more reliable data that specifically defined the disease burden.

Qualitative Arm (Objective three):

A purposive maximum-variation sampling strategy was used(Nyimbili & Nyimbili, 2024). Chart and file reviews of hospital records helped identify potential research participants who exhibited a wide range of sociodemographic and clinical characteristics, dimensions, outcomes and experiences related to cardiac disease during pregnancy. Additionally, conversations with patients attending inpatient and outpatient facilities were assessed. The goal was to select participants who would uncover core shared experiences that cut across the diverse pool, while also documenting unique variations (Nyimbili & Nyimbili, 2024). Researchers determined

which participants met the inclusion criteria. Patients with heterogeneous characteristics were then purposively selected and invited to enrol in the study.

3.5.2 SAMPLE SIZE CALCULATION

Quantitative Arm:

The sample included all eligible patients identified from the retrospective medical records of pregnant women with cardiac disease at JOOTRH over four years, from May 2022 to April 2026. Census sampling was utilised. Based on the comparative data from MTRH and preliminary hospital records at JOOTRH, the estimated total population for this study was approximately 40 participants.

MTRH is a slightly higher-volume referral hospital. It recorded 97 cases over a six-year period (2011-2016). The estimated average is 16.17 cases annually. JOOTRH reports an anecdotal average of 10 cases of cardiac disease in pregnancy per year. For the defined four-year study period from May 2022 to April 2026, a projected population (N) of 40 eligible cases was estimated. This complete enumeration was critical for establishing baseline data where no data currently exists.

31 medical records of patients with cardiac disease in pregnancy were identified from the JOOTRH registry. 4 files from this cohort were missing; therefore, their details could not be confirmed. These were therefore excluded. The remaining 27 medical record files were identified and found to meet the inclusion criteria over the four-year study window.

Qualitative Arm:

Qualitative studies do not typically have a predetermined sample size. Recruitment and interviews, therefore, continued until data saturation was judged to have been achieved, defined as the point at which no substantively new themes or insights emerged from the data. Data analysis began after the fifth interview. Saturation was assessed through an ongoing review of interview transcripts and coding. When no new themes were identified across consecutive

interviews, and the coding structure remained stable, the team determined that saturation had been reached. This process was dynamic throughout the analysis phase. By the eighth interview, no additional unique themes arose, and the ninth interview served to confirm rather than expand the thematic structure (Denzin, 2009; Patricia et al., 2015; Staller, 2021).

3.6 RECRUITMENT OF PARTICIPANTS

For the quantitative arm, a thorough review of the hospital registry was done. Admission, discharge and report records from the OBGYN and ICU departments covering the period from May 2022 to April 2026 were reviewed. The initial screening was for names, diagnosis and tests that inferred cardiac disease in pregnancy. An initial list was then populated. It was then screened for alignment with the criteria and then presented to the records department for file retrieval. Notably, the records department was going through a physical and systemic transition that compromised the availability of all files. Critically, at least four files that had been confirmed for alignment could not be traced. Once the available files were acquired, a final list was compiled after a filtering process, resulting in twenty-seven study participants with complete records.

For the qualitative arm, potential participants were identified from the final list compiled during the quantitative recruitment. A maximum variation strategy was used to purposively compile a list of all eligible study participants. Eligibility was open to any woman who had delivered before recruitment. Their main and alternative phone numbers were retrieved from the files. These potential participants were then approached systematically by phone. Interested individuals were educated on the study and given ample opportunities to ask questions. Those who declined were thanked for their time and consideration and excluded from the study. Those who agreed to participate were recruited for the study. Recruitment happened concurrently with the interviews and was stopped as soon as data saturation was achieved.

3.7 STUDY PROCEDURES

Quantitative:

Following recruitment of study participants, a pre-tested data abstraction form (ref: section 3.9 and Appendix II) was used to record the information on the characteristics and the outcomes of cardiac disease in pregnancy. All extracted data were de-identified to ensure patient privacy. Randomly selected forms underwent double data entry to minimise human error and researcher bias. Complementary data were also extracted from theatre records and nurse report books. The data were then uploaded to R version 4.6.0 for analysis (Ref: Section 3.10).

Qualitative:

Following recruitment of study participants, the principal researcher and a trained research assistant conducted face-to-face, in-depth interviews. A pretested semi-structured interview guide (Ref: Appendix III) was used. Before the interviews, the principal researcher had an informal training session with the second university supervisor (who has vast experience in qualitative research). The principal researcher also completed a short online course on qualitative study designs and other study procedures in preparation for starting this study. The research assistant was selected from the hospital's pool of medical officer interns.

The interviews were conducted in a comfortable and private room within JOOTRH. Upon arrival, the study subject was presented with an information sheet, educated about the details of the study, and written informed consent was subsequently obtained.

The interview guide was utilised to guide the conversation, whilst allowing for flexibility in the flow of the study participant's thought process. The interviews were audio-recorded with the patient's consent. A research assistant was also present as a scribe to record the field notes. The interviews were conducted in English and Kiswahili, depending on the study subject's preference. Occasionally, the study subject would speak in the predominant regional language, Dholuo, which was familiar to the principal researcher. A counsellor was on standby at all

times to handle incidents like emotional outbursts or distress. Each interview lasted about 35 to 45 minutes. Software integration followed the in-depth interview, during which recordings were saved as digital files (MP3s). Field notes and translated interview transcripts were then uploaded to NVivo.

3.8 VARIABLES

Quantitative Variables:

The independent variable was Cardiac disease in pregnancy, with dependent variables categorised into cardiac outcomes (heart failure, thromboembolic events, and arrhythmia), obstetric outcomes (maternal mortality, ICU admission, and referral to a specialised facility), and foetal outcomes (perinatal mortality and birth weight). The moderating variables for this study were identified as the characteristics of women with cardiac disease in pregnancy at JOOTRH, including the sociodemographic characteristics (age, marital status, occupation), the clinical characteristics (type of cardiac disease, NYHA class, comorbidities), and obstetric history (previous pregnancies and previous miscarriages/abortions).

Major Adverse Cardiovascular Events (MACE) served as a primary composite outcome. This was defined as a composite of maternal mortality, cardiac arrest, acute heart failure or pulmonary oedema requiring treatment, arrhythmias requiring pharmacological or electrical intervention, and thromboembolic events (deep vein thrombosis, pulmonary embolism or stroke). This study adopts the validated cardio-obstetric definition utilised in landmark pregnancy registries (e.g., the CARPREG study). This pregnancy-specific adaptation is biologically appropriate for LMIC cohorts, where RHD and PPCM predominate over atherosclerotic coronary disease.

Qualitative Variables (Patient Lived Experiences):

The variables were the emerging themes from the in-depth interviews, which explored the participants' lived experiences. However, the semi-structured interview guide for the in-depth interview was based on the literature review.

3.9 DATA COLLECTION TOOLS

This study utilised two data collection tools, one for each methodological arm (*Ref: Appendix II and III).* A data abstraction form, designed based on the conceptual framework and literature review, was used to capture the targeted information. This was used to extract numerical, categorical, and clinical record data from patient medical records. It collected sociodemographic and baseline data; clinical and cardiac characteristics; obstetric history and outcomes; in-hospital management; and complications. It was pre-tested to verify alignment with the study objectives and variables. It was then modified before the official study began. Similarly, a semi-structured interview guide was drafted based on the literature review. This was used to extract verbal narratives and experiential views during face-to-face interviews with surviving patients. It was also pre-tested and adjusted before the start of the official study. The questions and wording were simplified and shortened while maintaining the original meaning. Further, a high-quality dedicated digital audio recorder was used. Specifically, a smartphone equipped with a good external microphone was used to minimise background noise. The smartphone was dedicated solely to the study. The phone’s auto transcription features were complementary. Care was taken to ensure that manual settings on the phone saved interviews locally to the device. This prevented cloud storage issues or data security concerns.

3.10 DATA ANALYSIS

Data analysis was conducted using a convergent parallel mixed-methods approach. Quantitative data extracted from patient medical records and complementary sources were

processed using R statistical software (version 4.6.0), while qualitative interview transcripts were managed and coded using NVivo software. Both analytical arms were conducted concurrently and integrated during the final synthesis through data triangulation.

Quantitative Data Analysis

Qualitative analysis addresses objectives 1 and 2 by describing participant characteristics and evaluating clinical, obstetric and foetal/neonatal outcomes.

Before statistical analysis, raw data extracted via the data abstraction forms were audited for completeness and logical consistency. An independent abstractor performed double data entry on 40% of records. Discrepancies were resolved through consensus. Categorical variables were standardised. Continuous variables were screened for extreme values and non-normal distributions.

For descriptive statistics, categorical variables were summarised using absolute frequencies (n) and relative percentages (%). These included: sociodemographic parameters (e.g., age groups, marital status, county of residence, occupation), clinical profiles (e.g., specific cardiac diagnosis, timing of diagnosis, NYHA functional class, comorbidities), and discrete outcomes (e.g., mode of delivery, ICU admission, mortality, live births, stillbirths). For continuous variables, normality of continuous distribution (e.g., patient age, the length of hospital stay, birth weight, blood pressure, SP02) was evaluated using the Shapiro-Wilk test. Data significantly deviated from a normal distribution ($p < 0.05$). This was due to the relatively small population size (N=27). The continuous variables were presented using non-parametric summary metrics, i.e., medians and interquartile ranges, rather than means and standard deviations.

For inferential statistics, bivariate analysis was used to establish initial associations. Specifically, associations between clinical risk parameters and binary outcomes (MACE, Adverse obstetric outcomes and adverse neonatal outcomes). Fisher's exact test was applied to

test associations between categorical predictors (e.g., NYHA Class III/IV vs. I/II, Rheumatic Heart Disease vs. other diagnoses, pre-existing vs. pregnancy-onset diagnosis, specialised review vs non-specialised review) and binary clinical endpoints. Fisher's exact test was chosen over the Pearson Chi-Square test because cell counts in 2×2 cross-tabulations were frequently small (<5) due to the census sample size (N=27). The Wilcoxon Rank-Sum (Mann-Whitney U) Test was used in place of the t-test to evaluate differences in non-normally distributed continuous parameters across binary outcome groups. For univariate logistic regression, crude odds ratios (cOR) and corresponding 95% confidence intervals (95% CI) were calculated for individual dichotomous risk factors across composite cardiac, obstetric, and neonatal outcome clusters.

Multivariable analysis was done to isolate independent clinical predictors of primary outcomes while controlling for confounding variables (such as maternal age, parity, and baseline functional class). The Standard maximum-likelihood binary logistic regression failed due to data separation (where certain outcome events occurred exclusively within one stratum of a predictor, resulting in infinite maximum-likelihood estimates and unstable confidence intervals). Firth's penalised likelihood approach was employed to reduce small-sample bias, handle complete/quasi-complete separation, and yield stable, finite adjusted odds ratios (aOR) and 95% confidence intervals.

To respect the events-per-variable constraints imposed by the small cohort (N=27), multivariable models were restricted to three primary, clinically defensible covariates: NYHA Functional Status at Entry (Class III/IV vs. I/II), Primary cardiac diagnosis (RHD vs. other diagnoses) and Maternal age Group (>35 years vs. ≤35 years). Statistical significance across all inferential tests was set at a two-tailed alpha threshold of $p<0.05$.

Qualitative Data Analysis:

To address objective three, this study employed a thematic analysis to understand the participants' lived experiences and how they make sense of their world. Thematic data analysis started after the fifth interview and continued concurrently with the subsequent interviews until data saturation was reached.

The first step was data preparation. All audio-recorded in-depth interviews were transcribed verbatim in the language of administration (English, Kiswahili, or Dholuo) and translated into English (where applicable). Transcripts were cross-checked against original audio files for accuracy and fully anonymised by replacing personally identifiable information with participant identification codes (P001 through P009). The finalised text files were imported into NVivo qualitative data management software. Data were then analysed using thematic analysis following an inductive, iterative approach. Transcripts were read in full at least twice before coding. Three coders from different professional and sociocultural backgrounds were involved in the coding exercise. The principal researcher was an OBSGYN registrar practising at JOOTRH; a consultant OBSGYN with global health training and experience from a U.S.A.-based teaching hospital; and a statistician with limited medical knowledge from a Nairobi-based university. An initial inductive open-coding pass was performed on each interview separately to preserve participant-specific texture.

Codes were grouped into sub-themes and themes (biological journey, physiological journey and socio-structural journey) through iterative clustering. The resulting structure was checked back against each transcript to ensure no participant's experience had been overwritten by the thematic synthesis. Each sub-theme was given a clear, concise name and a detailed definition attached that articulated the core concept, scope, and boundaries. The sub-themes and illustrative quotes were then woven into a coherent narrative that directly answered research question three.

Field-note observations recorded by the interviewer (P001 cried about her husband; P003 cried about the lack of support; P005 broke down, reflecting on her losses; P009 was emotionally labile throughout) informed, but did not displace, the textual analysis. Identifying details were removed, and participants were referred to as P001 through P009 in the order of interview.

Coding proceeded iteratively alongside data collection. Data saturation was formally established after the 8th interview when no new codes or themes emerged, and confirmed with the 9th interview.

Data Triangulation

The quantitative and qualitative findings were triangulated during the final analysis phase. This provided a comprehensive understanding of the disease burden. Triangulation ensured complementarity and contextual validation. It also helped identify socio-biological factors that uniquely influence cardio-obstetric care in the Western Kenya context.

3.11 DATA VALIDITY AND RELIABILITY

Quantitative:

The data abstraction form was grounded in the study's literature review and conceptual framework. This was to ensure face, content, and criterion validity. The form had clear, precise questions and well-defined variables. Additionally, broad inclusion criteria allowed for a diverse range of subjects. Pretesting and subsequent adjustments to the form were made to further confirm its validity. For reliability checks, 40% of all quantitative records (12 out of 27) underwent double data entry by an independent abstractor, with discrepancies resolved through consensus within the team. Further, an independent reviewer randomly selected and checked 20% of records (5 out of 27) for data accuracy and completeness. Finally, methodological triangulation was used to validate the findings from both the medical records and the in-depth interviews.

Qualitative:

The qualitative findings were evaluated using the criteria proposed by Lincoln and Guba (Alexander, n.d.). To strengthen credibility and confidence in the findings, methodological triangulation was employed. Patient accounts were corroborated or contrasted with information from the data abstraction form. Secondly, although the findings were not intended to be statistically generalizable, a rich and detailed description of the study setting was provided (Chapter 3.1). This information is valuable for establishing transferability. Additionally, patient profiles were provided (Chapter 4.4). This will allow for the objective determination of the applicability of the findings. All methodological decisions, data coding processes, and any changes that occurred during the research were documented. This was to ensure dependability.

3.12 STUDY STRENGTHS

The two arms of this study were designed concurrently. They also had complementary frameworks. The studies were conducted by the same team led by the principal investigator. The quantitative arm used a census strategy. It was therefore a complete reflection of the entire target population. The qualitative arm reached saturation within the planned 8-12 interview range. The participants had maximum variation across age, diagnosis, timing of recognition, and outcome. The quantitative and qualitative data were integrated. This allowed for an understanding of the characteristics and outcomes in the context of patients' experiences. Grounding the qualitative inquiry in the “Three Delays Model” ensured theoretical rigour. The findings are therefore regionally actionable for maternal health policy and health system strengthening.

3.13 ETHICAL CONSIDERATIONS

Ethical approval was central to this study. The target population was vulnerable, and their condition was sensitive. Ethical and administrative approvals were acquired across three

distinct governing levels prior to study initiation. First, formal Ethical Approval was granted by the Jaramogi Oginga Odinga Teaching and Referral Hospital Institutional Scientific and Ethics Review Committee (JOOTRH ISERC, Reference: ISERC/JOOTRH/263/26). Second, Institutional Permission to collect data within the facility's inpatient wards, outpatient clinics, and medical records department was granted by the JOOTRH Administration and Chief Executive Officer (Reference: ST/2A/VOL:VI). Third, upon obtaining both ethical approval and institutional permission, an official Research License Certificate to conduct the study was issued by the National Commission for Science, Technology, and Innovation (NACOSTI, License No: NACOSTI/P/26/4189213).

The foundational principles of respect, beneficence and autonomy were upheld throughout the study. First, participation in the in-depth interviews was entirely voluntary. Initial verbal consent was obtained over the phone upon initial contact; a second informed consent was then obtained in writing. Both consents were administered in the participant's preferred language (English, Kiswahili, or Dholuo). Their right to withdraw at any time without penalty was explained, and each participant was assured of their confidentiality. Secondly, to comply with the Data Protection Act of the Republic of Kenya (2019), the following safeguards were implemented. Names and other personally identifiable information were removed from the collected data. Only the principal investigator, research assistant, and collaborators directly involved in the study had access to the raw data. Signed consent forms have been kept in a secure. Electronic data has been stored in password-protected, encrypted databases accessible only to the principal investigator. Audio recordings were transferred immediately to an encrypted drive, avoiding iCloud; anonymised during transcription, and will be deleted once the study is finalised in accordance with Maseno University and JOOTRH data retention policies. Thirdly, in acknowledgement that discussing high-risk pregnancies and adverse outcomes can trigger emotional distress, the researcher did a tutorial to train in trauma-

informed interviewing techniques and allowed participants to pause or terminate the session if they became overwhelmed. A counsellor was on standby during the interview sessions, and any signs of distress- such as emotional outbursts, withdrawal, or indicators of discomfort were monitored closely by both the principal researcher and the research assistant. The interviewing team maintained ongoing verbal and non-verbal checks for distress throughout each session and offered the option for breaks or termination of the interview. None of the participants was identified as having significant psychological distress that needed formal referral to the hospital's mental health team for immediate support. However, several referrals were made to the cardiology department for continued care.

CHAPTER FOUR

RESULTS

4.1 INTRODUCTION

To answer questions one and two, 31 medical records of patients with cardiac disease in pregnancy were identified. 4 files from this cohort were missing; therefore, their details could not be confirmed. These were therefore dismissed. The remaining 27 medical record files were identified and found to meet the inclusion criteria over the four-year study window. This was below the projected cohort of forty cases, extrapolated from anecdotal hospital averages and the Moi Teaching and Referral Hospital experience. Of the 27 files, 17 (63.0%) were classified as complete and 10 (37.0%) as partially complete. No record was excluded for incompleteness. Complementary data on key variables were extracted from nurse report books, ward round books and theatre records. Data completeness was audited across all extracted records. Primary diagnostic, functional, and outcome parameters exhibited 0% missingness (N=27). Secondary missing data (e.g., incomplete echocardiographic sub-measurements (22.2%) and unrecorded specialised review notes (11.1%)) were negligible to the study and were treated as missing at random.

To answer question three, nine in-depth interviews were conducted with women who had been pregnant in the context of cardiac disease and who had received care at JOOTRH between May 2022 and April 2026. Recruitment followed a purposive maximum-variation strategy, and interviews continued until saturation was deemed to have been reached. No substantively new themes were emerging by the eighth interview, and the ninth confirmed rather than expanded the thematic structure.

4.2 CHARACTERISTICS OF CARDIAC DISEASE IN PREGNANCY

Sociodemographic Factors

The cohort was skewed toward younger ages: 12 women (44.4%) were aged 18-24 years, 10 (37.0%) were aged 25-35 years, and 5 (18.5%) were older than 35 years. No participant was

under 18. Just over half were single (55.6%), and the remainder were married. Occupations were distributed among students (30%), formal employment (26%), unemployed (26%), and casual labourers (19%). Sixteen women (59.3%) were residents of Kisumu County, with the rest drawn from Busia (115km), Siaya (70km), Vihiga (45km), Homabay (110km) and Nyamira (90km) counties, confirming JOOTRH's regional referral role. The distances were estimated from the specific county referral hospitals to JOOTRH.

Table 1: ***The sociodemographic factors of women with cardiac disease in pregnancy at JOOTRH***

Characteristic	**N = 27**[1]	**(%)**
Age group		
<18 years	0	0.0
18-24 years	12	44.0
25-35 years	10	37.0
>35 years	5	19.0
Marital status		
Single	15	56.0
Married	12	44.0
County of residence and distance from the respective County Hospital to JOOTRH		
Busia (115km)	3	11.0
Homabay (110km)	2	7.4
Kisumu	16	59.0
Nyamira (90km)	1	3.7
Siaya (70km)	3	11.0
Vihiga (45km)	2	7.4
Occupation		
Unemployed / Housewife	7	26.0
Student	8	30.0
Casual Labourer	5	19.0
Formal Employment	7	26.0

[1]n (%)

Clinical Characteristics

Rheumatic heart disease was the leading single diagnosis, accounting for 11 of 27 cases (40.7%), followed by cardiomyopathy (5/27, 18.5%), congenital heart disease (3/27, 11.1%), pulmonary hypertension (2/27, 7.4%), infective endocarditis (2/27, 7.4%), hypertensive heart disease (2/27, 7.4%), one case of ischaemic heart disease, and one prosthetic-valve recipient. The cohort presented with severely compromised functional status. None of the 27 women was NYHA class I (asymptomatic), and only 5 (18.5%) were NYHA II. Twelve (44.4%) were NYHA III, and 10 (37.0%) were NYHA IV, giving an aggregate NYHA III/IV prevalence of 81.5%. Sixteen of 27 women (59.3%) had their cardiac disease first recognised during pregnancy or in the postpartum period; only 11 (40.7%) had a diagnosis established before conception. This is the structural counterpart to the high NYHA III/IV burden noted above at first contact.

Overall, 40.7% (11/27) of the cohort required admission to the Intensive Care Unit. Admissions were driven by acute cardiac decompensation (acute pulmonary oedema, 72.7%), co-occurring severe pre-eclampsia/eclampsia (45.5%), emergency post-Caesarean hemodynamic instability (36.4%), and acute thromboembolic crises (18.2%). All ICU-admitted patients were in baseline NYHA Class III (27.3%) or Class IV (72.7%) at hospital contact, reflecting high baseline physiological vulnerability.

Table 2*: The clinical characteristics of women with cardiac disease in pregnancy at JOOTRH*

Characteristic	N = 27[1]	(%)
Type of Cardiac disease		
Cardiomyopathy	5	19.0
CHD	3	11.0
Hypertensive heart disease	2	7.4
Infective endocarditis	2	7.4
Ischaemic heart disease	1	3.7
Pulmonary hypertension	2	7.4
RHD	11	41.0
Valvular (prosthetic/other)	1	3.7
Timing of cardiac diagnosis		
Before pregnancy	11	41.0
During/post pregnancy	16	59.0
NYHA class at first contact		
I	0	0.0
II	5	19.0
III	12	44.0
IV	10	37.0
Comorbidities		
Hypertension	4	15.0
Diabetes mellitus	0	0.0
Anaemia	15	56.0
Chronic kidney disease	0	0.0
HIV Positive	1	3.7

[1]n (%); Median [Q1, Q3]

Figure 2*: The clinical spectrum of cardiac disease in pregnancy at JOOTRH*

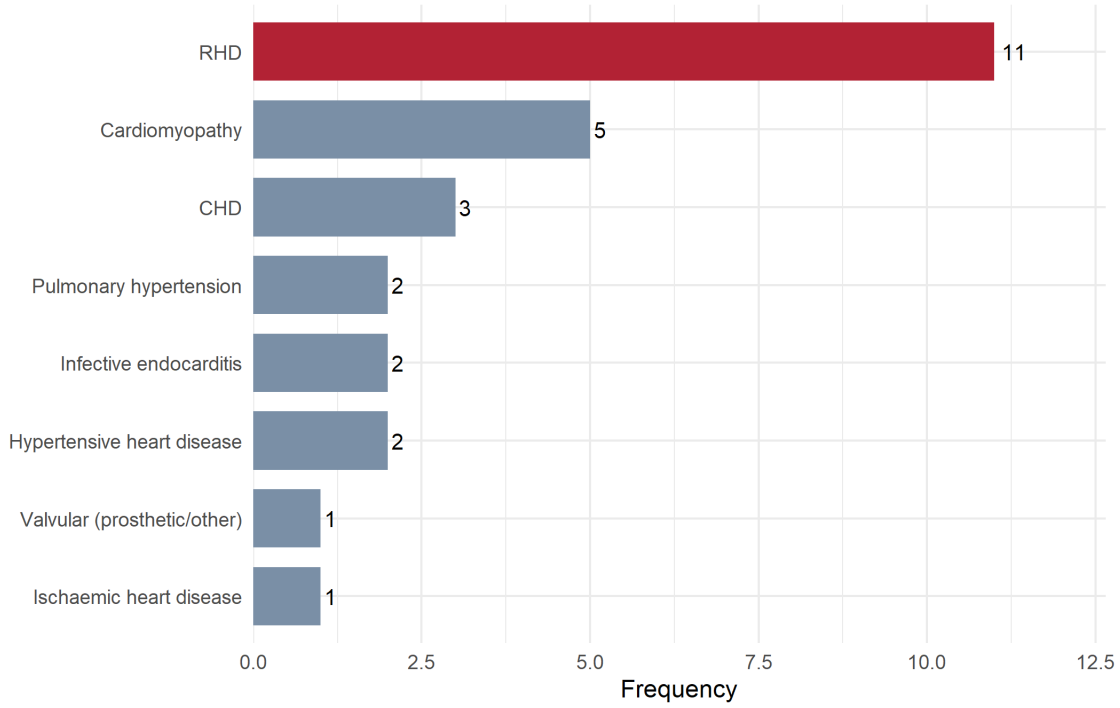
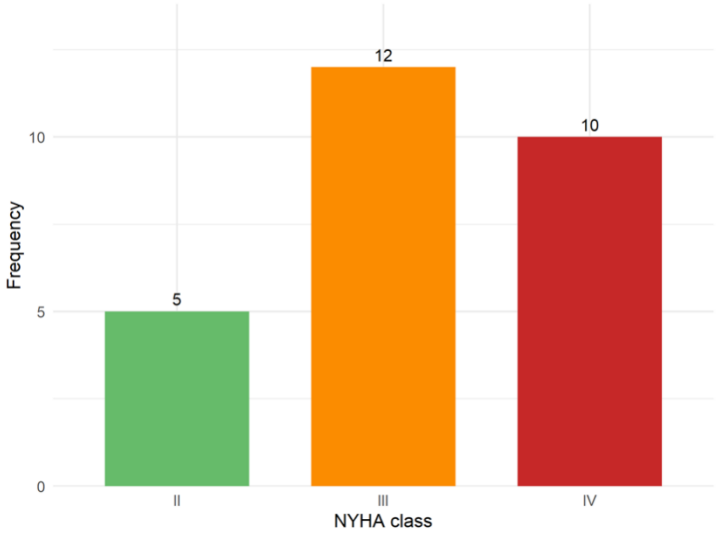


Figure 3: *The NYHA Functional Status at first contact in pregnant cardiac disease patients at*



JOOTRH

Obstetric History

Ten women (37.0%) had had only one previous pregnancy; the remainder were multiparous, including seven (25.8%) with pregnancy totals of 4 or more. Only 5 of 27 women (18.5%) attended the antenatal clinic in the first trimester, and 20 (74.1%) started attending in the second

trimester or later. Critically, only 9 of 27 women (33.3%) had a documented specialised obstetric or cardiology visit during pregnancy.

Table 3: ***Antenatal quality and utilisation in patients with cardiac disease in pregnancy at JOOTRH***

Characteristic	N = 27[1]	(%)
Trimester of first ANC contact		
1st	5	19.0
2nd	20	74.0
3rd	0	0.0
Not documented	2	7.4
Number of ANC contacts		
0	1	3.8
1	3	12.0
2	5	5.0
3	1	3.8
4	9	35.0
5	1	3.8
6	5	19.0
7	1	3.8
Not documented	1	3.8
Specialised visit (OBGYN/Cardiology)	**9**	**33.0**

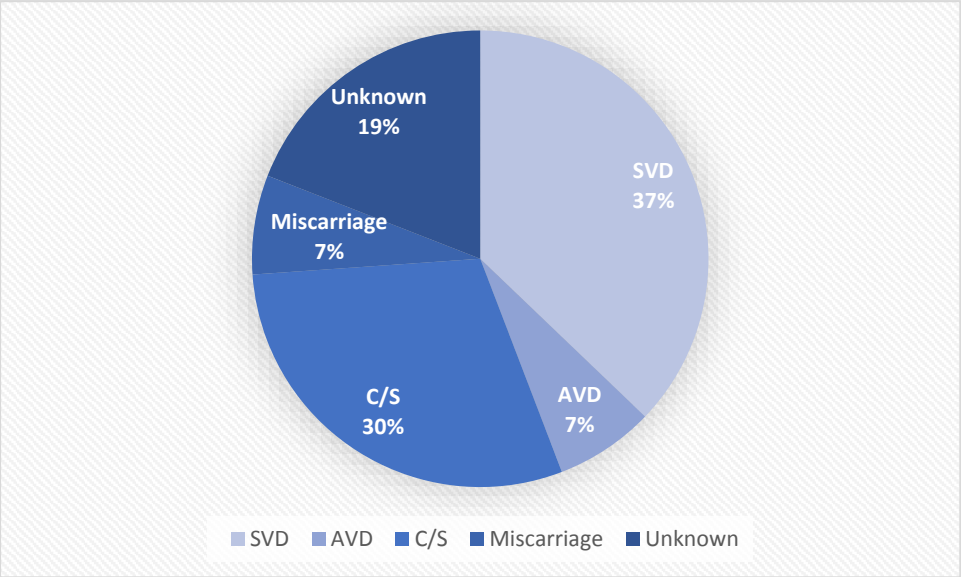
[1]n (%)

4.3 OUTCOMES OF CARDIAC DISEASE IN PREGNANCY

Spontaneous vaginal deliveries (SVD) accounted for less than half of the outcomes (37%), while 29.6% of the cohort required caesarean sections and 7.4% underwent assisted vaginal delivery (vacuum extraction). 7.4% had a miscarriage, and 18.6% mode of delivery is unknown. The median hospital stay was 13 days [IQR 7-18]. Of the 27 women in the retrospective census, 22 delivered within JOOTRH. This yielded an in-hospital delivery denominator of n=22 for mode of delivery analyses. The 5 women without delivery records at JOOTRH were referred

to external tertiary centres due to critical cardiac instability (n=3) or discharged antepartum before onset of labour (n=2).

Figure 4: *The mode of delivery in patients with cardiac disease in pregnancy at JOOTRH*



Obstetric Outcomes

Table 4: ***The obstetric outcomes in patients with cardiac disease in pregnancy at JOOTRH***

Outcomes N = 27[1]	**YES N = 27**[1]	**(%)**	**NO N = 27**[1]	**(%)**
Maternal mortality	4	15.0	23	85.0
ICU admission	11	41.0	16	59.0
Referral to specialised facility	3	11.0	24	89.0
Obstetric Complications				
Pre-eclampsia / eclampsia	11	41.0	16	59.0
Antepartum haemorrhage	0	0.0	27	100.0
Postpartum haemorrhage	3	11.0	24	89.0
Preterm labour	2	7.4	25	92.9

[1]n (%)

Maternal mortality was 4 of 27 (14.8%). Eleven women (40.7%) required ICU admission. 3 of 27 were referred to Moi Teaching and Referral Hospital for specialised care. Adverse obstetric outcomes occurred in 14 of 27 (51.9%), driven principally by an unusually high pre-eclampsia/eclampsia rate of 40.7%.

Cardiac outcomes

Table 5: ***The cardiac outcomes in patients with cardiac disease in pregnancy at JOOTRH***

Cardiac Outcomes N = 27[1]	**YES N = 27**[1]	**(%)**	**NO N = 27**[1]	**(%)**
Heart failure / pulmonary oedema	17	63.0	10	37.0
Arrhythmia requiring treatment	0	0.0	27	100.0
Thromboembolic event	7	26.0	20	74.0

[1]n (%)

Heart failure or pulmonary oedema was the dominant component (17/27). There were no documented arrhythmia events; however, this was not a reflection of absence but of a lack of express documentation. Seven women (25.9%) experienced a thromboembolic event. Anticoagulants were the most commonly prescribed agents (21/27, 77.8%), consistent with the high proportion of valvular and RHD in the cohort. Diuretics were prescribed to 20 women (74.1%), beta-blockers to 12 (44.4%) and digoxin to 10 (37.0%). ACE inhibitors were prescribed to 2 women (7.4%). ACE inhibitors were, however, initiated postpartum.

Foetal Outcomes

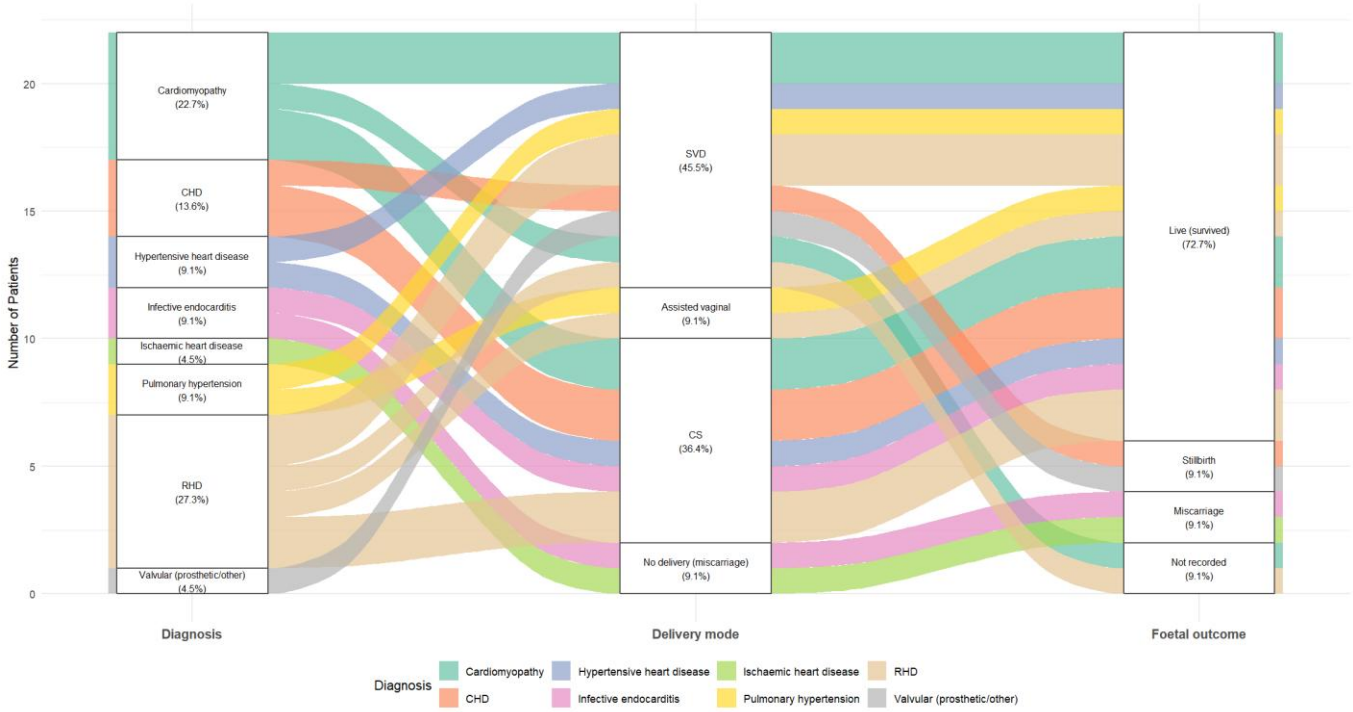
Table 6: ***The foetal/neonatal outcomes in patients with cardiac disease in pregnancy at JOOTRH***

Foetal Outcome	**N = 27**[1]	**(%)**
Live birth	16	59.0
Stillbirth	4	15.0
Neonatal death (<28 days)	2	7.4
Unknown	5	18.6
Birth weight (g)	2,145 [1,715, 2,660]	
Low birth weight (<2500 g)	11	41.0

[1]n (%); Median [Q1, Q3]

Live birth occurred in 16 of 27 pregnancies (59.3%). Stillbirth occurred in 4 (14.8%) and neonatal death within 28 days in 2 (7.4%). Total maternal cohort baseline is N=27. Known in-hospital pregnancy resolutions at JOOTRH accounted for n=22deliveries (16 live births, 4 stillbirths, and 2 early neonatal deaths). The remaining n=5 cases (18.5%) represent patients who were transferred to specialised tertiary facilities antepartum (n=3) or discharged antepartum without facility delivery documentation (n=2), and are explicitly accounted for as 'Unknown / Lost to Follow-up' to maintain denominator integrity (16+4+2+5=27). Among deliveries with documented birth weight, the median was 2,145 g [IQR 1,715-2,660 g], and 11 of 27 babies (40.7%) had LBW (<2,500 g). Delivery before 37 weeks affected 20 of 27 pregnancies (74.1%), and preterm birth before 34 weeks affected 10 (37.0%). The composite adverse neonatal outcome (stillbirth, neonatal death, or preterm birth before 34 weeks) was reached in 12 of 27 pregnancies (44.4%).

Figure 5: *An alluvial plot tracing the pregnancy pathways of the women with cardiac disease*



in pregnancy at JOOTRH, from diagnosis to mode of delivery and finally to foetal outcomes

Figure 5 shows the clinical pathways of a small cohort of 22 pregnant patients. It tracks these patients across three distinct stages from left to right: the cardiac diagnosis, the mode of delivery, and the final foetal outcome. Each ribbon represents a woman following a particular pathway. Wider ribbons indicate more women/cases. The diagram allows for easy mapping of how specific maternal heart conditions correlate with delivery methods and ultimately impact foetal survival rates. For example, you can visually trace the green cardiomyopathy stream to see that, while many underwent SVD or C/S, the vast majority resulted in a live outcome. The mode of delivery was not recorded for 5 patients. These were patients referred to MTRH. Additionally, these included those who were managed and discharged home before delivery. Although they were discharged, the recommendations are to keep them in place until delivery (Bright et al., 2021; Pfaller et al., 2020). Unknown foetal outcome refers to patients admitted to JOOTRH after delivery, during the puerperium. The figure shows that live births occurred across several cardiac diagnoses and delivery modes; adverse outcomes such as stillbirth, miscarriage/abortion, and unknown outcomes were also present. The figure highlights that foetal outcomes were influenced by multiple interacting factors. These included the type of cardiac disease, delivery route, and overall maternal condition, rather than cardiac diagnosis alone.

4.4 Bivariate and Multivariate Associations

Bivariate associations with MACE

A bivariate cross-tabulation analysis was performed. This was to determine whether specific maternal demographic features and baseline clinical characteristics significantly influenced the clinical course of pregnant women with cardiac disease. The aim was to evaluate whether factors such as the timing of the cardiac diagnosis, the specific type of cardiac lesion, and the patient's baseline functional status (NYHA Class) at first contact were statistically significantly associated with the development of severe adverse maternal outcomes. The study aimed to

identify high-risk maternal sub-groups requiring targeted clinical surveillance and early optimisation.

Table 7: *Bivariate associations of characteristics of patients with cardiac disease in pregnancy at JOOTRH with major adverse cardiac events*

Characteristic	**No** N = 10[1]	**(%)**	**Yes** N = 17[1]	**(%)**	**p-value**[2]
Age group					0.39
<18 years	0	0.0	0	0.0	
18-24 years	3	30.0	9	53.0	
25-35 years	4	40.0	6	35.0	
>35 years	3	30.0	2	12.0	
Marital status					0.71
Single	5	50.0	10	59.0	
Married	5	50.0	7	41.0	
Occupation					0.02
Unemployed / Housewife	0	0.0	7	41.0	
Student	2	20.0	6	35.0	
Casual Labourer	3	30.0	2	12.0	
Formal Employment	5	50.0	2	12.0	
RHD vs other	3	30.0	8	47.0	0.45
Cardiac diagnosis timing					0.04
Before pregnancy	7	70.0	4	24.0	
During/post pregnancy	3	30.0	13	76.0	
NYHA III/IV at entry	5	50.0	17	100.0	0.003
Specialised visit	7	70.0	2	12.0	0.004

[1]n (%); Median (Q1, Q3)

[2]Fisher's exact test; Wilcoxon rank sum exact test

Bivariate Association with Adverse Obstetric Outcome

This analysis was conducted to explore the relationship between maternal clinical variables and maternal health outcomes. It was to determine whether specific baseline clinical exposures

were statistically significantly associated with the occurrence of these obstetric complications. It also served as a filter to identify individual clinical risk factors before accounting for confounding variables.

Table 8: ***Bivariate association of characteristics of pregnant women with cardiac disease at JOOTRH with adverse obstetric outcomes***

Characteristic	**No** N = 13[1]	**(%)**	**Yes** N = 14[1]	**(%)**	**p-value**[2]
Age group					0.88
<18 years	0	0.0	0	0.0	
18-24 years	5	38.0	7	50.0	
25-35 years	5	38.0	5	36.0	
>35 years	3	23.0	2	14.0	
Marital status					0.45
Single	6	46.0	9	64.0	
Married	7	54.0	5	36.0	
Occupation					0.66
Unemployed / Housewife	5	38.0	2	14.0	
Student	3	23.0	5	36.0	
Casual Labourer	2	15.0	3	21.0	
Formal Employment	3	23.0	4	29.0	
RHD vs other	7	54.0	4	29.0	0.25
Cardiac diagnosis timing					>0.99
Before pregnancy	5	38.0	6	43.0	
During/post pregnancy	8	62.0	8	57	
NYHA III/IV at entry	12	92.0	10	71	0.33
Specialised visit	6	46.0	3	21	0.24

[1]n (%); Median (Q1, Q3)

[2]Fisher's exact test; Wilcoxon rank sum exact test

Bivariate Association with Adverse Neonatal Outcome

These associations were used to evaluate the relationship between key maternal clinical parameters and perinatal outcomes. It investigated the impact of maternal cardiac compromise on fetal and neonatal well-being. The aim was to determine if adverse neonatal events were significantly correlated with maternal factors. This evaluation helped establish the direct perinatal burden of maternal heart disease within the cohort.

Table 9: ***Bivariate Associations of the characteristics of pregnant patients with cardiac disease at JOOTRH with foetal outcomes***

Characteristic	**No** N = 15[1]		**Yes** N = 12[1]		**p-value**[2]
Age group					0.21
<18 years	0	0.0	0	0.0	
18-24 years	9	60.0	3	25.0	
25-35 years	4	27.0	6	50.0	
>35 years	2	13.0	3	25.0	
Marital status					0.06
Single	11	73.0	4	33.0	
Married	4	27.0	8	67.0	
Occupation					0.95
Unemployed / Housewife	3	20.0	4	33.0	
Student	5	33.0	3	25.0	
Casual Labourer	3	20.0	2	17.0	
Formal Employment	4	27.0	3	25.0	
RHD vs other	6	40.0	5	42.0	>0.99
Cardiac diagnosis timing					>0.99
Before pregnancy	6	40.0	5	42.0	
During/post pregnancy	9	60.0	7	58.0	
NYHA III/IV at entry	11	73.0	11	92.0	0.34
Specialised visit	6	40.0	3	25.0	0.68

[1]n (%); Median (Q1, Q3)

[2]Fisher's exact test; Wilcoxon rank sum exact test

Crude odds ratios for binary predictors against binary outcomes

A series of univariate logistic regression models was fitted. This quantified the strength and direction of the unadjusted relationships between specific binary risk factors and binary clinical endpoints. The aim was to compute crude odds ratios (cORs) and their corresponding 95% confidence intervals (CIs) for dichotomous predictors in relation to definitive binary maternal and perinatal outcomes. This approach provides a clear, unadjusted estimate of the odds of developing an adverse outcome when a single risk factor is present, compared with when it is absent.

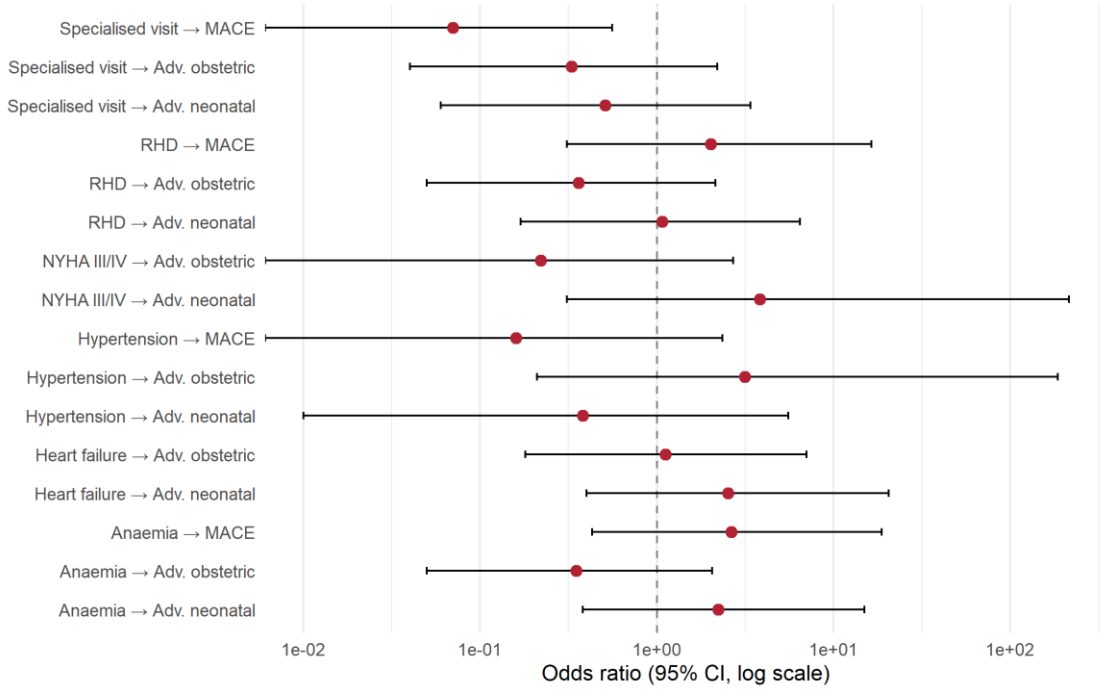
Table 10: ***Crude odds ratios for binary predictors against binary outcomes of patients with cardiac disease in pregnancy at JOOTRH***

Predictor	Outcome	OR	95% CI	p
RHD	MACE	2.02	0.31-16.35	0.45
RHD	Adv. obstetric	0.36	0.05-2.15	0.25
RHD	Adv. neonatal	1.07	0.17-6.45	1.00
RHD	Preterm <37wk	1.99	0.25-25.73	0.66
RHD	Low birth wt	0.39	0.05-2.46	0.43
RHD	Low Apgar	2.53	0.24-36.44	0.37
RHD	ICU admission	0.39	0.05-2.46	0.43
NYHA III/IV	MACE	Inf	2.12-Inf	0.003
NYHA III/IV	Adv. obstetric	0.22	0-2.71	0.33
NYHA III/IV	Adv. neonatal	3.82	0.31-214.28	0.34
NYHA III/IV	Preterm <37wk	0.68	0.01-8.97	1.00
NYHA III/IV	Low birth wt	1.04	0.1-14.81	1.00
NYHA III/IV	Low Apgar	0.89	0.06-54.59	1.00
NYHA III/IV	ICU admission	Inf	0.71-Inf	0.06
Hypertension	MACE	0.16	0-2.35	0.13
Hypertension	Adv. obstetric	3.14	0.21-185.64	0.59
Hypertension	Adv. neonatal	0.38	0.01-5.53	0.61
Hypertension	Preterm <37wk	1.06	0.07-64.71	1.00
Hypertension	Low birth wt	1.53	0.09-24.74	1.00
Hypertension	Low Apgar	0.00	0-7.37	0.56
Hypertension	ICU admission	0.45	0.01-6.57	0.62
Anaemia	MACE	2.64	0.43-18.68	0.26
Anaemia	Adv. obstetric	0.35	0.05-2.06	0.25
Anaemia	Adv. neonatal	2.22	0.38-14.96	0.44
Anaemia	Preterm <37wk	0.92	0.11-7.12	1.00
Anaemia	Low birth weight	0.51	0.08-3.07	0.45
Anaemia	Low Apgar	1.24	0.12-17.64	1.00
Anaemia	ICU admission	0.94	0.16-5.74	1.00
Heart failure	MACE	Inf	19.68-Inf	0.00
Heart failure	Adv. obstetric	1.12	0.18-7.03	1.00
Heart failure	Adv. neonatal	2.53	0.4-20.54	0.42
Heart failure	Preterm <37wk	1.38	0.16-10.98	1.00
Heart failure	Low birth weight	2.02	0.31-16.35	0.45
Heart failure	Low Apgar	2.68	0.21-151.15	0.62
Heart failure	ICU admission	11.69	1.16-616.05	0.02
Specialised visit	MACE	0.07	0-0.56	0.004
Specialised visit	Adv. obstetric	0.33	0.04-2.2	0.24
Specialised visit	Adv. neonatal	0.51	0.06-3.38	0.68
Specialised visit	Preterm <37wk	0.27	0.03-2.16	0.18
Specialised visit	Low birth weight	0.64	0.08-4.24	0.69
Specialised visit	Low Apgar	1.41	0.1-15.52	1.00
Specialised visit	ICU admission	0.30	0.02-2.2	0.23

Crude odds ratios for three composite outcomes (log scale)

Individual adverse events may have low baseline frequencies within the cohort. Three composite outcomes (integrating related severe maternal cardiac, severe obstetric, and adverse neonatal events) were therefore formulated to enhance statistical power and provide a comprehensive view of patient morbidity. Logistic regression analysis was used to estimate crude odds ratios for these composite clusters. The resulting odds ratios were transformed and plotted on a logarithmic scale. This ensured normalisation of the distribution of the estimated effects, accommodated wide confidence intervals, and enabled accurate graphical visualisation across highly varied risk predictors. The aim of this modelling was to identify maternal characteristics that exhibit the most robust unadjusted predictive strength across broad, composite dimensions of clinical failure or success.

Figure 6: *Crude odds ratios for three composite outcomes (log scale) for patients with cardiac disease in pregnancy*



Several variables were significantly associated with Major Adverse Cardiac Events on bivariate testing: NYHA functional class III/IV at first contact ($p = 0.003$), absence of a specialised cardio-obstetric visit ($p = 0.004$), occupation ($p = 0.022$), and cardiac diagnosis first established during or after pregnancy ($p = 0.040$). The crude protective odds ratio for the specialised visit against MACE was 0.07 (95% CI 0.00-0.56). For adverse obstetric outcome, there was no significant bivariate association. For adverse neonatal outcome, no tested variable reached the $p<0.05$ threshold.

Multivariable analyses

A multivariable logistic regression analysis was performed. It accounted for confounders. Additionally, it determined the independent predictors of adverse maternal and perinatal outcomes. All clinical and demographic variables that were significant ($p<0.20$) or showed strong clinical relevance in the preceding bivariate assessments were simultaneously entered into an adjusted model. The primary objective of this multivariable modelling was to isolate the independent effect of each risk factor. This was achieved by statistically controlling for overlapping clinical variables. This multi-variable adjustment ensures that the identified risk markers reflect true independent associations rather than surrogate effects driven by hidden clinical confounders.

Table 11*: Multivariate analyses of outcomes and predictors of patients with cardiac disease in pregnancy at JOOTRH*

Outcome	Predictor	Adjusted OR	95% CI	p
MACE	NYHA III/IV at entry	139.10	5.68-48342.66	0.00
	RHD vs other diagnosis	8.40	0.77-1151.57	0.08
	Age >35 years	0.25	0.02-2.58	0.24
Adverse obstetric outcome	NYHA III/IV at entry	0.19	0.01-1.35	0.09
	RHD vs other diagnosis	0.23	0.03-1.19	0.08
	Age >35 years	0.37	0.04-2.82	0.34
Adverse neonatal outcome	NYHA III/IV at entry	3.15	0.48-34.89	0.24
	RHD vs other diagnosis	1.43	0.3-7.43	0.65
	Age >35 years	2.21	0.34-17.95	0.41

Standard maximum-likelihood logistic regression was not appropriate for this dataset because of separation in several of the bivariate tables; Firth's penalised likelihood was used instead. For MACE, NYHA III/IV at entry remained the only significant adjusted predictor (adjusted OR 139.1, 95% CI 5.68-48 342.66; p<0.001). RHD did not reach statistical significance after adjustment (adjusted OR, 8.40; p = 0.088). For adverse obstetric outcome, no predictor reached significance. For adverse neonatal outcome, no predictor reached significance.

In the Firth-penalised logistic regression model for cardio-obstetric MACE, NYHA functional class III/IV at entry was the sole significant predictor (aOR 139.10, 95% CI: 5.68- 48,342.66; p<0.001). This large point estimate and wide confidence interval reflect data separation within the small cohort (N=27). Consequently, this result confirms a strong, statistically significant association with MACE. However, it does not provide a precise estimate of risk magnitude, highlighting NYHA Class III/IV as an essential clinical triage marker.

4.5 EXPERIENCES OF CARDIAC DISEASE IN PREGNANCY

INTRODUCTION

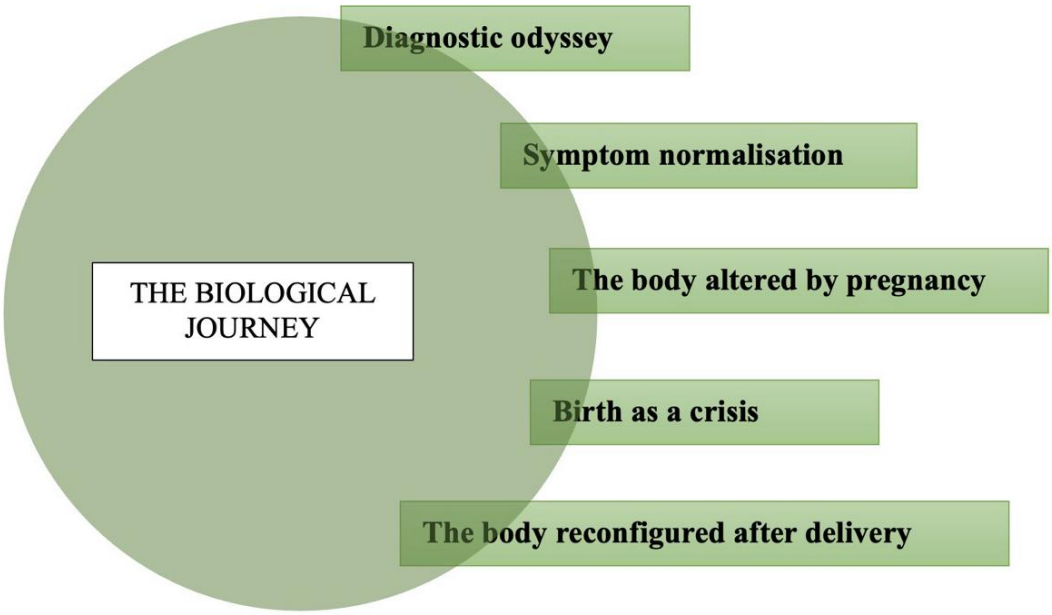
The nine participants ranged from a 20-year-old primigravida to a woman above 40 years multipara with a prior mitral valve replacement; they included women whose cardiac disease was known before pregnancy (P003, P005, P006, P007, P008, P009) and women whose cardiac disease was first recognised during or after pregnancy (P001, P002, P004). The diagnostic mix

included RHD, CHD with severe pulmonary hypertension, PPCM, infective endocarditis, a prior mitral valve replacement, and sickle-cell-related cardiac involvement. Outcomes ranged from live births with maternal recovery (P001, P003, P004, P005, P006) to live births with serious maternal morbidity (P008), stillbirth (P007), and second-trimester intrauterine foetal death at home (P009). The interviewed cohort comprised women whose deliveries had occurred between 1 and 3 years before the interview.

The sub-themes below are presented across three overarching thematic domains (the biological journey, the psychological journey, and the social and structural journey), with the structural sub-themes mapped to the Three Delays Framework. Each sub-theme is illustrated with verbatim participant quotes. Where a finding is shared across many participants, this is stated; where it is more particular, the specific participant is named so the reader can see the texture without losing the analytic claim.

THEME A: THE BIOLOGICAL JOURNEY

Figure 7: *The Biological Journey of patients with cardiac disease in pregnancy at JOOTRH*



Sub-theme 1: The diagnostic odyssey (repeated misrecognition before a correct diagnosis)

A feature of nearly every interview was the journey through multiple misdiagnoses, treatments for the wrong condition, or symptom normalisation that preceded an eventual correct cardiac diagnosis. Six of the nine participants described being treated extensively for conditions other than cardiac disease before their actual diagnosis was made.

P001 was treated for pneumonia in pregnancy, with intravenous antibiotics for two months in a peripheral hospital before being referred to JOOTRH, where she was correctly diagnosed with infective endocarditis: "They treated me for pneumonia for two months. I was on ceftriaxone … When I came to JOOTRH, they tested me and found infective endocarditis." P003 was treated in secondary school for "an untreated throat-something" with ibuprofen and unspecified medicines; her palpitations were attributed to examination stress by her aunt and to possible pregnancy by her teachers before rheumatic heart disease was identified at a specialist's clinic. P005's account is the most striking: she lived with undiagnosed congenital heart disease for the entirety of her childhood and through six pregnancies, with her childhood symptoms attributed by her grandmother to her being "a very fragile and lazy child" and her later obstetric losses attributed to contraceptive use, before the actual diagnosis of a CHD was made in a seventh pregnancy at age 35: "I've gone to so many hospitals, and no one ever mentioned anything about my fingers … If they'd made the diagnosis earlier, then I would not have had to go through everything I've been through."- This was in reference to her finger clubbing.

In the participants for whom the cardiac diagnosis came only after a major adverse event, the delay had clear clinical consequences: P007's congenital heart disease was identified only after her second stroke; P002 was treated for unidentified symptoms in a private hospital with no clear diagnosis given to her, despite the doctors discussing her condition at the bedside.

Sub-theme 2: Symptom normalisation and self-management before help-seeking

Across the cohort, women described long periods during which they normalised severe cardiac symptoms before considering medical help. The normalisation followed three patterns: attribution to pregnancy itself, attribution to character or constitution, and attribution to the spiritual realm.

P002 had been chronically fatigued before her pregnancy but had never sought care for it: "Even before my pregnancy, I used to get tired all the time. I didn't think to go to the hospital." Her response to symptom worsening was the same in pregnancy as before it, namely to wait it out and to pray: "Whenever I would feel really sick, I would just sit and rest for some time, then continue with my daily routines." P003 sustained the same strategy for nearly two academic years in boarding school: "In form three, I persevered through the same condition without telling anyone." She actively rejected help-seeking because she did not want to be regarded as fragile or unusual.

P005 lived for three decades with symptoms she had been taught to view as a feature of who she was rather than a sign of illness: "My grandma used to say that I was a very fragile and lazy child … None of us knew that it was an actual issue." P001, by contrast, normalised her cardiac symptoms specifically as features of pregnancy: "I already knew I was pregnant by the time I started feeling the chest pain, so I imagined that these were pregnancy symptoms."

The symptoms normalised across the cohort were not minor: profound easy fatigability, palpitations, near-syncope, bilateral leg swelling, orthopnoea (P007 slept upright for entire nights), exertional dyspnoea sufficient to prevent stair-climbing, and oxygen saturations in the 70s and 80s. Where the normalisation eventually broke down, the trigger was usually a discrete acute event (an episode of vaginal bleeding (P005), a stroke (P007), a collapse at home with respiratory distress (P002)) rather than a re-evaluation of the underlying chronic symptom.

Sub-theme 3: The body altered by pregnancy (cardiopulmonary decompensation)

The women in this cohort clearly described their cardiac symptoms during pregnancy. Their descriptions clustered around a similar physiological picture. They experienced fluid overload, breathlessness on exertion, palpitations, fatigue, and orthopnoea. The vividness of the descriptions is worth quoting verbatim. It is data on the weight of the disease.

P004: "My feet were too big for my shoes … sometimes I would feel my heart rate throbbing as though something had startled me … I couldn't even walk upstairs. Not even stairs, even on flat ground … we would be walking at a slow pace, but I'd be gasping for breath."

P007: "I even used to stay awake all night, because I couldn't breathe at all when I would sleep on my back. I would spend full nights sitting on a chair just so I could breathe properly."

P008: "I have trouble sleeping. I can't breathe properly when I lie down. I scare my mother sometimes because I breathe so deeply."

Sub-theme 4: Birth as crisis (vivid and frightening intrapartum experiences)

Childbirth in this cohort was rarely uncomplicated and seldom described in the language of joy. The accounts were dominated by emergency surgery, loss of consciousness, retained placenta, postpartum haemorrhage, and the bodily aftermath. Several women described moments at which they understood that their lives were in danger.

P008 was partially conscious for her caesarean and overheard the operating team: "As they were finishing up on the surgery, the doctor who was behind me asked how I was feeling … I couldn't answer coherently … I heard someone say: 'Doctor, I don't think this one is still with us. She's going.'"

P005's caesarean was followed by uncontrollable bleeding requiring three separate theatre trips: "After the operation, as I was waiting to go back to the ward, I started bleeding excessively, as usual. The next thing, I found myself waking up from an unconscious state … even after that second time, I was taken to the theatre a third time."

P003 fainted during her delivery at a peripheral hospital, was assigned to a student practitioner without supervision, retained her placenta, and bled severely. Her account is unusual in the cohort for containing an explicit critique of clinical supervision: “When I go to the delivery room, I’m not trying to look down on others, but if I’m assigned a student to attend to me, I feel like it’s very risky … even if a student were assigned, there should be a supervisor.”

P007 delivered an already-dead baby on the ward bed at night because, in her account, the staff had fallen asleep: “The baby was ready to come out, but they were not ready. They had fallen asleep, and everything happened so fast that they couldn’t take me all the way to the delivery room … It all happened at night, and most of them had dozed off.”

P009’s labour started at home (a second-trimester intrauterine foetal death) after she had been discharged from JOOTRH following a confusing cycle of repeated consents for termination that were never carried through. The amniotic sac ruptured as she was riding to JOOTRH on a commercial motorcycle. She described the experience in dramatic imagery: “The fluid that came out scared me because it was a strange colour. I am a mother, I’ve delivered before, but I’ve never seen anything like that. It was brownish, and it looked like the dirty water on the ground after rain. And it was ice-cold.”

Sub-theme 5: The body after delivery (incomplete recovery and chronic illness reconfigured)

A recurring biological sub-theme was that delivery did not end the illness. Most women described that their symptoms persisted in the postpartum period. They sometimes attributed them to the cardiac condition and sometimes simply lived with them.

P001 reported continuing to feel dizzy. She sensed that her body felt different from before: “My body feels a little different from before I got pregnant. But I think I’m recovering.” P002 reported persistent chest pain and exertional fatigue several months postpartum: “I’m still unwell post-delivery. My chest is painful, and I can’t do any heavy work … Occasionally, I get tired, but it’s manageable.”

For the participants who had a pre-existing cardiac disease, the postpartum period reconfigured their long-standing chronic illness around motherhood. P005 described her continued life on sildenafil as the new baseline; P008 was waiting to travel for definitive heart surgery; P009 was back on warfarin for life. Recovery for these women is not a return to a prior state. It was an adjustment to a permanently changed physiology. These were further compounded by the demands of an infant.

THEME B: THE PSYCHOLOGICAL JOURNEY

Figure 8: *The Psychological Journey of patients with cardiac disease in pregnancy at JOOTRH*



Sub-theme 1: Fear, anticipatory grief, and the imagination of one's own death

The most prevalent emotional theme in the interviews was fear of dying. This was expressed both as immediate anticipation during acute episodes and as a chronic background presence through the pregnancy. The fear was rarely directly elicited by the interviewer but emerged spontaneously in nearly every account.

P001 expressed it plainly: "I just didn't want to die. You know heart conditions are very serious. They are very risky. I just didn't want to die." For her, the fear was reinforced by the words of

family and community: “When the people around me, including my mother, heard that I had heart disease, everyone thought I was going to die. I also often felt like I was doomed.” For P003, the fear was articulated in existential terms: “I was very scared for my life during the entire duration of pregnancy.” For P007, the fear was concrete and had been realised: “I only had one fear during that time, and it happened: my baby’s death.”

Sub-theme 2: Desire to terminate (ambivalence about the pregnancy itself)

Several participants impulsively raised an early desire to terminate their pregnancy. The desire arose for different reasons. Sometimes it was from the symptom burden of the pregnancy itself, sometimes from external pressure, and sometimes from internal calculation of risk.

P001 wanted to terminate from the start: “From the beginning, I just wanted to terminate that pregnancy, because it was a very bothersome pregnancy.” P003 considered termination at 12 weeks once she understood the cardiac risk: “I even thought of getting rid of the pregnancy instead of risking my life.” P009’s account is the most institutionally complex: she did not herself want to terminate, but every other actor in her care pathway (her cardiologist, her husband, her doctor-relatives, the senior gynaecologist at JOOTRH) was united in their insistence that she do so. She experienced this as an erasure: “Everyone was on one side, and I felt like I was on my own.” When she eventually relented and consented, the system then failed to carry out the procedure. She ultimately experienced a second-trimester intrauterine foetal death at home.

There was ambivalence about pregnancy in the cardiac patients. They held simultaneously with hope, religious conviction, maternal desire, and clinical fear. This is a thread that runs through almost every interview. It is rarely resolved cleanly. P005 describes both an active desire for another child and an accepted clinical injunction not to conceive again. P008 says she will not get pregnant again. However, from her account, no clinical procedure was performed to ensure this.

Sub-theme 3: Coping by silence, prayer, and self-isolation

The main coping strategies described in this cohort were silence, prayer, and withdrawal. Few participants described actively seeking emotional support; many described actively avoiding it.

P002 returned repeatedly to a posture of unspoken endurance: “I couldn’t speak to anyone about my struggle. I would tell God. I would just pray about it.” The same posture appears in her account of the postpartum period: “I didn’t talk to anyone about the things I would hear doctors discussing. I would just keep it in my heart. I couldn’t even speak to my mum.”

P003 described a more severe withdrawal: “I would lock myself in my room for up to three days. I even thought of getting rid of the pregnancy instead of risking my life … I would just take walks and listen to music.” She was suspected by her university course-mates of drug use because of her changed behaviour.

For the women who had a strong religious frame, prayer was a primary resource. P002 “left it all to God”; P006 invoked God repeatedly throughout her account; P003 reported a shift toward belief in God arising from the experience itself: “I didn’t use to believe there was a God. But maybe. Maybe these experiences show that there is a higher power.”

A handful of participants described more proactive coping. P007 used Google to research her own condition, finding that knowledge reduced rather than amplified her fear: “I’m a very curious person who likes to research. I used to Google my condition and the symptoms. Somehow, that alleviated my fears.” P004 described herself as naturally talkative and used conversation with friends and family as her primary coping mechanism. These exceptions help define the rule: most participants did not have, or did not use, accessible counsellors for the psychological weight they carried.

Sub-theme 4: Identity reconfiguration (chronic illness, motherhood, and altered futures)

For the participants with chronic cardiac disease, the experience of pregnancy was inseparable from a wider reconfiguration of identity around being a person with a permanent, life-shaping illness. This sub-theme was particularly visible in the older interviewees.

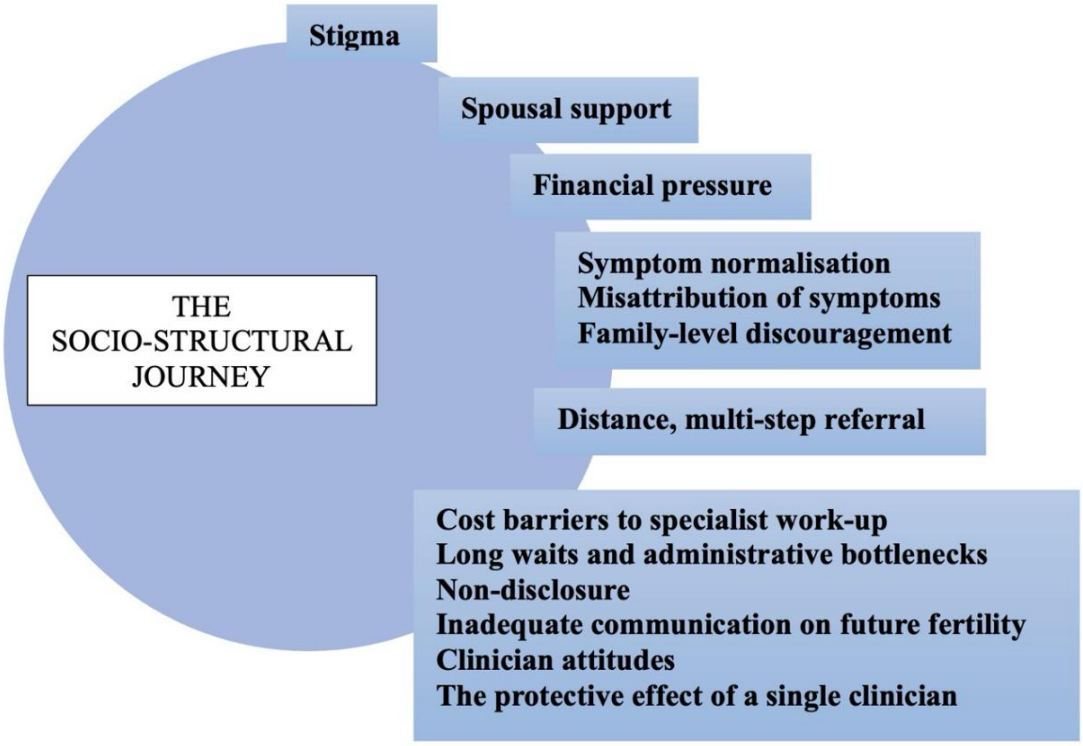
P005's reconfiguration is shaped by surrender to chronicity: "I had been managing it sufficiently since I was born. He told me to pretend that I was normal and okay. That's exactly how I've been living, and I've surrendered my life to God. Only God knows when I will die."

P009's reconfiguration is more activist: "When you have a chronic disease, you have to accept. Like me, I'm on warfarin, for life, willingly … I'm happy to speak for and advocate for people like me."

P003, the youngest woman with established cardiac disease, occupied a difficult middle position: old enough to recognise her chronicity but young enough to still resent its constraints: "I usually don't want to tell even my closest friends about this. Because I feel like life is not fair to me. There are things that they can do, and I am not able to do. Like I can't travel a lot, and I can't party like my friends."

THEME C: THE SOCIAL AND STRUCTURAL JOURNEY

Figure 9: *The Socio-structural Journey of patients with cardiac disease in pregnancy at JOOTRH*



Sub-theme 1: Stigma (perceived inadequacy, hiddenness, and the social cost of chronic illness)

Stigma in this cohort took several forms. There was anticipation of negative judgment, active concealment of the illness, and direct experiences of being treated as defective or irresponsible. P003 used performance to manage her condition in social space: "I have decided that in this life, you fake everything until you make it. Because as I walk, you would never know that I have any challenges. I pray that I never have any stigmatisation because of my condition."

P005's stigma was historical and accumulated. As a child, she was framed as fragile and lazy. As a woman, she experienced a different sort of stigma at the chemist when collecting sildenafil for her pulmonary hypertension: "I remember the chemist asking me if I was sure that was what I wanted. He looked at me suspiciously … sometimes it's a little embarrassing. People may assume that I am buying them because I have an old sugar daddy side piece."

P006's stigma was rooted in childhood taunting about her sickle cell disease ("my classmates used to taunt me and say that I'd die very early") and was compounded in adulthood by the

social embarrassment of having a child outside marriage: “I don’t want to embarrass my family again.”

In several cases, stigma also emerged from clinicians themselves. P008 was scolded post-delivery for having become pregnant: “He scolded me so much, saying that a person with my condition should never get pregnant. He asked me why I got pregnant. And what I had been seeking for.” P009 critiqued the health care workers at length: “I didn’t like that they made me feel like I was going to die the next day; that the pregnancy would make me die the next day … Why would they treat me like I was irresponsible for getting pregnant? I understand that there are emergency cases where decisions are made on behalf of the patients, but for my situation, I was conscious and I could make decisions.”

Sub-theme 2: Spousal Support

The single most polarising social variable in this cohort was the response of the woman’s male partner. The partners ranged from devoted to aloof, and the trajectory of the pregnancy mapped closely onto that variable.

P004’s husband was actively involved at every stage: present in the clinic, present at admission, present at discharge, dressing the baby because she could not, sorting out the file-retrieval issues. P005’s husband, faced with seven obstetric losses, kept asking her to try one more time and supported her through college in between her pregnancies, and stayed when many men, in her words, would have left. P006’s family (mother, sister, sister-in-law) converged around her in the absence of her absconding partner, with her brother personally paying for the inter-facility ambulance.

At the other end, three participants reported partners who were actively destructive of their care. P001 described pre-pregnancy and early-pregnancy intimate-partner emotional violence (she used the word “tortured”) and attributed her cardiac illness in part to the stress this produced: “I have to admit that just before and during the first months of my pregnancy, he

tortured me a lot … I believe that the stress he took me through caused my illness." P002's boyfriend used her vulnerability to demand cohabitation as a precondition for help. P008's partner abandoned her on hearing of the pregnancy. P003's boyfriend was loyal but financially destitute, leaving her aunt to bear the cost of her care.

The social support sub-theme is structurally important to this study because it interacts with every other domain. The women whose partners absented themselves or harmed them were also the women most likely to delay seeking care, to suppress symptoms, and to face cost barriers alone.

Sub-theme 3: Delay in seeking care

Symptom normalisation

The most common driver of Delay 1 in this cohort was the symptom normalisation already presented under Theme A, Sub-theme 2. Where women had been chronically symptomatic for years, the threshold for help-seeking was set high. P002's account is again classic: she had been chronically fatigued for years and had never sought care, and only sought care in pregnancy when the fatigue became unbearable. P005's lifelong symptoms had been so integrated into her self-concept that she could not see them as illness; her seeking-care trigger was not her own chronic dyspnoea but a discrete obstetric emergency. P003's delay in seeking care for her rheumatic heart disease symptoms was, paradoxically, motivated by a desire not to be perceived as someone who needed care.

Misattribution of symptoms to pregnancy itself

A second specific cause of Delay 1 was the attribution of cardiac symptoms to the pregnancy that was occurring simultaneously. P001 plainly described this trap: "I already knew I was pregnant by the time I started feeling the chest pain, so I imagined that these were pregnancy symptoms. But I later went for a general check-up when it became too much."

Family-level discouragement of help-seeking

In two cases (P003 and P008), help-seeking was actively delayed by family members' responses. P003's aunt told her that her palpitations and dizziness were the result of examination stress. She was told to ignore her symptoms. P008 hid her symptoms from her mother as long as possible. Her mother had already once told her not to get pregnant. The relevant point is that Delay 1 in this cohort was not confined to the individual woman. It was distributed across her social networks.

Sub-theme 4: Delay in accessing care

Distance, transport, and the burden of multi-step referral

Several participants described complex, multi-step journeys to reach an appropriate facility. P007's pathway started in a dispensary in Busia. She was then redirected through a sub-county hospital. She eventually ended at JOOTRH at eight months. P005 initially had to travel to Kisumu and then to Mater Hospital in Nairobi for her specialist pre-pregnancy work-up, incurring corresponding travel and accommodation costs. P006 was referred from a small dispensary in Kilgoris. She was then transferred to a larger hospital in Kilgoris. She landed at Kisii Referral but was ultimately transferred to JOOTRH. She travelled by ambulance, with the financial burden resting on a brother and a friend rather than the health system.

The financial aspects of Delay 2 are concrete. P008 was offered an ambulance for the Kisii-JOOTRH journey at KES 8,000. Her sister could not afford it. She eventually had to travel by public transport in critical condition: "The referral from Kisii to JOOTRH was a little difficult; they wanted 8,000 shillings for an ambulance to bring me here. My sister didn't have that money, so we did a self-referral and took public transport all the way to Kisumu."

Sub-theme 5: Delay in receiving care

Cost barriers to specialist work-up

For participants whose work-up required private-sector cardiology care, the cost barriers were substantial. P005 reported: "Cardiologists are so expensive. Consultation alone is 4,000

shillings; the cost is even more: echo is 12k, and ECG is 5k." P003 reported spending KES 70,000 on her cardiac evaluation in Nairobi. Her aunt eventually expressed resentment at funding her: "My aunt used to cater for these expenses, but at some point, she said I was finishing her money."

Long waits and administrative bottlenecks at JOOTRH

Once at JOOTRH, several participants described long waits before receiving clinical attention. P001 described an entire day in the outpatient waiting area, an overnight wait, and an admission only the next morning. She also had the additional complication of an insurance approval issue. P004 described an entire day spent in line at a gynaecological outpatient clinic. She later discovered that her file had not been retrieved and the doctor could therefore not attend to her. P008 stayed admitted on a JOOTRH ward for two weeks, waiting for the specialist who would conclusively direct her management.

P009's account is the most extended example of Delay 3. She was admitted at JOOTRH and asked to sign repeated consents for termination. She then watched several days pass without the procedure being performed: "I would sign a consent for termination on one day, then on the next day, the team who had gotten my consent don't show up, then another doctor wouldn't make me sign again, and it kept on happening for a couple of days. I wondered why we had delays, and yet, I had already accepted." Her three-week admission ended with discharge home, where her second-trimester foetus died.

Non-disclosure (clinical information withheld from the patient)

A recurrent but strange sub-theme of Delay 3 was the systematic non-disclosure of clinical information to patients. Several participants reported overhearing their diagnosis discussed at the bedside. They were, however, not told the diagnosis directly.

P002 was emphatic: "No doctor told me anything about my heart condition. I would hear them talk during ward rounds. One time, I heard them say that I shouldn't get pregnant again. They

said this should be my last. It scared me." And again, in the postpartum: "No one has ever talked to me about my condition. I am curious about what those imaging tests revealed. I would like to understand … I honestly don't know what's wrong with my heart." P002 was 20 years old, a first-time mother, postpartum, and did not know what her diagnosis was at the time of the interview.

P004 had been managed through a complete inpatient stay, a caesarean section, and a discharge, and still did not know her diagnosis: "I came here today because I was curious. You know, I've always suspected that there was something wrong with my heart, and as the doctors were speaking before and after my delivery, I would overhear them talking about it. But no one told me anything … I left the hospital not knowing what the issue was. So, I thought perhaps it's just a very difficult pregnancy."

Inadequate communication around contraception and future fertility

Closely related to the above theme was a recurring pattern of inadequate communication about future fertility. Three participants (P006, P008, P009) actively requested bilateral tubal ligation and did not receive it. P006 reported being "taken round in circles" by a doctor unwilling to commit; P008's sister requested it on her behalf and was refused; P009 consented to it after vaginal delivery, and the anaesthetist cancelled the operative procedure. In each case, the patient left the institution still capable of conceiving, despite having explicitly requested permanent contraception and despite having a cardiac condition that she and her clinicians both considered to make further pregnancy unsafe.

In contrast, two participants (P001 and P003) reported clear contraceptive counselling and the placement of a chosen method. P002 received no contraception counselling at discharge and only a generic group talk at a later MCH visit, from which she withdrew. The variance is substantial and is not explained by clinical severity.

Clinician attitudes (scolding and moralising)

A specific sub-theme of Delay 3 was the experience of being scolded or moralised at by clinicians once admitted. P008 reported a postoperative scolding from a doctor: "He scolded me so much, saying that a person with my condition should never get pregnant. He asked me why I got pregnant. And what I had been seeking for." P009 described the same experience in a different language: "They made me so anxious … Some would talk badly, and I would cry in private." P007 reported a perception of disengagement and a "blame game" at the hospital.

There were also some positive experiences recorded with this cohort. P001, P003, P004, and P006 spoke positively about some clinicians at JOOTRH. They named specific nurses, doctors, and members of the cardiology team. They were kind, attentive, and present. Negative experiences are not the whole story. Their frequency, however, suggests that they form a clear pattern rather than isolated incidents.

The protective effect of a single empathetic clinician

In several cases, the trajectory of a participant's care turned on a single clinician. An empathetic, attentive clinician was willing to listen and to advocate. P004's referral to JOOTRH from KCRH happened because a doctor-friend insisted. P009's eventual discharge from a chaotic admission came when a senior female gynaecologist arrived and questioned the management. P008's dental clearance was halted by an MFM specialist. He refused to allow further teeth to be extracted on top of everything else she had endured. These small, specific acts of advocacy show that the system can work when the right person is in the room. By implication, the system fails because the right person is not always there.

Sub-theme 6: Financial pressure as a determinant of every other delay

Financial pressure was experienced across the cohort. The limitation affected help-seeking, reaching care, and receiving care. P005 described the cost of being a cardiac patient outside the public-sector pathway. P008 travelled by public transport in critical condition because she could not afford a referral ambulance. P003 spent at least KES 70,000 in medical costs. She eventually lost her aunt's financial support partway through. P002 was managed at a private hospital, which provided her with no diagnosis before transferring her care. P001 spent a full day waiting at JOOTRH because her county government insurance was not active.

CHAPTER FIVE

DISCUSSION

5.1 CHARACTERISTICS OF CARDIAC DISEASE IN PREGNANCY

The cohort skewed towards younger ages. 44.4% of women were aged 18-24 years and 37% were aged 25-35 years. This aligns with previous regional studies with a median age of 26 years in western Kenya (Lumsden et al., 2020; Snelgrove et al., 2021). This is also a unique epidemiological pattern that contrasts with trends in HIC countries. Age-related inferred issues include educational interruptions, financial hardship, the burden of long-term or permanent contraception, and chronic medical care at a young age. More than half of the participants were single (55.6%). This high percentage of unmarried status is a significant variable that directly affects clinical prognosis and care-seeking behaviour (Poli et al., 2020). In developing countries, single motherhood often entails socioeconomic strain and reduced support networks. With 56% (15/27) of the cohort unemployed (homemakers and students), patients are financially dependent on extended family networks, who may not prioritise or understand chronic cardiac care. Clinical management cannot focus solely on medical prescriptions. It should incorporate social work assessments and financial subsidy pathways early in care. Without addressing partner support or economic vulnerability, treatment adherence and clinic attendance will remain severely compromised.

Regarding the clinical profile, the characteristics of this cohort demonstrate an advanced disease state. The spectrum is heavily dominated by acquired lesions, predominantly RHD and PPCM. The proportion of RHD at JOOTRH (40.7%) is lower than the 75% reported at MTRH (Lumsden et al., 2020) and substantially lower than the 92% reported in Senegal (Diao et al., 2011). However, RHD remains the leading aetiology. The presence of cases of infective endocarditis, Ischaemic Heart Disease, and a prosthetic-valve recipient (conditions absent or rare in earlier regional series) points to a broadening disease spectrum that demands diversified

clinical preparedness. The persistence of RHD reflects ongoing gaps in primary healthcare prevention, specifically the under-diagnosis and inadequate penicillin prophylaxis of streptococcal pharyngitis in childhood. Furthermore, the clustering of patients in NYHA Class III/IV at first contact occurs because early cardiac symptoms (fatigue, exertional breathlessness) are routinely normalised by women, families, and primary health workers as standard discomforts of pregnancy. Relying on secondary or tertiary symptom-driven presentation means that cardio-obstetric care remains reactive rather than proactive. This highlights an urgent necessity for routine first-trimester NYHA screening and targeted clinical training for nurses and clinical officers at Level 2 and 3 health facilities to flag subtle cardiac symptoms early.

The cohort presented with severely compromised functional status. This is a concern, given that the CARPREG II investigators and the mWHO classification state that prior functional state more reliably drives risk than the type of cardiac lesion (Silversides et al., 2018). The complete absence of patients presenting with NYHA Functional class one reveals that women are entirely missing from early risk stratification windows. Instead, they enter the tertiary healthcare system late, frequently intrapartum or during an acute peripartum crisis, already in advanced NYHA functional classes II, III and IV. The physiological volume expansion and hyperdynamic state of pregnancy act as an unmasked "stress test" on a structurally compromised heart, triggering pulmonary congestion and acute heart failure. The strikingly high co-occurrence of pre-eclampsia (40.7%) suggests a shared pathophysiological pathway of vascular strain, altered placental perfusion, and endothelial dysfunction, compounding systemic vascular resistance against an already failing ventricle. Pregnant women with structural heart lesions should automatically be managed as high-risk for hypertensive disorders of pregnancy, warranting early initiation of low-dose aspirin and routine

multidisciplinary co-management between cardiologists and maternal-foetal medicine specialists.

The possibility of over-representation of severe cases at JOOTRH may be considered; however, this skew reflects an accurate clinical reality rather than a selection artefact. The clinical reality is driven by various socio-biological factors found in this data set. First, JOOTRH functions as the main referral centre for the Lake Victoria Basin. Patients in NYHA Class I (asymptomatic during ordinary physical activity) remain invisible to peripheral facilities and are therefore never triaged or referred up the care ladder. JOOTRH naturally aggregates patients mostly when they cross into decompensation. A vast majority of high-risk cardiac patients present with advanced NYHA functional classes due to the complete absence of early first-trimester screening and structured risk stratification (Wiradnyana et al., 2025). Importantly, while the majority of the patients (59.3%) resided within Kisumu County, the remaining 40.7% were referred from surrounding counties across western Kenya. This wide geographic distribution confirms JOOTRH's critical role as a regional tertiary referral hub. However, the extensive catchment area also reveals a structural vulnerability, with patients travelling from as far as 115 km (Busia) for critical care.

Secondly, there was an exceptionally poor ANC utilisation and uptake. Only 5 of the 27 high-risk patients attended the first ANC during the first trimester, and only 1 of the 27 came close to attending the 8 recommended contacts for low-risk pregnancies (WHO Recommendations on Antenatal Care for a Positive Pregnancy Experience, n.d.). Additionally, only 9 patients (33%) visited a specialist, such as an obstetrician/gynaecologist or cardiologist. This means that a majority of these high-risk pregnancies began without the benefit of pre-conception counselling, medication optimisation, or anaesthetic and delivery planning. There is currently no systematic clinical mechanism in primary care to screen for, flag, and capture asymptomatic (NYHA I) cardiac lesions early in gestation. This blind spot aligns with the retrospective profile

compiled at an Indonesian referral centre, which shares the same critical operational feature. A vast majority of high-risk cardiac patients present with advanced NYHA functional classes due to the complete absence of early first-trimester screening and structured risk stratification (Wiradnyana et al., 2025).

Thirdly, sixteen of the 27 women (59.3%) had their cardiac disease first recognised during pregnancy or in the postpartum period. These women were subclinical or entirely ignorant of their underlying structural heart lesions during early pregnancy. The normal physiological challenges of pregnancy, which peak during the second trimester, compromised their heart. This plunged the previously asymptomatic women directly into an acute cardiovascular crisis (NYHA II/II/IV), bypassing the early presentation entirely.

Regarding obstetric history, most participants in this cohort were primigravida. However, of the multiparous women, two had had one previous stillbirth while one had had three previous stillbirths. Additionally, two participants had had 2 miscarriages, while one had had three. Perinatal mortality is linked to the highly compromised cardiovascular state of pregnancy with cardiac disease (Bright et al., 2021; Owens et al., 2018).

5.2 OUTCOMES OF CARDIAC DISEASE IN PREGNANCY

Spontaneous vaginal deliveries (SVD) accounted for less than half of the outcomes (45%), while 36% of the cohort required caesarean sections and 9.1% underwent assisted vaginal delivery (vacuum extraction). This reliance on operative delivery highlights the high frequency of complex obstetric situations and urgent clinical distress.

Maternal mortality was 14.8%, exceeding the 12.2% reported at MTRH (Lumsden et al., 2020) for a comparable Western Kenya cohort and approximately twenty-four times the general obstetric mortality at JOOTRH. Alongside an intensive care unit (ICU) admission rate of 41%. These statistics reflect a major clinical vulnerability in low-resource settings. Late recognition driven by various barriers to health allows cardiac conditions to escalate to advanced, life-

threatening functional classes (Poli et al., 2020). A referral from a regional hub to a more specialised hospital highlights gaps in capabilities. This calls for the immediate deployment of resources and infrastructure upgrades to provide comprehensive patient care.

Cardio-obstetric MACE (ref. operational definition of terms) occurred in 63% of the cohort. This was dominated by heart failure or pulmonary oedema, and thromboembolic events affected 26% of the women. This high rate of cardiovascular failure is characteristic of decompensation caused by cardiac disease in the context of the physiological changes in pregnancy.

Over 41% of the cohort had concurrent pre-eclampsia or eclampsia, illustrating a dangerous intersection of pregnancy and cardiac complications. This worsens the systemic vascular strain on an already failing maternal heart. It highlights the need for multidisciplinary intervention (Easter et al., 2020; Mayer et al., 2018). The 40.7% pre-eclampsia rate is biologically plausible: cardiac pregnancies share endothelial-dysfunction pathways with pre-eclampsia, and the cohort's high valvular and rheumatic burden heightens that risk.

A key finding in this study was the predictive strength of baseline functional compromise. On bivariate testing using Fisher's exact test, presentation in NYHA functional class III/IV at entry was significantly associated with Major Adverse Cardiovascular Events ($p=0.003$). On multivariable Firth-penalised logistic regression, NYHA III/IV remained the sole independent predictor of MACE. It yielded a very large adjusted odds ratio of 139.10 (95% CI: 5.68-48,342.66; $p<0.001$). Methodologically, this analysis establishes the direction and statistical significance of the relationship, thus confirming that advanced functional compromise is strongly linked to adverse cardiac outcomes. It, however, does not reliably establish the exact point magnitude of risk. This is due to the extremely wide confidence interval resulting from small-sample separation (N=27). Clinically, therefore, NYHA Class III/IV is best understood

as an urgent triage marker indicating acute cardiac vulnerability at tertiary presentation, rather than a proven antecedent risk factor.

5.3 EXPERIENCES OF CARDIAC DISEASE IN PREGNANCY (TRIANGULATION)

The qualitative findings contextualise and complement our quantitative findings. The interview sample reflects the full breadth of the quantitative spectrum: P003 had RHD diagnosed in secondary school; P005 had congenital VSD with severe pulmonary hypertension diagnosed only in her seventh pregnancy; P001 had infective endocarditis; P004 had hypertensive heart disease; P008 had congenital heart disease known since she was two weeks of age but never surgically corrected; P009 had undergone mitral valve replacement five years earlier and was on lifelong anticoagulation. The qualitative material confirms the spectrum but also adds an important interpretive observation about how it is currently being identified. P001's pathway is classic: she was treated with intravenous ceftriaxone for presumed pneumonia in pregnancy for two months at a peripheral facility before being referred to JOOTRH, where infective endocarditis was identified. The disease spectrum is broadening, but the clinical infrastructure to identify the newer entities at the peripheral level lags behind the epidemiological transition. The sociodemographic distribution is also not socially neutral. The qualitative material adds a critical observation about the cohort's youth. The youngest women in the interview sample were often the least financially supported and the least likely to have had a preconception clinical evaluation. P002, a twenty-year-old primigravida postpartum, was dependent on her family's income. P003, a university student, described running out of family support midway through her care:

"My aunt used to cater for these expenses, but at some point, she said I was finishing her money." -P003

The implication is that the cohort's youth correlate with economic dependence and disrupted education, both of which compound the access barriers that emerge in the findings.

Participants reported physical limitations. These included severe nocturnal orthopnoea requiring them to sleep sitting up (007) and extreme exertional dyspnoea (P004). They reflect a marked mismatch between baseline cardiac reserve and the predictable haemodynamic demands of pregnancy. These biological challenges are explained by maternal cardiovascular adaptations. These changes lead to increases in plasma volume, stroke volume, and heart rate, acting as an in-built "stress test" that unmasks or rapidly exacerbates subclinical structural heart lesions (Bright et al., 2021; Costantine, 2014). For younger women with cardiac disease, these physical limitations are not merely medical events but significantly shape their early self-perceptions. This aligns with the qualitative insights of a Japanese study that observed that adolescent girls living with congenital heart defects experience anxiety about their bodies' capacity to sustain a future pregnancy, often viewing their biological identity through a lens of anticipated maternal vulnerability (Nakamura et al., 2018).

Sixteen of 27 women (59.3%) had their cardiac disease first recognised during pregnancy or in the postpartum period. The descriptions in the biological journey are clinically congruent with the high prevalence of NYHA III/IV functional status (81.5%) and the high MACE rate (63.0%) documented in the quantitative arm. The qualitative material allows for contextualisation of what those rates mean in an individual's life. Further, these high-risk pregnancies began without the benefit of pre-conception counselling, medication optimisation, or anaesthetic and delivery planning. The qualitative arm identifies three mechanisms that produce this rate. The first is misattribution of cardiac symptoms to pregnancy itself, articulated by P001 in textbook form:

"I already knew I was pregnant by the time I started feeling the chest pain, so I imagined that these were pregnancy symptoms. But I later went for a general check-up when it became too much." -P001

The clinical mistake (assuming that chest pain in pregnancy is a feature of pregnancy) is well-described in the cardio-obstetric literature; the qualitative material confirms that patients themselves make this mistake and use it to delay help-seeking (Chang et al., 2018; Dawson et al., 2018).

The second mechanism is misattribution of long-standing cardiac symptoms to constitution or character, sustained for years and reinforced by family members. P005 lived for three decades with undiagnosed congenital heart disease while her grandmother attributed her symptoms to laziness:

"My grandma used to say that I was a very fragile and lazy child … None of us knew that it was an actual issue." -P005

The third mechanism is misdiagnosis at peripheral facilities. P001 was treated for pneumonia for two months before infective endocarditis was identified. P003 was treated as a secondary school student for an "untreated throat-something" with ibuprofen and unspecified medicines before rheumatic heart disease was finally recognised. The 59.3% figure is therefore not the product of a single failure but of a chain of failures distributed across the patient, her family, and peripheral health facilities.

The qualitative arm reveals that women presenting in NYHA III/IV had usually been functioning at that level for an extended period before any clinician documented the class. P007 spent entire nights sitting upright because she could not breathe lying down:

"I even used to stay awake all night, because I couldn't breathe at all when I would sleep on my back. I would spend full nights sitting on a chair just so I could breathe properly." -P007

P004 described being unable to walk on flat ground without gasping for breath:

"My feet were too big for my shoes … sometimes I would feel my heart rate throbbing as though something had startled me … I couldn't even walk upstairs. Not even stairs, even on flat ground … we would be walking at a slow pace, but I'd be gasping for breath." -P004

None of these women had received a formal NYHA assessment before her admission for the index pregnancy. The clinical implication is that the NYHA III/IV variable in the quantitative dataset is not simply a measure of the acute severity of cardiac disease; it is a measure of how long advanced functional class has been allowed to develop unrecognised.

The qualitative material clarifies what the "specialised visit" variable actually captures. In this cohort, it functions partly as a marker of socioeconomic access and prior specialist relationship, rather than purely as a marker of clinical contact. P005 described the cost structure of private cardiology in Kisumu and Nairobi in concrete terms:

"Cardiologists are so expensive. Consultation alone is 4,000 shillings; the cost is even more, echo is 12k, and ECG is 5k." -P005

The women who accessed specialised review tended to be the women who already had a pre-existing chronic-disease specialist relationship: P003 with her rheumatic heart disease clinic, P005 with her cardiologist at Mater Hospital in Nairobi, P009 with her cardiothoracic team since her mitral valve replacement. The policy implication is direct: recommending specialised review without simultaneously addressing financial barriers will reinforce existing inequalities rather than reduce them.

The psychological burden of navigating a high-risk cardiac pregnancy at JOOTRH was characterised by acute emotional isolation and existential fear, driving some women to isolate themselves for days or even to consider pregnancy termination to preserve their lives (P003). This severe psychological burden is corroborated by an Australian-based study (Hutchens et al., 2022c). The characterised cardiac disease in pregnancy and the post-partum period is a 'story of mental health, identity and connection', in which women must reconstruct their identity under the threat of maternal death (Hutchens et al., 2022a). The long-term implications of this distress were highlighted in the same study, whose quantitative evaluation showed that women with a peripartum cardiac diagnosis experience lower long-term health-related quality

of life and persistent mental health morbidity compared with general obstetric populations (Hutchens et al., 2022b). Furthermore, the reliance on religious coping mechanisms and the sense of total vulnerability found in the JOOTRH cohort echo the phenomenological findings of a Jordan-based qualitative study. They noted that pregnant women with congenital heart disease frequently experience a lack of autonomy, relying heavily on external support networks to mitigate overwhelming anxieties regarding foeto-maternal survival (AL Obieat et al., 2023). Additionally, the JOOTRH cohort experienced a phenomenon similar to that reported in a qualitative study in Uganda. Reproductive-age women living with RHD reported facing significant societal and clinical stigma. In their study, women experienced judgment regarding childbearing expectations. This affected their emotional well-being and willingness to engage openly with care pathways and systems (Chang et al., 2018).

What is distinctive about this cohort is that fear of death identified in the psychological journey was not paranoid or unfounded: four of the 27 women in the broader census did die, and several of the interviewees came close. P008 overheard the operating-theatre team declare she was dying; P005 was returned to the theatre three times. The psychological texture of these accounts is therefore not anxiety in the conventional clinical sense but a reasoned anticipation of a real, statistically supported possibility.

The qualitative material identifies several pathways that contributed to the severity of obstetric and cardiac outcomes that the records alone could not have surfaced. The most acute theme is the in-facility delay. P007, who experienced an intrapartum foetal death during her admission, described a perception of clinical disengagement and a sense that her decompensation was not being treated as urgent:

“I delivered in the ward, on the same bed where I’d been admitted. The baby was ready to come out, but they were not ready. They had fallen asleep, and everything happened so fast that they

couldn’t take me all the way to the delivery room. It all happened at night, and most of them had dozed off.” -P007

P009 was admitted for three weeks during which she signed repeated consents for termination of pregnancy that were never carried through; she was eventually discharged still pregnant and experienced a second-trimester intrauterine foetal death at home a week later. P008, who survived a near-fatal caesarean section, overheard the operating team during the procedure:

“As they were finishing up on the surgery, the doctor who was behind me asked how I was feeling … I couldn’t answer coherently … I heard someone say: ‘Doctor, I don’t think this one is still with us. She’s going.’” -P008

The 14.8% maternal mortality figure is therefore best understood not as a fixed property of the cohort but as the product of a chain of failures, each of which is amenable to specific intervention. The 13-day median length of stay captures both the clinical severity of the cohort and episodes of in-facility delay that contributed to deterioration, a finding the dataset alone could not have produced.

The 25.9% thromboembolic event rate is biologically consistent. Pregnancy is hypercoagulable. The high proportion of valvular disease therefore independently raises thromboembolic risk (Bright et al., 2021; Pfaller et al., 2020). The 77.8% anticoagulant prescription rate reflects appropriate clinical recognition of this risk. The qualitative material notes that the practical demands of warfarin or enoxaparin management (frequent INR monitoring, the cost of Clexane, dietary discipline) are not trivial. Especially in a context where pre-existing chronic-disease specialist relationships are uncommon. P009, on lifelong warfarin switched to enoxaparin in pregnancy because of warfarin teratogenicity. She described the regimen as sustainable only because she had means and family support; this is not universal.

The 36.4% caesarean section rate among documented deliveries exceeds the 22.1% reported in Senegal for a comparable cohort (Diao et al., 2011). The qualitative material indicates that the

high rate in this cohort is not a function of clinical preference but of acute clinical decompensation that forces operative delivery. P001 underwent caesarean because of cardiac instability and chest pain. P005's caesarean was an emergency at 28 weeks for oligohydramnios. P008's caesarean was an emergency after failure to progress in induced labour, conducted in conditions she experienced as near-fatal. The high caesarean rate is therefore best interpreted as a downstream consequence of late recognition and late presentation rather than as an independent finding.

The qualitative material does not directly address birth weight but illuminates the pathway to prematurity. Almost none of the interviewees described a planned delivery at full term in the absence of a crisis. P005 delivered at 28 weeks by emergency caesarean for oligohydramnios with a 1.5 kg neonate. P007 delivered an already-dead foetus at 32 weeks after a period of acute maternal deterioration. P008 underwent an emergency caesarean after failure to progress in induced labour. P001 was delivered at 37-38 weeks because, in her words, "because of my chest pain and my condition, I couldn't go back home." The pattern across the interviews is that delivery was driven by maternal cardiac decompensation, by acute foetal compromise, or by both, not by elective scheduling.

The implication is direct: the 74.1% preterm birth rate is the result of two compounding processes. Late maternal recognition leads to an advanced functional class at presentation, and delivery is then driven by acute decompensation rather than by elective scheduling. The single most plausible lever for improving neonatal outcomes is therefore not a foetal intervention but earlier maternal recognition, which would, in turn, permit later planned delivery.

High preterm birth rates in this cohort are primarily *iatrogenic* or *physiologically forced* rather than spontaneous. Deliveries were consistently precipitated by acute maternal cardiac decompensation, severe pre-eclampsia, or acute foetal distress, forcing clinicians to perform emergency interventions (caesarean sections or inductions) before term to save maternal life.

Chronic maternal hypoxia and reduced uterine blood flow in advanced NYHA classes also contribute directly to intrauterine growth restriction and low birth weight. Improving neonatal survival depends directly on optimising maternal cardiac function earlier in pregnancy. Extending gestational age and reducing neonatal ICU stays cannot be achieved through foetal monitoring alone, but through structured maternal hemodynamic stabilisation.

Qualitative findings not triangulated

Three findings emerged from the qualitative arm of this study that have no corresponding measurement in the medical records dataset. They are reported here in full because their substantive importance exceeds what the finding-by-finding integration above could capture.

Intimate partner interaction as a contributor to illness onset and to care-seeking delay

Three of the nine interviewees (P001, P002, P008) described partner dynamics that significantly affected their cardiac illness or their care pathway. The issue arose unprompted in each interview. P001 explicitly attributed her infective endocarditis to the stress of partner violence:

"Me and my husband did not have a good relationship, especially earlier on … just before and during the first months of my pregnancy, he tortured me a lot. But I'm not in the right state of mind to talk about this. Let's talk about something else. However, I believe that the stress and torture he took me through caused my illness." -P001

P002 described a coercive boyfriend with a criminal history who used her vulnerability to demand cohabitation as a precondition for support. P008's partner abandoned her after discovering the pregnancy. The data extraction tool did not capture partner dynamics (appropriately, given the constraints of retrospective records review), and the quantitative arm is therefore silent on this determinant. One-third of the interview sample is a sufficiently high prevalence to demand an institutional response, including routine and sensitive screening for partner support at the cardio-obstetric specialised visit.

Failed bilateral tubal ligation requests: a discrete service-design failure

Three of the nine interviewees (P006, P008, P009) actively requested bilateral tubal ligation as a permanent contraceptive method. In each case, the patient and her clinicians both considered further pregnancy unsafe. In each case, the patient left the institution still able to conceive. P006 reported circular communication:

"I spoke to a doctor here in JOOTRH to help me get a BTL, but he seemed hesitant. He kept on taking me round in circles, and wouldn't commit to it. I really want a BTL. I don't want a third pregnancy. My body clearly can't handle it. I almost died during my last pregnancy. I don't understand why I couldn't get a BTL." -P006

P008's sister requested the procedure on her behalf and was refused with no recorded explanation. P009 consented to BTL post vaginal delivery to a stillbirth; her surgery was cancelled at the theatre door by an anaesthetist who deferred the procedure to cardiology clearance, and it was never rescheduled. The medical records capture procedures performed, not procedures requested and refused, and the quantitative arm is therefore silent on this finding. It is one of the clearest service-design failures identified in this study.

The finding above represents a critical, unmeasured breakdown in the postpartum service design, leaving vulnerable women exposed to life-threatening risks of subsequent pregnancies. This systemic failure to provide safe, definitive contraception to high-risk cardiac patients is a documented challenge globally and regionally. (Miranda-Silva et al., 2021) demonstrated that even in settings with robust infrastructure, there is low physician awareness and significant provider hesitancy regarding formal contraceptive counselling for women with chronic diseases. This leads to fragmented care and missed opportunities for reproductive optimisation. This gap is particularly dangerous, as shown in Tanzania, where a hospital-based cross-sectional study revealed that, despite high objective pregnancy risks, reproductive-age women with RHD have low rates of effective contraception utilisation and a profound lack of access

to structured family planning counselling within cardiac clinics (Poli et al., 2020). The poor communication and clinical hesitation experienced by P006 at JOOTRH directly reflect this regional failure to bridge the gap between maternal health and cardiology, transforming family planning from a routine intervention into a critical structural blind spot.

This failure stems from fragmented inter-departmental communication between obstetrics, cardiology, and anaesthesia, combined with clinical conservatism or moralising attitudes among healthcare providers regarding permanent sterilisation in young women. Without a clear institutional protocol, individual clinicians default to hesitation, deferring decisions and leaving vulnerable patients exposed to high-risk future pregnancies. Refusing or delaying requested contraception in women with severe cardiac disease constitutes a critical service-design failure that directly contributes to preventable maternal mortality. There is an immediate need to establish a clear, auditable institutional policy for postpartum contraception that respects reproductive autonomy and streamlines multi-speciality clearances.

Clinical non-disclosure to the patient

Two of the nine interviewees (P002, P004) were admitted to JOOTRH for serious cardiac disease, managed through entire admission cycles, and discharged without ever being told their diagnosis. P002 reported:

"No doctor told me anything about my heart condition. I would hear them talk during ward rounds. One time, I heard them say that I shouldn't get pregnant again. They said this should be my last. It scared me, but I left it all to God." -P002

P004 came to her interview, in her own words, "out of curiosity", because she had been managed at JOOTRH for a week antepartum, delivered by caesarean section, and discharged on multiple medications without ever being told what her diagnosis was. The finding has a direct implication for a care environment in which clinical decisions are not consistently communicated to the patient and in which the patient cannot challenge clinical errors.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 CONCLUSION

The objective of this study was to investigate the characteristics, outcomes, and experiences of pregnant women with cardiac disease managed at JOOTRH between May 2022 and April 2026. This was guided by three specific research questions. The findings were drawn from a complete census of 27 medical records and nine in-depth phenomenological interviews. Each question was answered in turn and then considered together. The findings describe a population that is young, socially vulnerable, structurally disadvantaged, and clinically fragile. This high-risk group exists in a health system which often recognises their disease too late and offers limited support once it does.

Concerning the first research question, on the characteristics that define pregnant women with cardiac disease at JOOTRH, the cohort was predominantly young and single. The participants were drawn largely from Kisumu County and its surrounding referral counties. The dominating cardiac disease was rheumatic heart disease, which accounted for four in every ten cases. Most women presented in advanced functional compromise, with over 80% in NYHA class III or IV at first contact. For nearly six in ten of them, the cardiac diagnosis was made only during pregnancy or the postpartum period rather than beforehand. Antenatal care utilisation was poor by any standard. Less than 20% of the women with cardiac disease attended antenatal clinic in the first trimester, and only a third ever received a documented specialised obstetric or cardiology review. The qualitative findings supply the explanatory mechanism behind these numbers. The diagnostic odyssey described by six of the nine interview participants, the normalisation of severe symptoms as features of pregnancy or of personal constitution, and the financial and geographic burden of multi-step referral together account for why so many

women arrived at JOOTRH already in functional crisis and already pregnant rather than as planned, pre-counselled patients.

Regarding the second research question on cardiac, obstetric, and foetal outcomes, the cohort experienced a burden of adverse outcomes considerably higher than that observed in general obstetric populations. The burden was also noted to be higher than comparable regional cohorts. Maternal mortality reached 14.8%. This exceeded the previously reported rate at a comparable Western Kenya referral hospital and was well above JOOTRH's general obstetric mortality rate. Heart failure or pulmonary oedema affected almost two-thirds of women, and four in ten required ICU admission. Foetal and neonatal outcomes were similarly compromised. Preterm birth before 37 weeks affected three-quarters of pregnancies. Four in ten babies were born with low birth weight. The composite adverse neonatal outcome was reached in nearly half of all pregnancies. The qualitative accounts described birth as a crisis. There were caesareans complicated by near-fatal haemorrhage, a stillbirth delivered unattended at night, and a second-trimester intrauterine death following a stalled termination pathway. All these accounts give the statistics their human shape and confirm that the numerical outcomes are not abstractions but lived, often traumatic, events.

Regarding the third research question on the lived experiences of pregnant women with cardiac disease, the qualitative findings describe a journey with three interlocking dimensions. Biologically, women endured prolonged and repeated misdiagnosis. They had severe and often unrecognised cardiopulmonary decompensation. All these ended in frightening intrapartum emergencies. The postpartum period did not resolve their chronic illness. Instead, their condition was redefined. Psychologically, the women had a sustained but reasonable fear of death. There was also a recurring ambivalence about the pregnancy itself. The coping strategies relied on silence and prayer rather than on professional support. For most of the cohort, there was then a gradual renegotiation of identity around permanent illness. Socially and structurally,

the women's trajectories were affected by stigma from family, community, and clinicians. There was a sharp divide between supportive and destructive partners. These were in addition to failures distributed across all three points of the Three Delays Framework. There has been delayed recognition driven by symptom normalisation and absent preconception counselling. The delayed arrival at the hospital was driven by cost and a multi-step referral. Delayed or inadequate care was experienced at JOOTRH itself. This was through the repeated non-disclosure of diagnoses and the unfulfilled requests for permanent contraception. The chain describing these biopsychosocial gaps has multiple links.

Link 1: Within the woman and her household. This is a first delay in which severe cardiac symptoms are normalised as features of pregnancy, of constitution, or of moral weakness. The threshold for help-seeking is set high. This link is the qualitative explanation for the quantitative late-recognition finding and the high NYHA III/IV burden at presentation.

Link 2: Accessing Healthcare. This is a second delay, in which high costs and long, winding travel distances to access specialised care represent structural delays that prevent timely access to healthcare services

Link 3: At peripheral health facilities. This is a third delay in which cardiac symptoms are misattributed to other diagnoses. Diagnostic infrastructure, such as echocardiography, is absent. Referral chains are multi-step and financially costly. This link is the qualitative explanation for the quantitative late-recognition finding, the late-booking pattern, and late access to cardio-obstetric specialists.

Link 4: At tertiary admission. This is also a third delay in which outpatient and admission bottlenecks delay entry to definitive care. Specialist review is unevenly available. Clinical information is not consistently communicated to patients. This link provides a qualitative explanation for the quantitative findings of high rates of adverse events and long stays.

Link 5: Postpartum continuation of care. This is yet another third delay in which contraceptive requests are inconsistently honoured. Specialist follow-up is difficult to obtain. Chronic-illness frames are not integrated with the postnatal pathway. This link is the qualitative explanation for the failed BTL finding.

Read together, the three arms of this study converge on a single overarching conclusion: cardiac disease in pregnancy at JOOTRH is not principally a problem of clinical unpredictability but one of systemic delay and incomplete information. The disease itself, once recognised and treated, behaves much as the international literature would predict. What distinguishes this cohort is the typically late recognition. Critically, the women in this cohort have little say in decisions about their own bodies and futures once they are admitted. All the while, the burden of managing the gap between symptom onset and definitive care falls on the woman herself, her family, and chance encounters with individual clinicians willing to advocate for her. Addressing this disease in Western Kenya, therefore, calls for improved cardiology and obstetric protocols. This is in addition to a deliberate, system-level investment in earlier recognition, stronger communication, and consistent reproductive autonomy for the women who survive it.

Subsequent studies should pursue multi-centre studies across Western Kenya and comparable settings to increase sample size and external validity. Additionally, prospective cohort designs that can capture cardiac, obstetric, and foetal outcomes as they occur would be more valuable than retrospective studies. Further work should also include key informant interviews with clinicians to balance the patient-centred perspective of the present study. This would provide an institutional perspective of those delivering care. Deliberate efforts should be made to capture the experiences of women with the most serious outcomes, including bereaved family members of women who died. This way, the most acute end of this disease's burden is no longer systematically excluded from qualitative inquiry.

To address the empirical and methodological constraints identified in this study, future research should embrace multi-centre collaborations across regional referral networks to capture larger sample sizes over extended multi-year observation windows. Expanding the quantitative cohort across multiple tertiary institutions will enhance statistical power, improve generalizability, and allow for robust predictive modelling without the statistical limitations of small-sample data separation. Additionally, prospective qualitative studies should incorporate key informant interviews with healthcare workers (including obstetricians, cardiologists, and midwives) as well as relatives and partners of affected women. Engaging healthcare providers will offer critical system-level insights into institutional bottlenecks, inter-departmental workflows, and referral gaps, while interviewing relatives (particularly in cases involving maternal mortality) will ensure that the perspectives of families experiencing the most severe adverse outcomes are no longer systematically excluded from qualitative inquiry.

6.2 RECOMMENDATIONS

Characteristics of patients

Routine NYHA assessment and structured cardiac symptom screening at first antenatal contact at every level of facility. The discriminative value of the NYHA functional class for adverse maternal cardiac events requires only a simple structured questionnaire and is feasible at any level of antenatal care. Service providers at lower-level facilities should be sensitised through CMEs to enhance their index of suspicion of cardiac disease. Knowledge of signs/symptoms of cardiac disease will prompt early detection. High-risk patients from the peripheral facilities would then be referred to JOOTRH for antenatal echocardiographic screening.

Outcomes of patients

Institutionalisation of a multidisciplinary cardio-obstetric team at JOOTRH with defined, time-bound clinical milestones. The team should include obstetrics/gynaecology, cardiology, anaesthesia, neonatology, and mental health, with monthly meetings and a documented decision register for each cardio-obstetric patient. The dedicated cardio-obstetrics team will execute structured risk stratification and proactive care management. This model is the gold standard, as shown in the 2018 ESC Guidelines for the Management of Cardiovascular Diseases during Pregnancy (Regitz-Zagrosek et al., 2018). Defining clear roles, communication pathways, and specialised protocols of a Pregnancy Heart Team significantly reduces institutional delays and prevents reactive crisis management (Easter et al., 2020; Ernst et al., 2024; Mayer et al., 2018).

Lived experiences of the patients

A patient-communication and disclosure standard for cardio-obstetric admissions at JOOTRH. Every cardio-obstetric patient should leave the facility with a plain-language written information sheet that includes her diagnosis, current medications, the rationale for those medications, her contraception plan, and her follow-up plan. The standard should be auditable. Introduction of shared decision-making (SDM) where patients and the healthcare workers collaborate to choose interventions and treatments based on clinical evidence and patients' personal values. It has been proven to improve outcomes by increasing patient knowledge, reducing treatment regret, and significantly boosting adherence to prescribed care plans.

A documented institutional pathway for permanent or long-term contraception in cardio-obstetric patients who request it. The failed BTL finding is a discrete service-design failure that institutional action alone can correct. The pathway should specify clinical indications, consent process, timing, and clearance steps. Where the procedure is declined, the reason should be documented and an alternative offered.

Subsidised, public-insurance-funded, or no-cost referral and specialist work-up for women with confirmed or suspected cardio-obstetric pathology. The financial-barrier theme cuts across every link of the chain. Without a facility-level subsidy program or formal integration with the Social Health Authority Fund pathway, the other recommendations cannot be fully operationalised.

6.3 STUDY LIMITATIONS

The study had three major limitations. First, the quantitative cohort was small (N = 27). The precision of even the strongest inferences is limited. The qualitative material can contextualise the findings but cannot statistically address this constraint. Moreover, the small sample size and the single-site study design limit the generalizability of these findings to the broader population of pregnant women with cardiac disease in Western Kenya. Second, the qualitative interviews could only be conducted with women who survived long enough to be interviewed. The four women who died, and any others with severe morbidity that prevented participation, are silent in the qualitative arm; the triangulation, therefore, systematically under-represents the worst outcomes. This survivor bias further limits the external validity of the results, as the experiences of those with the most severe outcomes are not captured. Third, some of the important qualitative findings (non-disclosure, refused BTL requests, intimate partner violence) are by their nature invisible to a retrospective medical record review. Their identification depends on the qualitative arm. Future research should address these constraints through multi-centre collaboration, larger sample sizes across several years, conducting key informant interviews, and prospective study designs that enable the inclusion of a wider range of patient experiences, including those with severe or fatal outcomes.

Previously predicted limitations for the qualitative arm, such as loss to follow-up and compromised functional status, were not observed. Although one study subject rescheduled her appointment at the last minute, another lost her phone before the interview and couldn’t be

reached. The latter was contacted through her sister's phone, and she presented for the interview. The presence of a counsellor ensured the stabilisation of study participants who experienced emotional distress. For the quantitative arm, the quality and completeness of medical record data slightly limited the study. For specific records, additional information had to be extracted from theatre records and the nurses' daily report book. Four patient files couldn't be traced, specifically those of patients seen in 2022 and 2023. Their data could not be verified, and they were completely excluded from the study.

6.4 STUDY DELIMITATIONS

The study was strictly limited to Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) in Kisumu County, Kenya. Although JOOTRH serves as a regional referral hub for the Lake Region and Western Kenya, covering 14 counties, the investigation focused exclusively on the inpatient wards and outpatient clinics of its Obstetrics and Gynaecology department. Other tertiary regional centres, such as Moi Teaching and Referral Hospital (MTRH), were excluded from primary data collection. The study population comprised women of reproductive age (15 to 49 years) with a confirmed, documented diagnosis of cardiac disease. The spectrum of cardiac disease included congenital, genetic, and acquired disorders. Patients with isolated hypertensive diseases were excluded. The cohort comprised women who had experienced pregnancy in the context of cardiac disease. The investigation covered a 48-month period, including cases managed between May 2022 and April 2026. The research design employed a convergent parallel mixed-methods approach. The quantitative component comprised a retrospective, analytical cross-sectional review of patient files identified through census sampling. This yielded a final cohort of 27 complete medical records. Simultaneously, the qualitative component utilised a cross-sectional phenomenological design involving nine in-depth interviews. Participants were selected using purposive maximum-variation sampling. For the quantitative registry review, files with critical missing variables, structural

incompleteness, or clerical illegibility were excluded. For the qualitative component, patients who were clinically unstable at recruitment and women with ongoing pregnancies were deliberately excluded. Excluding ongoing pregnancies ensured that interviewees could provide a comprehensive, reflective account of their entire reproductive journey from diagnosis through delivery and recovery.

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APPENDICES

APPENDIX 1: CONSENT FORM

ENGLISH
Principal Investigator: Dr Caren Otadoh
Supervisors: Dr Jackton Omoto; Dr Rosebenter Owuor

Introduction

You are invited to participate in a research study that explores the experiences of women who have been pregnant while having a cardiac disease. This study is being conducted at Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH)

Purpose of Study

The purpose of this study is to gain a deeper understanding of the experiences of women with cardiac disease during pregnancy, childbirth, and the post-delivery period. This includes understanding your physical and emotional well-being, communication with healthcare providers, and social support. The findings from this study may help improve healthcare services for pregnant women with cardiac disease. It is part of a broader study that will also examine the characteristics and outcomes of women with cardiac disease who have been managed in JOOTRH between May 2022 and April 2026.

Study Procedures

If you agree to participate, you will be asked to:

- Participate in an in-depth interview lasting approximately 45minutes. The interview will be audio-recorded with your permission.
- Answer questions about your experiences with pregnancy, childbirth, and post-delivery care while having a cardiac disease.
- The interview will be conducted in a private and comfortable setting at JOOTRH.

Risks and Benefits

There are minimal risks associated with this study. You may experience some discomfort discussing your experiences. You are free to withdraw from the discussion at any time.

There are no direct benefits to you for participating in this study. However, the information you share may help improve the care provided to pregnant women with cardiac disease in the future.

Confidentiality

All information you provide will be kept confidential. Your name and other identifying information will not be included in any reports or publications resulting from this study. The audio recordings will be anonymized, securely stored, and later discarded.

Compensation

You will not be compensated for your participation in this study.

Voluntary Participation

Your participation in this study is voluntary. You have the right to refuse to participate or to withdraw from the study at any time without any penalty.

Questions and Concerns

If you have any questions or concerns about the study, please feel free to ask me **(Dr. Caren Otadoh)** at **+254710254325** during the functional hours: **9 am to 4 pm,** or send me an email at **dr.otadoh@gmail.com.** Should you wish to contact the JOOTRH ethics board directly, you may send an email to: **ercjootrh@gmail.com**.

Your Decision

You will be given a copy of this consent form to keep for your records. Please take a moment to review this form before deciding whether to participate.

Statement of Consent

I have read, understood, and agree to the information presented in this consent form. I have had the opportunity to ask questions and have received satisfactory answers in a language that I understand. I voluntarily agree to participate in this study.

Participant Name…… Participant Signature……. Date…….

I have explained all the relevant details of this research study to the participant above, in a language they understand. I am convinced that the participant has understood and given their consent freely.

Researcher Signature…… Date……

SWAHILI TRANSLATION: FOMU YA RIDHAA

MADA: TAJRIBA ZA MAISHA, SIFA, NA MATOKEO YA WANAWAKE WAJAWAZITO WENYE UGONJWA WA MOYO KATIKA HOSPITALI YA RUFAA YA JARAMOGI OGINGA ODINGA (JOOTRH), KISUMU, KENYA.

Mtafiti Mkuu: Dr. Caren Otadoh

Wasimamizi: Dr. Jackton Omoto; Dr. Rosebenter Owuor

Utangulizi

Unakaribishwa kushiriki katika utafiti unaochunguza tajriba za wanawake waliokuwa na uja uzito huku wakiwa na ugonjwa wa moyo. Utafiti huu unafanyika katika Hospitali ya Rufaa ya Jaramogi Oginga Odinga (JOOTRH).

Madhumuni ya Utafiti

Lengo ni kuelewa kwa undani tajriba za wanawake wenye ugonjwa wa moyo wakati wa uja uzito, kujifungua, na baada ya kujifungua. Hii ni pamoja na kuelewa hali yako ya kimwili na kihisia, mawasiliano na wahudumu wa afya, na msaada wa kijamii. Matokeo haya yanaweza kusaidia kuboresha huduma za afya. Utafiti huu ni sehemu ya mradi mpana unaochunguza sifa na matokeo ya wanawake waliotibiwa JOOTRH kati ya Mei 2022 na Aprili 2026.

Utaratibu wa Utafiti

Ukikubali kushiriki, utaombwa:

- Kushiriki katika mahojiano ya kina kwa muda wa dakika 45 hivi. Mahojiano yatarekodiwa kwa sauti kwa idhini yako.
- Kujibu maswali kuhusu tajriba zako za uja uzito na matibabu.
- Mahojiano yatafanyika mahali pa siri na pa faragha katika hospitali ya JOOTRH.

Hatari na Faida

Kuna hatari ndogo sana katika utafiti huu. Unaweza kuhisi unyonge au huzuni unapozungumzia tajriba yako. Uko huru kusitisha mahojiano wakati wowote. Ikiwa utahisi shinikizo la kihisia, utapewa msaada wa ushauri wa kisaikolojia na wataalamu wa hospitali hapa JOOTRH.

Hakuna malipo ya moja kwa moja, lakini maelezo yako yatasaidia kuboresha huduma kwa akina mama wengine siku zijazo.

Usiri na Ulinzi wa Data

Kulingana na Sheria ya Ulinzi wa Data ya Kenya (2019), maelezo yako yote yatawekwa siri. Jina lako halitatumika kwenye ripoti yoyote. Rekodi za sauti zitalindwa kwa nambari ya siri na zitafutwa baada ya utafiti kukamilika.

Kushiriki kwa Hiari

Ushiriki wako ni wa hiari kabisa. Una haki ya kukataa au kujiondoa wakati wowote bila kuadhibiwa au kunyimwa huduma zako za matibabu.

Maswali

Ikiwa una maswali,: mpigie **Dr. Caren Otadoh** kwa simu: **+254710254325** (Saa tisa asubuhi hadi saa kumi jioni) au barua pepe: **dr.otadoh@gmail.com**

Kauli ya Ridhaa

Nimesoma na kuelewa maelezo haya. Nimepata nafasi ya kuuliza maswali na nimejibiwa kwa lugha ninayoielewa. Nakubali kushiriki kwa hiari.

Jina la Mshiriki: _____ Sahihi: _____ Tarehe: _____
Sahihi ya Mtafiti: _____ Tarehe: _____

APPENDIX II: DATA ABSTRACTION FORM

Research Assistant Name: **Research Record Number (RRN):**

Section A: Sociodemographic & Baseline Data

Patient Age (years at time of pregnancy)

- ◯ <18 years
- ◯ 18–24 years
- ◯ 25–35 years
- ◯ >35 years

Marital Status

- ◯ Single
- ◯ Married
- ◯ Other (specify)

Specify Marital Status (Other)

County of Residence

Occupation

- ◯ Unemployed / Housewife
- ◯ Casual Laborer
- ◯ Formal Employment
- ◯ Student
- ◯ Other (specify)

Specify Occupation (Other)

Section B: Clinical & Cardiac Characteristics

Type of Cardiac Disease

Objectively diagnosed with a specific cardiac lesion, e.g., Aortic Regurgitation, Mitral Stenosis

- ◯ Rheumatic Heart Disease (RHD)
- ◯ Congenital Heart Disease (CHD)
- ◯ Cardiomyopathy
- ◯ Valvular Heart Disease (VHD)
- ◯ Arrhythmia
- ◯ Other (specify)

Specify Other Cardiac Disease

Specify Cardiomyopathy Type (Peripartum / Dilated / Hypertrophic)

Specify Valve Involved and Severity

Timing of Cardiac Diagnosis

- ◯ Before Pregnancy
- ◯ After Pregnancy (during or post-partum)

NYHA Functional Status at First Hospital Contact

- ◯ Asymptomatic
- ◯ Mild symptoms with ordinary activity
- ◯ Marked limitation with less than ordinary activity
- ◯ Symptoms at rest
- ◯ Not documented

Record the following at the first medical encounter (if available):

Blood Pressure (BP)

e.g., 120/80 mmHg

Heart Rate (HR)

beats per minute

SpO_2 (%)

Comorbidities (check all that apply)

- ☐ Hypertension
- ☐ Diabetes Mellitus
- ☐ Anaemia
- ☐ Chronic Kidney Disease
- ☐ Other (specify)

Specify Other Comorbidity

HIV Status

- ◯ Positive
- ◯ Negative
- ◯ Unknown

Echocardiography Findings (if available/last available)

◯ Yes

◯ No

» Echocardiography Findings

Left Ventricular Ejection Fraction – LVEF (%)

Right Ventricular Systolic Pressure – RVSP (mmHg)

Pulmonary Artery Pressure – PAP (mmHg)

Valve Gradients / Regurgitation (if applicable)

Other Significant Echo Findings

Section C: Obstetric History & Outcomes

Gravida (Total number of pregnancies)

Parity (Total live births)

Total previous stillbirths

Total previous miscarriages/abortions

Antenatal Care (ANC) Details:

ANC Timing (Trimester of first contact)

- ◯ 1st Trimester (< 14 weeks)
- ◯ 2nd Trimester (14–28 weeks)
- ◯ 3rd Trimester (> 28 weeks)
- ◯ Not documented

Number of ANC Contacts

ANC Location (hospital name and level)

Specialized visits (OBGYN / Cardiologist)?

- ◯ Yes
- ◯ No

Gestational Age at Outcome (weeks)

Birth Weight Available

- ◯ Yes
- ◯ No

If the birth weight is available, record the number

Mode of Delivery

- ◯ Spontaneous Vertex Delivery (SVD)
- ◯ Assisted Vaginal Delivery (Vacuum)
- ◯ Cesarean Section (CS)
- ◯ Spontaneous Abortion / Miscarriage

Specify Cesarean Section Indication
Describe delivery circumstances (induction, epidural, MDT involvement, etc.)

- ☐ Diuretics
- ☐ Beta-blockers
- ☐ Anticoagulants
- ☐ Digoxin
- ☐ ACE Inhibitors
- ☐ Other (specify)

Specify Other Medication
Cardiac Complications (check all that apply)

- ☐ Heart Failure / Pulmonary Edema
- ☐ Arrhythmia (specify type)
- ☐ Thromboembolism (DVT / Pulmonary Embolism)
- ☐ Other (specify)

Specify Arrhythmia Type (complication)
Specify Other Cardiac Complication
Obstetric Complications (check all that apply)

- ☐ Pre-eclampsia / Eclampsia
- ☐ Placenta Previa
- ☐ Antepartum Haemorrhage (APH)
- ☐ Postpartum Haemorrhage (PPH)
- ☐ Preterm Labor
- ☐ Other (specify)

Specify Other Obstetric Complication
Section E: Data Quality & Completeness
Record Completeness

- ○ Complete (all key variables available)
- ○ Partially Complete (some missing variables)
- ○ Incomplete (many key variables missing)

Comments / Notes on Data Abstraction
Add any contextual information, ambiguities, or challenges encountered in the record.

Foetal Outcomes (check all that apply)

- ☐ Live Birth
- ☐ Stillbirth
- ☐ Neonatal Death (within 28 days)
- ☐ Unknown (specify)

Specify Unknown Outcome
State Apgar Score if Available

- ○ **Yes**
- ○ **No**

» Apgar Scores
Apgar Score at 1 min; at 5 min; at 10 min
Maternal Adverse Outcomes (check all that apply)

- ☐ Maternal Mortality
- ☐ ICU admission
- ☐ Referral to a specialized facility
- ☐ Other (specify)

Other Specify
Section D: In-Hospital Management & Complications
Length of Hospital Stay (days)
Medications Prescribed (check all that apply)

APPENDIX III: IN-DEPTH INTERVIEW GUIDE

Preamble and Introduction

(Approximately 5 minutes)

Hello. Thank you for agreeing to participate in this interview. My name is *(Researcher's Name)*, and I am conducting a study on the experiences of women with cardiac disease who have been pregnant. The purpose of this interview is to learn about your personal journey- your feelings, challenges, and how you managed your condition during pregnancy. We will record our conversation with an audio device. There are no right or wrong answers, and I want you to feel comfortable sharing your story. Your identity will remain completely confidential. Do you have any questions/clarifications before we begin?

Section 1: The Lived Biological Experience

(Approximately 15-20 minutes)

Objective: To explore the physical and medical aspects of the participant's experience.

1. What was your experience when you found out you were pregnant, considering your heart condition? What was that moment like for you?
2. What were the most noticeable symptoms or changes that you experienced in your pregnancy?
3. What information was offered to you by the healthcare workers about your condition during your clinic visits?
4. Did you experience any complications related to your heart condition during your pregnancy? Can you tell me about those?
5. Please describe your delivery experience.
6. Did you have any complications after giving birth?

Section 2: The Lived Psychological Experience

(Approximately 15-20 minutes)

Objective: To explore the participant's emotional and mental state throughout the journey.

7. Did your condition or pregnancy affect your mental well-being or mood? Can you describe any emotional highs and lows you experienced?
8. How did you cope with your emotions?
9. What were your greatest fears or concerns during this time?

Section 3: The Lived Social and Structural Experience

(Approximately 15-20)

Objective: To explore the role of social support and external factors in the participant's journey, using the Three Delays Model as a guide.

10. Delay 1: Seeking Care
    - When you noticed symptoms, what were your first considerations?
    - Did you feel confident seeking help right away, or were there things that made you hesitate?
11. Delay 2: Reaching Care
    - Were there any challenges in accessing healthcare?
12. Delay 3: Receiving Care
    - Describe your experience with the healthcare staff at the hospital.
    - What was your experience with the health system at the hospital?
13. What support systems were available to you during this time?
14. Was there any support you wish you had received but did not?

Closing

(Approximately 5 minutes)

Is there anything else you would like to add or any part of your story that we did not discuss? Thank you so much for sharing your story with me. Your experiences are incredibly valuable to this research.

APPENDIX IV: APPROVAL FROM MASENO

MASENO UNIVERSITY
SCHOOL OF GRADUATE STUDIES

Office of the Dean

Our Ref: MMED/SM/00011/022

Private Bag, MASENO, KENYA
Tel:(057)351 22/351008/351011
FAX: 254-057-351153/351221
Email: sgs@maseno.ac.ke

Date: 11 February, 2026

TO WHOM IT MAY CONCERN

RE: PROPOSAL APPROVAL FOR CAREN MILLICENT OMORO OTADOH — MMED/SM/00011/022

The above named is registered in Master of Medicine in Obstetrics and Gynaecology Programme in the School of Medicine, Maseno University. This is to confirm that her research proposal titled "**Experiences, Characteristics and Outcomes of Pregnant Women with Cardiac Disease at Jaramogi Oginga Oding Teaching and Referral Hospital in Kisumu County, Kenya**" has been approved for conduct of research subject to obtaining all other permissions/clearances that may be required beforehand.

SCHOOL OF GRADUATE STUDIES MASENO UNIVERSITY 12 FEB 2026 P.O. BOX PRIVATE BAG, MASENO

Prof. [illegible] Onyango
DEAN, SCHOOL OF GRADUATE STUDIES

APPENDIX V: APPROVAL FROM JOOTRH ISERC
APPENDIX VI: APPROVAL FROM JOOTRH ADMINISTRATION

REPUBLIC OF KENYA

STATE DEPARTMENT FOR MEDICAL SERVICES

JARAMOGI OGINGA ODINGA TEACHING & REFERRAL HOSPITAL

Email: ceo@jootrh.go.ke | jootrhksm@gmail.com

Website: www.jootrh.go.ke

P.O Box 849-40100 Kisumu

Tel: 0733-888579, 0756-353477

Ref: ISERC/JOOTRH/263/26

Date: 27TH APRIL, 2026

To:

Dr. Caren Millicent Omoro Otadoh

Dear Madam,

RE: APPROVAL TO CONDUCT THE STUDY TITLED: "EXPERIENCES, CHARACTERISTICS, AND OUTCOMES OF PREGNANT WOMEN WITH CARDIAC DISEASE AT JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL IN KISUMU, KENYA, FROM 2022 TO 2026".

This is to inform you that the JOOTRH Institutional Scientific and Ethics Review Committee (ISERC) has reviewed and approved your Protocol referenced above. Your approval number is **ISERC/JOOTRH/263/26**, and the approval period is 27th April 2026 to 27th April, 2027.

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used.
ii. All changes including (amendments, deviations, and violations) should be submitted for review and approval by JOOTRH - ISERC.
iii. Death and life-threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to JOOTRH - ISERC within 72 hours of their occurrence.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to JOOTRH - ISERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewals should be done at least 60 days before expiry of the previous approval. A progress report should be attached to support the renewal.
vii. An executive summary report should be submitted to JOOTRH -ISERC within 90 days of completing the study.
viii. In the event that the study site is JOOTRH you will be required to write a letter to the CEO JOOTRH requesting for permission to collect data.

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://resarch-portal.nacosti.go.ke and also obtain other clearances needed.

Yours sincerely,

MR. JEREMIAH NYONI
ISERC - SECRETARY
JOOTRH-KISUMU

JOOTRH ETHICS & REVIEW COMMITTEE
P. O. Box 849 - 40100
KISUMU

REPUBLIC OF KENYA

STATE DEPARTMENT FOR MEDICAL SERVICES

JARAMOGI OGINGA ODINGA TEACHING & REFERRAL HOSPITAL

P.O Box 849-40100 Kisumu

Email: ceo@jootrh.go.ke | jootrhksm@gmail.com

Tel: 0733-888579, 0756-353477

Website: www.jootrh.go.ke

Ref: ST/2A/VOL.VI

Date: 5TH MAY ,2026

To:

Dr. Caren Millicent Omoro Otadoh,

Dear Madam,

RE: PERMISSION TO COLLECT DATA

On the strength of the approval letter from our Institutional Scientific and Ethical Review Committee for your proposal titled "Experiences, Characteristics, And Outcomes of Pregnant Women with Cardiac Disease at Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu, Kenya, From 2022 To 2026", **Ref: ISERC/JOOTRH/ 263/26.**

I take this opportunity to grant you permission to collect data from Jaramogi Oginga Odinga Teaching and Referral Hospital between 5th May, 2026 to 5th May, 2027.

Thank you.

Yours

CHIEF EXECUTIVE OFFICER
JARAMOGI OGINGA ODINGA TEACHING
& REFERRAL HOSPITAL (JOOTRH)
05 MAY 2026
P.O BOX 849 - 40100,
KISUMU

DR. JOSHUA CLINTON OKISE, PhD
Ag. CHIEF EXECUTIVE OFFICER
JOOTRH-KISUMU

APPENDIX VII: RESEARCH PERMIT FROM NACOSTI

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **243892**

Date of Issue: **29/May/2026**

RESEARCH LICENSE



This is to Certify that Dr.. CAREN MILLICENT OMORO OTADOH of Maseno University, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Kisumu on the topic: EXPERIENCES, CHARACTERISTICS, AND OUTCOMES OF PREGNANT WOMEN WITH CARDIAC DISEASE AT JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL IN KISUMU, KENYA, FROM 2022 TO 2026 for the period ending : 29/May/2027.

License No: **NACOSTI/P/26/4189213**

243892

Applicant Identification Number

Ag. Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

See overleaf for conditions

APPENDIX IX: CODE BOOK FOR QUALITATIVE DATA ANALYSIS

- Codebook Table

The codebook table presents the full coding framework. Each row records the study objective the code informs, the main theme and sub-theme under which it sits, the code itself, its definition, a supporting verbatim extract, and an interpretive note relating the code to the study objective. The study objectives referenced are: Objective 1 (to explore the lived experiences of pregnant women with cardiac disease); Objective 2 (to describe the characteristics of pregnant women with cardiac disease at JOOTRH); and Objective 3 (to determine the maternal-fetal outcomes of women with cardiac disease).

Main Theme A: The Biological Journey

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
1, 2	A. The biological journey	Diagnostic odyssey	MISDIAGNOSIS	Treatment for an incorrect condition before the cardiac diagnosis was made	"They treated me for pneumonia for two months. I was on ceftriaxone." (Participant 1)
1, 2	A. The biological journey	Diagnostic odyssey	LATE-DIAGNOSIS	Cardiac disease first recognized only during or after the pregnancy	"If they'd made the diagnosis earlier, then I would not have had to go through everything I've been through." (Participant 5)
1	A. The biological journey	Symptom normalisation	SYMPTOM-NORMALISED	Severe symptoms reinterpreted as ordinary or unremarkable	"Even before my pregnancy, I used to get tired all the time. I didn't think to go to the hospital." (Participant 2)
1	A. The biological journey	Symptom normalisation	SYMPTOM-AS-PREGNANCY	Cardiac symptoms attributed to pregnancy itself	"I imagined that these were pregnancy symptoms." (Participant 1)
1, 2	A. The biological journey	Cardiopulmonary decompensation	EXERTIONAL-DYSPNOEA	Breathlessness on minimal exertion	"We would be walking at a slow pace, but I'd be gasping for breath." (Participant 4)
1, 2	A. The biological journey	Cardiopulmonary decompensation	ORTHOPNOEA	Inability to breathe when lying flat	"I would spend full nights sitting on a chair just so I could breathe properly." (Participant 7)
1, 3	A. The biological journey	Birth as crisis	EMERGENCY-DELIVERY	Delivery precipitated by acute maternal or foetal compromise	"Because of my chest pain and my condition, I couldn't go back

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
					home." (Participant 1)
1, 3	A. The biological journey	Birth as crisis	NEAR-DEATH-AWARENESS	Awareness during the peripartum period of imminent risk to life	"I heard someone say: 'Doctor, I don't think this one is still with us. She's going.'" (Participant 8)
1, 3	A. The biological journey	Birth as crisis	INTRAPARTUM-NEGLECT	Perceived absence of clinical attention at the moment of delivery	"They had fallen sleep and everything happened so fast that they couldn't take me all the way to the delivery room." (Participant 7)
1, 3	A. The biological journey	Incomplete recovery	PERSISTENT-SYMPTOMS	Continued cardiac symptoms after delivery	"I'm still unwell post-delivery. My chest is painful, and I can't do any heavy work." (Participant 2)

Main Theme B: The Psychological Journey

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
1	B. The psychological journey	Fear of death	DEATH-FEAR	Explicit fear of dying during pregnancy or delivery	"I just didn't want to die. You know heart conditions are very serious." (Participant 1)
1	B. The psychological journey	Fear of death	EXTERNAL-DOOM	Fear reinforced by the expectations of family or community	"Everyone thought I was going to die. I also often felt like I was doomed." (Participant 1)
1	B. The psychological journey	Ambivalence about pregnancy	TERMINATION-WISH	Expressed desire to end the pregnancy	"From the beginning, I just wanted to terminate that pregnancy." (Participant 1)
1	B. The psychological journey	Coping	SILENCE-COPING	Managing distress by withholding it from others	"I would just keep it in my heart." (Participant 2)
1	B. The psychological journey	Coping	PRAYER-COPING	Reliance on faith and prayer as the principal coping strategy	"I would tell God. I would just pray about it." (Participant 2)
1	B. The psychological journey	Coping	WITHDRAWAL	Social withdrawal or self-isolation in response to distress	"I would lock myself in my room for up to three days." (Participant 3)
1	B. The psychological journey	Stigma	CONCEALMENT	Active hiding of the illness to avoid judgement	"In this life, you fake everything until you make it." (Participant 3)

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
1	B. The psychological journey	Stigma	MEDICATION-STIGMA	Embarrassment or suspicion attached to obtaining medication	"People may assume that I am buying them because I have an old sugar daddy side piece." (Participant 5)
1	B. The psychological journey	Identity reconfiguration	CHRONIC-IDENTITY	Reorganization of self-concept around permanent illness	"I'm on warfarin, for life, willingly." (Participant 9)

Main Theme C: The Social And Structural Journey

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
1	C. The social and structural journey	Delay 1: Seeking care	HELP-SEEKING-DELAY	Delay between symptom onset and the decision to seek care	"In form three, I persevered through the same condition without telling anyone." (Participant 3)
1	C. The social and structural journey	Delay 1: Seeking care	FAMILY-DISCOURAGEMENT	Family attribution of symptoms to non-medical causes	"My grandma used to say that I was a very fragile and lazy child." (Participant 5)
1, 3	C. The social and structural journey	Delay 2: Reaching care	REFERRAL-BURDEN	Multi-step referral journeys to reach an appropriate facility	"We did a self-referral and took public transport all the way to Kisumu." (Participant 8)
1, 3	C. The social and structural journey	Delay 2: Reaching care	COST-BARRIER	Financial cost as an obstacle to reaching or accessing care	"They wanted 8,000 shillings for an ambulance to bring me here. My

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
					sister didn't have that money." (Participant 8)
1, 2	C. The social and structural journey	Delay 2: Reaching care	SPECIALIST-COST	High cost of specialist cardiac assessment	"Consultation alone is 4,000 shillings … echo is 12k, and ECG is 15k." (Participant 5)
1, 3	C. The social and structural journey	Delay 3: Receiving care	IN-FACILITY-DELAY	Delay between arrival at the facility and receipt of definitive care	"The processes and treatment were so slow. I got to JOOTRH in a critical state." (Participant 7)
1	C. The social and structural journey	Delay 3: Receiving care	NON-DISCLOSURE	Failure to communicate the diagnosis to the patient	"No doctor told me anything about my heart condition." (Participant 2)
1	C. The social and structural journey	Delay 3: Receiving care	CLINICIAN-MORALISING	Being scolded or judged by clinicians	"He scolded me so much, saying that a person with my condition should never get pregnant." (Participant 8)
1	C. The social and structural journey	Delay 3: Receiving care	CLINICIAN-ADVOCACY	A single empathetic clinician altering the care trajectory	No direct quote provided.

Objective	Main Theme	Sub-theme / Category	Code	Code Definition	Supporting Quote / Excerpt
1, 3	C. The social and structural journey	Social support	PARTNER-SUPPORT	Presence and quality of partner support	"If it were another man, he would have left." (Participant 5)
1	C. The social and structural journey	Social support	PARTNER-HARM	Partner violence, coercion, or abandonment	"Just before and during the first months of my pregnancy, he tortured me a lot." (Participant 1)
1, 3	C. The social and structural journey	Reproductive autonomy	BTL-REFUSED	Request for permanent contraception not honored	"He kept on taking me round in circles, and wouldn't commit to it. I really want a BTL." (Participant 6)

- Coding structure table

The following table shows how the initial codes were grouped into sub-themes and then into the three main themes.

Initial Codes	Sub-theme / Category	Main Theme
MISDIAGNOSIS; LATE-DIAGNOSIS	Diagnostic odyssey	A. The biological journey
SYMPTOM-NORMALISED; SYMPTOM-AS-PREGNANCY	Symptom normalization	A. The biological journey
EXERTIONAL-DYSPNOEA; ORTHOPNOEA	Cardiopulmonary decompensation	A. The biological journey
EMERGENCY-DELIVERY; NEAR-DEATH-AWARENESS; INTRAPARTUM-NEGLECT	Birth as crisis	A. The biological journey
PERSISTENT-SYMPTOMS	Incomplete recovery	A. The biological journey
DEATH-FEAR; EXTERNAL-DOOM	Fear of death	B. The psychological journey

Initial Codes	Sub-theme / Category	Main Theme
TERMINATION-WISH	Ambivalence about pregnancy	B. The psychological journey
SILENCE-COPING; PRAYER-COPING; WITHDRAWAL	Coping	B. The psychological journey
CONCEALMENT; MEDICATION-STIGMA	Stigma	B. The psychological journey
CHRONIC-IDENTITY	Identity reconfiguration	B. The psychological journey
HELP-SEEKING-DELAY; FAMILY-DISCOURAGEMENT	Delay 1: Seeking care	C. The social and structural journey
REFERRAL-BURDEN; COST-BARRIER; SPECIALIST-COST	Delay 2: Reaching care	C. The social and structural journey
IN-FACILITY-DELAY; NON-DISCLOSURE; CLINICIAN-MORALISING; CLINICIAN-ADVOCACY	Delay 3: Receiving care	C. The social and structural journey
PARTNER-SUPPORT; PARTNER-HARM	Social support	C. The social and structural journey
BTL-REFUSED	Reproductive autonomy	C. The social and structural journey

- Summary Of Key Themes

Main Theme	Key Codes	Overall Meaning
A. The biological journey	MISDIAGNOSIS, LATE-DIAGNOSIS, SYMPTOM-NORMALISED, EXERTIONAL-DYSPNOEA, ORTHOPNOEA, EMERGENCY-DELIVERY, NEAR-DEATH-AWARENESS	Cardiac disease was experienced and endured long before correct recognition; delivery occurred under crisis conditions, and recovery was partial.
B. The psychological journey	DEATH-FEAR, TERMINATION-WISH, SILENCE-COPING, PRAYER-COPING, WITHDRAWAL, CONCEALMENT	A reasoned fear of death dominated the experience, managed largely through silence, faith and withdrawal, reflecting an unmet need for psychological support.
C. The social and structural journey	HELP-SEEKING-DELAY, REFERRAL-BURDEN, COST-BARRIER, IN-FACILITY-DELAY, NON-DISCLOSURE, PARTNER-HARM, BTL-REFUSED	Delays in seeking, reaching and receiving care, compounded by financial constraint and variable partner support, structured the care journey and shaped outcomes.

APPENDIX X: SUMMARY OF THE QUALITATIVE FINDINGS

Table 12: *A Summary of Qualitative Findings*

THEME	SUB-THEME	SAMPLE QUOTATIONS
The Biological Journey	**The diagnostic odyssey**	P001- "They treated me for pneumonia for two months. I was on ceftriaxone … When I came to JOOTRH, they tested me and found infective endocarditis." P005- "I've gone to so many hospitals, and no one ever mentioned anything about my fingers … If they'd made the diagnosis earlier, then I would not have had to go through everything I've been through."
	Symptom normalisation and self-management before help-seeking	P002- "Even before my pregnancy, I used to get tired all the time. I didn't think to go to the hospital." P002- "Whenever I would feel really sick, I would just sit and rest for some time, then continue with my daily routines." P005- "My grandma used to say that I was a very fragile and lazy child … None of us knew that it was an actual issue." P001- "I already knew I was pregnant by the time I started feeling the chest pain, so I imagined that these were pregnancy symptoms."
	The body altered by pregnancy	P004: "My feet were too big for my shoes … sometimes I would feel my heart rate throbbing as though something had startled me … I couldn't even walk upstairs. Not even stairs, even on flat ground … we would be walking at a slow pace, but I'd be gasping for breath." P007: "I even used to stay awake all night, because I couldn't breathe at all when I would sleep on my back. I would spend full nights sitting on a chair just so I could breathe properly." P008: "I have trouble sleeping. I can't breathe properly when I lie down. I scare my mother sometimes because I breathe so deeply."
	Birth as a crisis	P008: "As they were finishing up on the surgery, the doctor who was behind me asked how I was feeling … I couldn't answer coherently … I heard someone say: 'Doctor, I don't think this one is still with us. She's going.'" P005: "After the operation, as I was waiting to go back to the ward, I started

		bleeding excessively, as usual. The next thing, I found myself waking up from an unconscious state … even after that second time, I was taken to the theatre a third time." P003: "When I go to the delivery room, I'm not trying to look down on others, but if I'm assigned a student to attend to me, I feel like it's very risky … even if a student were assigned, there should be a supervisor." P007: "The baby was ready to come out, but they were not ready. They had fallen asleep, and everything happened so fast that they couldn't take me all the way to the delivery room … It all happened at night, and most of them had dozed off." P009: "The fluid that came out scared me because it was a strange colour. I am a mother, I've delivered before, but I've never seen anything like that. It was brownish, and it looked like the dirty water on the ground after rain. And it was ice-cold."
	The body after delivery	P001: "My body feels a little different from before I got pregnant. But I think I'm recovering." P002: "I'm still unwell post-delivery. My chest is painful, and I can't do any heavy work… Occasionally, I get tired, but it's manageable."
The Psychological Journey	**Fear, anticipatory grief, and the imagination of one's own death**	P001: "I just didn't want to die. You know heart conditions are very serious. They are very risky. I just didn't want to die." P001: "When the people around me, including my mother, heard that I had heart disease, everyone thought I was going to die. I also often felt like I was doomed." P003: "I was very scared for my life during the entire duration of pregnancy." P007: "I only had one fear during that time, and it happened: my baby's death."
	Desire to terminate	P001: "From the beginning, I just wanted to terminate that pregnancy, because it was a very bothersome pregnancy." P003: "I even thought of getting rid of the pregnancy instead of risking my life." P009: "Everyone was on one side, and I felt like I was on my own."

	Coping by silence, prayer, and self-isolation	P002: "I couldn't speak to anyone about my struggle. I would tell God. I would just pray about it." P002: "I didn't talk to anyone about the things I would hear doctors discussing. I would just keep it in my heart. I couldn't even speak to my mum." P003: "I would lock myself in my room for up to three days. I even thought of getting rid of the pregnancy instead of risking my life … I would just take walks and listen to music." P002 "left it all to God" P003: "I didn't use to believe there was a God. But maybe. Maybe these experiences show that there is a higher power."
	Identity reconfiguration	P005: "I had been managing it sufficiently since I was born. He told me to pretend that I was normal and okay. That's exactly how I've been living, and I've surrendered my life to God. Only God knows when I will die." P009: "When you have a chronic disease, you have to accept. Like me, I'm on warfarin, for life, willingly … I'm happy to speak for and advocate for people like me." P003: "I usually don't want to tell even my closest friends about this. Because I feel like life is not fair to me. There are things that they can do, and I am not able to do. Like I can't travel a lot, and I can't party like my friends."
The Social and Structural Journey	**Stigma**	P003: "I have decided that in this life, you fake everything until you make it. Because as I walk, you would never know that I have any challenges. I pray that I never have any stigmatization because of my condition." P005: "I remember the chemist asking me if I was sure that was what I wanted. He looked at me suspiciously … sometimes it's a little embarrassing. People may assume that I am buying them because I have an old sugar daddy side piece." P006: "I don't want to embarrass my family again." P008 "He scolded me so much, saying that a person with my condition should

		never get pregnant. He asked me why I got pregnant. And what I had been seeking for." P009: "I didn't like that they made me feel like I was going to die the next day; that the pregnancy would make me die the next day … Why would they treat me like I was irresponsible for getting pregnant? I understand that there are emergency cases where decisions are made on behalf of the patients, but for my situation, I was conscious and I could make decisions."
	Spousal Support	P001: "I have to admit that just before and during the first months of my pregnancy, he tortured me a lot … I believe that the stress he took me through caused my illness."
	Symptom normalisation as a cause of seeking-care delay	P002 had been chronically fatigued for years and had never sought care, and only sought care in pregnancy when the fatigue became unbearable. P005's lifelong symptoms had been so integrated into her self-concept that she could not see them as illness; her seeking-care trigger was not her own chronic dyspnoea but a discrete obstetric emergency. P003's delay in seeking care for her rheumatic heart disease symptoms was, paradoxically, motivated by a desire not to be perceived as someone who needed care.
	Misattribution of symptoms to pregnancy itself	P001: "I already knew I was pregnant by the time I started feeling the chest pain, so I imagined that these were pregnancy symptoms. But I later went for a general check-up when it became too much."
	Family-level discouragement of help-seeking	P003's aunt told her that her palpitations and dizziness were the result of examination stress and should be ignored. P008 hid her symptoms from her mother as long as possible because her mother had already once told her not to get pregnant.
	Distance, transport, and the burden of multi-step referral	P008: "The referral from Kisii to JOOTRH was a little difficult; they wanted 8,000 shillings for an ambulance to bring me here. My sister didn't have that money, so we did a self-referral and

		took public transport all the way to Kisumu."
	Cost barriers to specialist work-up	P005: "Cardiologists are so expensive. Consultation alone is 4,000 shillings; the cost is even more: echo is 12k, and ECG is 5k." P003: "My aunt used to cater for these expenses, but at some point, she said I was finishing her money."
	Long waits and administrative bottlenecks at JOOTRH	P009: "I would sign a consent for termination on one day, then on the next day, the team who had gotten my consent don't show up, then another doctor wouldn't make me sign again, and it kept on happening for a couple of days. I wondered why we had delays, and yet, I had already accepted."
	Non-disclosure	P002: "No doctor told me anything about my heart condition. I would hear them talk during ward rounds. One time, I heard them say that I shouldn't get pregnant again. They said this should be my last. It scared me." P002: "No one has ever talked to me about my condition. I am curious about what those imaging tests revealed. I would like to understand … I honestly don't know what's wrong with my heart." P004: "I came here today because I was curious. You know, I've always suspected that there was something wrong with my heart, and as the doctors were speaking before and after my delivery, I would overhear them talking about it. But no one told me anything … I left the hospital not knowing what the issue was. So, I thought perhaps it's just a very difficult pregnancy."
	Inadequate communication around contraception and future fertility	Three participants (P006, P008, P009) actively requested bilateral tubal ligation and did not receive it. P006 reported being "taken round in circles" by a doctor unwilling to commit; P008's sister requested it on her behalf and was refused; P009 consented to it post vaginal delivery, and the anaesthetist cancelled the operative procedure. In contrast, two participants (P001 and P003) reported clear contraceptive

		counselling and the placement of a chosen method. P002 received no contraception counselling at discharge and only a generic group talk at a later MCH visit, from which she withdrew.
	Clinician attitudes	P008: "He scolded me so much, saying that a person with my condition should never get pregnant. He asked me why I got pregnant. And what I had been seeking for." P009 described the same experience in a different language: "They made me so anxious … Some would talk badly, and I would cry in private." P007 reported a perception of disengagement and a "blame game" at the hospital. P001, P003, P004, and P006 all described some clinicians at JOOTRH in warm terms:
	The protective effect of a single empathetic clinician	P004's referral to JOOTRH from KCRH happened because a doctor-friend insisted. P009's eventual discharge from a chaotic admission came when a female senior gynaecologist arrived and questioned the management. P008's dental clearance was halted by an MFM specialist who refused to allow further teeth to be extracted on top of everything else she had endured.
	Financial pressure as a determinant of every other delay	P005 captured the cost of being a cardiac patient outside the public-sector pathway. P008 could not afford a referral ambulance and travelled by public transport in critical condition. P003 estimated KES 70,000 in care costs and lost her aunt's continued support partway through. P002 was managed in a private hospital that gave her no diagnosis before transferring her care. P001 spent a full day waiting at JOOTRH because her county government insurance was not active.