

# Contraceptive Utilization and Lived Experiences of Women with Rheumatic Heart Disease Attending Uganda Heart Institute and Mbarara Regional Referral Hospital

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**Introduction:** Women with rheumatic heart disease (RHD) face high risks during pregnancy due to hemodynamic stress and teratogenic medications. Appropriate contraceptive use is therefore critical, yet little is known about utilization patterns and lived experiences among this population in Uganda.

**Methods:** We conducted a mixed-methods study at Uganda Heart Institute and Mbarara Regional Referral Hospital. A cross-sectional survey of 84 women with RHD assessed contraceptive use, while in-depth interviews with 13 participants explored lived experiences. Quantitative data were analyzed descriptively, and qualitative data thematically using Van Manen's existential framework.

**Results:** Study found only 25 (29.7%) women reported using contraception, and 40% were using contra-indicated methods. Among those who discontinued, 34.6% cited side effects such as heavy bleeding, weight gain and palpitation. Notably, 69.6% of women on a teratogenic medication were not using contraception. Qualitative findings revealed themes of fear (of side effects and complications), communication gaps with health providers, hopelessness and frustration due to method failure, and ingenuity in coping strategies. These findings highlight limited counseling and high reliance on inappropriate methods, putting women at risk of unplanned and high-risk pregnancies.

**Conclusion:** Contraceptive utilization among women with RHD in Uganda is low, inconsistent, and often involves unsafe methods. The absence of adequate counseling and reliance on contraindicated options underline the urgent need for multidisciplinary, guideline-based contraceptive counseling and support for women with RHD to prevent unplanned pregnancies and reduce maternal and fetal risks.

**Keywords:** contraception, rheumatic heart disease, utilisation, lived experiences

## Introduction and Background

Contraception, often referred to as birth control or family planning, has been defined in multiple ways by scholars. It is broadly understood as the intentional prevention of conception and the practice of spacing children using both natural (traditional) and modern (artificial) methods.<sup>1-3</sup> However, most definitions rarely address women with medical conditions, who have unique contraceptive needs starting from puberty and continuing throughout their reproductive years.<sup>4</sup> For women with Rheumatic Heart Disease (RHD), contraception is particularly important, as conception should ideally occur only when clinically stable and after adjustment of chronic medications.

Rheumatic Heart Disease (RHD) is a chronic condition that develops as a long-term complication of untreated or recurrent rheumatic fever, which itself follows infection with group A streptococcal pharyngitis. RHD primarily affects



the heart valves, leading to inflammation, scarring, and reduced cardiac function.<sup>5</sup> The condition is found more in females than males due to increased expression of collagen and inflammatory genes, leading to severe valve pathology in females.<sup>6</sup> In these women, pregnancy carries a substantially elevated risk of complications due to hemodynamic burden and the teratogenicity of certain cardiac medications. Recent studies in sub-Saharan Africa show high maternal morbidity and mortality, as well as adverse fetal outcomes, among women with RHD who become pregnant.<sup>7</sup> Effective contraception therefore plays a lifesaving role by enabling pregnancy planning when disease activity is quiescent and medications are optimized. Contraception has been defined as the intentional prevention of conception<sup>2</sup> and as the practice of spacing children using both natural and modern methods.<sup>3</sup> Therefore, the definition of contraception employed in this study is “a guided voluntary decision process by women with RHD, as individuals or couples to choose as to when to have children when clinically fit by using highly effective and safe methods of contraception”. This unique definition is chosen due to the nature of the medical condition of these women. They need help from a multidisciplinary team, which specifically includes cardiologist, obstetricians/midwives and counsellors in order to choose a highly effective and safe contraceptive method.<sup>7</sup> These women differ significantly from their counterparts who have no known medical conditions and can buy over the counter method of their choice.

Globally, expert guidelines such as those from the World Health Organization (WHO), European Society of Cardiology (ESC), and American Heart Association (AHA) recommend preconception counseling and individualized contraceptive planning for women with cardiac conditions.<sup>8</sup> However, Uganda and many other sub-Saharan African countries lack specific guidance tailored to RHD, despite its high prevalence and impact. This absence of structured, guideline-based counseling increases the risk of inappropriate contraceptive choices, unsafe pregnancies, and preventable maternal and fetal complications.

Effective contraception enables couples to enjoy a physical relationship without fear of an unwanted pregnancy, and ensures enough freedom to have children when desired by choice and not by chance.<sup>9</sup> A number of women of reproductive age wish to regulate their fertility.<sup>2</sup> This is even more important for women with RHD who need to be guided on appropriate and effective methods.<sup>10</sup>

Arguably, the support given to women with RHD regarding contraceptive utilization could lead to positive experiences. It is documented that there is communication gaps regarding contraception utilization between physicians and clients with medical conditions frequently leading to negative experiences.<sup>11</sup> A clear understanding of contraceptive utilisation and the lived experiences of women with RHD is critical to ensure right choice of methods to prevent unplanned pregnancies.

Contraception for women with RHD is to avoid risky pregnancies that may lead to maternal and fetal complications.<sup>8</sup> In addition, women with RHD take chronic medications, yet some are teratogenic, increasing risk and emphasizing the need for planned pregnancies prior to conceptions to allow for adjustments in drug therapy.<sup>12</sup> Furthermore, some contraceptive methods among women with RHD have been found to worsen the heart disease.<sup>13</sup> Therefore, contraception counselling of women with RHD ought to begin early, even with the adolescents transitioning to adult care, depending on sexual maturity and regardless of sexual activity.<sup>14,15</sup> This study assessed contraception utilisation among women with RHD and explored their lived experiences.

Contraception represents an important area of reproductive health for patients with heart diseases, given the potential pregnancy risks associated, teratogenic medications, and severe disease-related damage.<sup>8</sup> Jakes and Coad<sup>8</sup> further suggest that contraceptive methods should be addressed by both experts in heart disease and reproductive health to enable selection of the safest, most effective, and most convenient form for each patient. Appropriate methods of contraception should be selected considering possible adverse effects or beneficial interactions, state and complications of the disease, and possible drug interaction with the woman’s medical treatment.<sup>13</sup> It should be noted that there is no risk-free and efficacious contraceptive options for women with RHD, but the contraceptive risk may be lower than carrying an unplanned pregnancy.<sup>16</sup> Contraception utilization has to be accompanied by close support and surveillance of any complications.

Contraception is important for all women to be able to attain their reproductive health rights.<sup>17</sup> Globally, there are unmet needs for contraception among reproductive aged women in many countries. The 41 countries participating in Family planning 2020 (FP2020) have reported unmet contraceptive needs of 21.6% and in Uganda it registers at 33.2%.<sup>18</sup>

According to USAID (2006) unmet need for FP is defined as a woman who is productive, sexually active, not using any contraceptive methods and does not want a child for at least two year (spacers); or does not want more children at all (limiters). Although contraception usage in women in Uganda has improved, unmet need for family planning still exists (USAID, 2006).

## Family Planning Usage in Uganda

Uganda has one of the highest total fertility rates (5.4) in the world and a contraception prevalence of only 39%.<sup>19</sup> The Ugandan government has set a goal of contraceptive use of 50% by 2020. This finding suggests the need to prioritize contraception usage among women of child-rearing age and create an enabling environment that supports improved access to accurate information about FP services and the rights of individuals and couples to make informed choices.<sup>9</sup>

There are a number of challenges in encouraging the use of family planning methods in Uganda that include cultural factors, attitudes, illiteracy and distance from government health units.<sup>9,20,21</sup> These challenges together with living with RHD puts women with RHD at risk of inappropriate contraceptive choices hence negative outcomes.<sup>10</sup>

In Uganda, more than four out of 10 births are unplanned,<sup>22</sup> but among women with RHD pregnancy must be planned. Despite these risks, little is known about contraceptive utilization and counseling among women with RHD in Uganda. Although it is important to prevent unintended pregnancy, contraception may uniquely benefit these women by delaying pregnancy until their diseases are quiescent and they are not taking teratogenic medication.<sup>4</sup>

The culture of belonging in a model that symbolises an ideal woman as participating in procreation is taken seriously by many women of reproductive age.<sup>23</sup> This creates a double peril for women with RHD who wish to fulfil their cultural roles yet live with RHD. Sedgh and Hussain<sup>23</sup> argues that contraceptive utilisation calls for the health care teams to consider subjective values and offer comprehensive support and advice. Thus, in the absence of such consideration; women will have no choice but have unplanned pregnancy, which will put them at greater risks. This study is critical because, despite the high prevalence of RHD in sub-Saharan Africa, there is limited literature on contraceptive counseling and utilization in this vulnerable group, leaving them at risk of both unplanned pregnancy and method-related complications.

## Methodology

### Description of Study Design

We conducted a mixed method using Concurrent triangulation design where both qualitative and quantitative data were collected in the same phase, but preliminary qualitative interviews were conducted first to enable modification of quantitative tool. The mixed methods were used to enable triangulations of information to better understand contraception utilization and lived experiences in-depth.<sup>24</sup>

The quantitative component employed a descriptive cross-sectional design to assess contraception utilization among women aged 15–49 years with confirmed diagnosis of RHD. This design was chosen to allow the researcher to collect data on different variables in the shortest possible time.<sup>25</sup> The qualitative component adopted Van Manen's hermeneutic phenomenological study to explore lived experiences of contraceptive use among the women with RHD. Phenomenology design was chosen because it seeks to understand deeply lived experiences and provide rich data.<sup>26</sup>

### Description of Study Area

This study was done at two sites with established RHD registries. These included Uganda Heart Institute (UHI) and Mbarara Regional Referral Hospital (MRRH). UHI is an autonomous government facility, which undertakes and coordinates the prevention and treatment of cardiovascular diseases in Uganda. The hospital receives referrals from other hospitals within and outside the country (eg DRC, South Sudan). It is located on Mulago Hill in the northern part of the capital city of Kampala. It operates within Mulago Hospital Complex and occupies block 1C.<sup>27</sup> MRRH is a regional referral hospital in south-western Uganda, which also serves as a teaching hospital for Mbarara University of Science and Technology and other institutions in the region.<sup>28</sup> The hospital has a cardiology clinic, which offers specialised care to patients with cardiac related problems within the hospital. It has official bed capacity of approximately 600. It serves

districts of central and western Uganda and some neighbouring countries (MOH, 2019). The two study sites were chosen because they have established Rheumatic Heart Disease Registries and offers chronic care to patients living with rheumatic heart disease. Medtronic report of May 2018 reports 942 females registered in UHI registry and 67 females registered in MRRH.

## Description of Study Population

The study population was women of reproductive age 15–49 years diagnosed with Rheumatic Heart Disease and receiving care services at UHI and MRRH.

## Sampling Method

Purposive sampling method was used to recruit participants within the reproductive age of 15–49 years attending cardiology clinic for the second time or more. The practice is that these women are given detailed explanation of their conditions on diagnosis. It was assumed that they would have been counselled about family planning methods in relation to their heart disease. This sampling method was chosen because it will enable selection of information-rich participants for the study.<sup>29</sup> The green Benzathine cards submitted on arrival by all RHD patients were used to identify participants who meet inclusion criteria at triage point, those without green cards were identified with the help of physicians who linked them with the research team.

## Sample Size

Quantitative sample size

The Cochran formula states that:

$$n = \frac{Z^2 pq}{e^2}$$

Where:

- n-Sample size required
- e - the desired level of precision (margin of error-0.05)
- p - the (estimated) proportion of the population of women with RHD that use contraception which is 8.8%<sup>10,31</sup>
- q- 1- proportion (0.92)

considering 95% confidence with 5% margin of error precision Z values would be 1.96 in the Z tables.

$$n = \frac{(1.96)^2 (0.08) (0.92)}{(0.05)^2} = 113$$

However only 84 participants were recruited and 15 participants were recruited from MRRH participants and 69 participants were recruited from UHI. This was because those who were in school could not come to the clinic since they were doing exams. However, the research team controlled for small sample size by ensuring the response rate was 100% by minimizing missing data, and supplementing the quantitative findings with qualitative data to enhance depth of understanding.

## Qualitative Sample Size

Qualitative study recruited 13 participants and sample size was determined by redundancy when no new information was being generated. Research has found that small sample sizes in qualitative data generate rich information, which answer research question in depth.<sup>32</sup> Conducting interviews stopped when no new responses were generated.<sup>33</sup>

## Inclusion Criteria

- Women with RHD aged 15–49 years who consented to the study.
- Women with RHD coming for at least second appointment, which is usually after three months.
- Women who were clinically stable and not requiring any emergency procedures.

## Exclusion Criteria

- Women who broke down emotionally and could not talk about their experiences.
- Women who were shy to talk about their experiences about contraception because some were minors.

## Description of Variables

A study variable is a quantity or quality that varies within the framework of the research and can be measured.<sup>34</sup> For the quantitative component of this study, there were independent and dependent variables. The independent variable affects the dependent variable, which is the outcome. The independent variables that were assessed in this study to find out how they relate with the dependent variable are as below:

### Selected Independent Variables

- Demographic: age, religion, level of education, marital status, medications, presence of metallic valve
- Years of disease
- Number of Pregnancies
- Outcomes of Pregnancies
- Consultation with health worker about contraception
- Reasons for not using contraception
- Reasons for stopping method

### Selected Dependent Variables

- Contraceptive utilisation
  - If yes, -Method of contraception used
  - Method stopped
  - If No, -why

## Data Collection Tools

These are instruments used by researcher to collect data according to objectives of research.<sup>35</sup>

### Quantitative Data Collection Tool

The study employed a structured questionnaire with closed ended questions to capture the patients' demographic data and utilisation of contraceptives. The questionnaire tool was chosen because it is fast, practical and easier to obtain a larger sample in the shortest possible time.<sup>36</sup> This enabled collection of data, which could easily be coded and analysed.

### Qualitative Data Collection Tool

Qualitative data were collected using in-depth semi-structured face-to-face interviews to explore the lived experiences of contraceptive use. Semi-structured interviews with probes guided areas to be explored and gave interviewer and interviewee flexibility to diverge to get more details about phenomena (Gill, Stewart, Treasure, Chadwick 2008).

## Data Collection

### Access to Study Participant

Before accessing the participants for the study, permission was sought from the gatekeepers. According to Marshall,<sup>32</sup> gate keepers are formal authority that link researcher to the organisation. They grant or withhold access to participants

depending on perceived threat. In this study, the gatekeepers were the Executive director of Uganda Heart Institute and the Director Mbarara Regional Referral Hospital. After Research Ethics Committee (REC) approval permission was sought from both hospital administrations of MRRH and UHI to implement the study.

### Pre-Test for Quantitative Research Tool

The researcher did a small-scale preliminary data collection to test the feasibility of the research tools. It was done prior to ensure the tool had credibility and was understood by the respondents. The pre-test was done with 5 respondents receiving services at Joint Clinic Research centre (JCRC) in Lubowa. The site was chosen because it has a treatment centre for RHD patients who usually go for routine reviews. The process involved asking the questions and getting feedback on the tool from the respondent. Any question that was not clearly understood was reframed adjusting the questionnaire for maximum credibility; for example, open-ended questions in the quantitative tool were removed since responses were being given in the interviews for the qualitative study. In addition, this gave the researcher an insight into data collection, how long it would take to collect the data. It also helped the research team become familiar with the data tool.

### Data Collection Process

Data was collected from 6th August to 20th August in the two hospitals. The researcher hired two research assistants to help in data collection. They were trained on the process of data collection since the study was sensitive and could evoke past experiences and some participants were minors. The researchers were trained on how to handle such cases as explained in the ethical consideration section. Qualitative data was collected first followed by quantitative data though both were collected in the same phase and then triangulated to capture different aspects of contraception in women with RHD.<sup>24</sup>

### Qualitative Data Collection Process

Information rich participants were purposively selected considering various demographic variables to participate in the study. They were given appointment to come for an in-depth interview, and this will be through the help of staff and research assistants. The interviewees were given a transport refund of 20,000 UGX upon attending the interview. All in-depth interviews were conducted in a quiet, private environment agreed upon by the participant, and this was in the hospital's board room. Data was collected using audio recording with consent from the participant. The interview took about 45 minutes. The interviewer also took notes during the interview process. The interviews were done until redundancy was achieved.<sup>37</sup>

### Quantitative Data Collection Process

The research assistants gave the questionnaire to study participants who could read and write. Those unable to read and write, the research assistants assisted in filling the questionnaire by asking them questions in Runyakitara and Luganda since these were the languages captured in their records. This process happened after a brief explanation of the study and written consent. The participants were selected from the clients who are attending the outpatient clinic for cardiovascular disease and meet the sample requirement. The trained research assistant identified in collaboration with clinic staff identified the women who met the inclusion criteria. The participants were told that the questions took about twenty minutes. They were free to ask any questions and withdraw from the study at any time. The research assistant ensured completeness of the questionnaire and by looking at their prescription form to complete the demographic data.

### Quality Control Measures for the Quantitative Data

This was achieved by ensuring validity and reliability. Validity is defined as the extent to which a concept is accurately measured in a quantitative study. Internal validity and external validity will be ensured.<sup>38</sup>

## Validity

### Internal validity

This was achieved by having a team of experts review the study and pre-testing the tool with a similar population. Extensive literature reviews were also done during tool development to ensure content validity.<sup>39</sup>

### External Validity

The extent to which the findings are generalizable, this was ensured by recruiting representative sample participants.<sup>39</sup>

## Reliability

Accuracy of the instrument and whether it would yield the same results if used under same settings.<sup>39</sup> This was achieved by carefully training the research assistants to ask the questions in the same way, not altering the questions, and not discussing the questions with the respondents. It was also guaranteed by carefully monitoring the research assistants and observing their questioning of the respondents.

## Rigours of Research for Qualitative Data

Trustworthiness or believability was achieved by addressing the four elements; credibility, dependability, confirmability and transferability as described by Korstjens and Moser.<sup>40</sup>

Credibility (Truthfulness) is accuracy or truthful depiction of a participant's lived experience towards contraception use. This was ensured by giving participants enough time to talk about their experiences. Two researchers independently coded all transcripts and compared emerging codes. Discrepancies were resolved by discussion until consensus was reached. Member checking was performed with three participants to confirm interpretation of key themes. Building trust and rapport before audio interviews was also ensured to achieve credibility.<sup>41,42</sup> The interview guide questions were also translated in the local languages, Luganda and Runyakitara to be able to overcome language barrier.<sup>43</sup>

Dependability (consistency) refers to whether we would obtain the same results if we could observe the same thing twice. This was achieved by having expert qualitative researcher review transcribed material and providing an audit trail of research process.<sup>40,44</sup>

Confirmability (neutrality) refers to the degree to which the results will be confirmed or corroborated by others. Confirmability is concerned with establishing that data and interpretations of the findings are not fabrications of the inquirer's imagination, but clearly derived from the data.<sup>41</sup> This was achieved by providing an audit trail of research steps taken from the start of a research project to the development and reporting of the findings.<sup>41,44</sup>

Transferability (applicability) refers to "external validity" is concerned with the extent to which the findings of one study can be applied to other situations.<sup>40</sup> This was achieved by thick description of contextual information about the fieldwork sites to enable the ability to transfer study in another setting.<sup>40,44</sup>

## Data Analysis

### Quantitative Analysis

Data from questionnaire was cleaned, coded and entered into Microsoft Excel, then taken into STATA 12. The analysis determined the contraception utilization rates and the relationship between utilization and the different demographic variables and choice of contraceptive mode. Contraceptive utilisation using Stata to find methods used, methods stopped, reasons for stopping. Multiple linear regression was done to test if there was a relationship between contraception utilisation among women with RHD and their different demographic variables.

### Qualitative Data Analysis

Qualitative data was transcribed into written narratives, which was analysed using Van Manen's hermeneutic phenomenological approach.<sup>45</sup> This approach explores the structure of human lifeworld as experienced every day. Van Manen hermeneutic phenomenological approach considers four components that include temporality (lived time), Spatiality (space), corporeality (body) and relationality (relation). To understand lived experiences of contraception, use while living with RHD, Audio taped recorded interviews were familiarized by listening and re-listening and taking notes. The

interviews not in English were translated into English and back translated to the local language to ensure meaning was not lost. The interviews were transcribed verbatim. Transcribed information was read and re-read highlighting common emerging statements. The statements were then grouped into themes according to the four components as categorised by Van Manen.<sup>45</sup>

## Ethical Considerations

Ethical approval for the study was obtained from the University Research Ethics Committee (REC) of Mbarara University of Science and Technology, as well as administrative clearance from Uganda Heart Institute and Mbarara Regional Referral Hospital. All participants provided written informed consent (and assent with parental consent for minors) before participation.

Eligible participants were given an explanation about the study and were requested to participate in the study, and those willing were asked to sign a consent form. Minors below 18 years had their parents on their behalf and assented before the study. Participants were informed that participation in the study is purely voluntary and that they are free to withdraw at any time they wish and it would not affect their clinical services and participants consented and accepted for their anonymized responses/direct quotes to be published. The study also complied with the Declaration of Helsinki.

Participants' privacy and confidentiality was ensured. They were told not to write names on the data collection tools except on the consent form. They were given identification codes for use throughout the study. The informed consent forms with names were kept in a secure place from the list of identification codes. Electronic data were only available to the researchers by password protected computers. Interviews and completion of the questionnaire were conducted in private rooms with maintenance of confidentiality.

## Presentation of Findings

This chapter presents findings of a cross sectional mixed method study of both quantitative and qualitative design. The quantitative study presents findings of contraception utilization among women with Rheumatic Heart Disease, while the qualitative study presents findings of lived experiences of contraception utilization among women with Rheumatic Heart Disease. Data was collected over a period of two weeks and response rate was 100%. Data were analysed and presented in tables.

## Data Analysis for the Quantitative Study

### Demographic Characteristics (N=84)

Majority of the respondents were above 18 years and the highest level of education was degree 20 (24%) Protestants dominated in the study 26 (31%), and majority were single 38 (45%) as shown in [Table 1](#).

**Table 1** Demographic Characteristics (N=84)

Variable	(N=84)	%
<b>Age</b>		
18 and below	10	(12)
Above 18	74	(88)
<b>Education level</b>		
Degree	20	(24)
Diploma/certificate	12	(14)
Secondary	31	(37)
Primary	18	(21)
None	3	(4)

(Continued)

**Table 1** (Continued).

Variable	(N=84)	%
<b>Religion</b>		
Protestant	26	(31)
Catholic	22	(26)
Moslem	20	(24)
Pentecostal	16	(19)
<b>Marital status</b>		
Single	38	(45)
Married	35	(42)
Divorced	4	(5)
Widowed	1	(1)
Cohabiting	6	(7)
<b>Residence</b>		
Urban	51	(61)
Rural	33	(39)

## Contraceptive Utilisation, Teratogenic Medication Use and Unplanned Pregnancies Among Women with RHD (N=84)

In [Table 2](#), majority 59 (70.2%) were not using contraception. Those taking teratogenic medication were 56 (66%) and of the participants who said they had ever been pregnant since diagnosis with RHD, 27 (77.1%) had unplanned pregnancy.

## Use of a Modern Method of Contraception While Taking Teratogenic Medication

A small percentage (30.3%) were taking modern method of contraception while taking a teratogenic medication as shown in [Table 3](#).

**Table 2** Contraceptive Utilisation Among Women with RHD, Use Teratogenic Medication and Occurrence of Unplanned Pregnancy While Living with RHD

	Current use of Contraception	Taking a Teratogenic Medication (Warfarin)	History of Unplanned Pregnancy with RHD
Yes	25 (29.7%)	56 (66.6%)	27 (77.1%)
No	59 (70.2%)	28 (33.3%)	8 (22.7%)

**Table 3** Use of a Modern Method of Contraception While Taking Teratogenic Medication

Contraception Use	Use of Teratogenic Medication (Warfarin)	Not Using Teratogenic Medication (Warfarin)	Total
Using FP method	17 (30.3%)	8 (28.6%)	25
Not using FP method	39 (69.6%)	20 (71.4%)	59
<b>Total</b>	<b>56</b>	<b>28</b>	<b>84</b>

## Commonly Used Methods of Contraception Among Women with RHD

The commonly used method of contraception was hormonal short-term, which included pills and injections 10 (40%) followed by long acting non-hormonal IUD 7 (28%). Least used method was the barrier method, which mostly consisted of male condom as shown in [Table 4](#)

## Commonly Stopped Methods of Contraception

According to [Table 5](#), Majority had stopped using hormonal short-term contraception 19 (73%) which comprised of pills and injections followed by barrier methods 3 (11.54%). IUD and permanent methods had high continuity rates since no one reported to have stopped them.

## Reasons for Stopping to Use Contraception

Majority 9 (34.6%) stopped using contraception due to side effect and desire to conceive as shown in the [Table 6](#).

**Table 4** Commonly Used Methods of Contraception Among Women with RHD

Method of Contraception	Percentage Using (%)
Hormonal short term	10 (40)
Hormonal long term	4 (16)
Barrier	2 (8)
LARC-non hormonal (IUD)	7 (28)
Permanent	2 (8)
TOTAL	25 (100)

**Table 5** Commonly Stopped Methods of Contraception

Method of Contraception	Percentage Stopped Using (%)
Hormonal short term	19 (73.0)
Hormonal long term	1 (3.8)
Barrier	3 (11.54)
Natural method	2 (7.6)
LARC-non hormonal (IUD)	0
Permanent	0

**Table 6** Reasons for Stopping to Use Contraception

Variable	Frequency	Percentage
Side effect	9	34.6
Desire to conceive	6	23
Method failure	5	19.3

## Discussed Safety of Contraception Before Choosing a Method of Contraception

Majority of the respondents (78.8%) did not know the safety of the contraception method they were taking as shown in the Table 7.

## Multiple Linear Regression to Assess for Relationship Between Contraceptive Utilisation and Demographic Variables

Multiple linear regression was done to analyse for relationship between different demographic variables. Most categories did not have a significant relationship with contraceptive utilisation since P-value was more than 0.05. However, a few categories had a significant relationship and these include level of education being diploma (P-value 0.049) and being a Pentecostal by religion (P-value 0.028) as shown in the Table 8.

## Data Analysis for the Qualitative Study

The qualitative study involved 13 participants, aged 18–39 years (mean age 28.5 years). Their years of RHD were 3–20 years. Nine were married, 3 single, 2 cohabiting and protestants were dominating in religion. Qualitative study answered research question 2; What are the lived experiences of contraception used among women with RHD.

**Table 7** Discussed Safety of Contraception Before Choosing a Method of Contraception

Variable	YES	NO
Discussed safety of method	21.3%	78.6%

**Table 8** Multiple Linear Regression to Assess for Relationship Between Contraceptive Utilisation and Demographic Variables

Demographic Characteristic	Co-eff	95% CI	P-value
<b>Age category</b>			
Above 18 years	0.1088436	−0.2465537 0.464241	0.543
<b>Education</b>			
Diploma	−0.3344481	−0.6667362 −0.00216	<b>0.049</b>
Secondary	−0.0911083	−0.3720551 0.1898385	0.520
Primary	−0.2340837	−0.5628819 0.0947144	0.16
None	−0.0740606	−0.7815761 0.6334548	0.835
<b>Religion</b>			
Catholic	0.0131216	−0.2538185 0.2800617	0.922
Moslem	0.0396812	−0.2368664 0.3162288	0.77
Pentecostal	0.335182	0.0374273 0.6329367	<b>0.028</b>
<b>Marital status</b>			
Married	0.1749276	−0.0593255 0.4091806	0.141
Divorced	−0.1012553	−0.6159972 0.4134867	0.696
Widowed	−0.1994846	−1.354933 0.9559637	0.732
Cohabiting	0.1923645	−0.2272382 0.6119673	0.364
<b>Residence</b>			
Rural	−0.0248374	−0.2448591 0.1951844	0.823

**Note:** Bold values indicate statistically significant results ( $p < 0.05$ ).

## Themes and Categories

In the current study, lived body refers to how women with Rheumatic heart disease experience their body while using contraception, how using contraception while living with Rheumatic Heart disease experiences the way they feel and their bodily changes. All this is shown in [Table 9](#).

### Thematic Category of Fear

This theme emerged from fear of side effects of family planning, fear of complications of the heart, embarrassment and fear of parents.

The fear of side effects was due too much bleeding, they bled continuously and were worried as noted in their excerpts;

I had just started using family planning injection, it treated badly.... I was bleeding too much, 3 months ended and I was still bleeding.... (P.5)

...Used coil...started bleeding continuously without stopping in a month., I wanted to remove, when I bled a lot, it worried me....

Fear was also due to complications where participants claimed the heart would beat too first or too low and they were dying as noted.

...I tried to use pilplan, haa I was dying ...I got other complications because our lives are fragile.... I could be walking and feel my heart is beating too fast, I have to hold on something and sometimes it is beating too low I cannot even feel it (P.2, P.9)

...When you use family planning, sometimes they make you big. And they tell us a heart patient should avoid being big because it may worsen the heart disease. Me what the doctor told me scared me most... (P.3)

If other normal people have problems with family planning, how about you with a heart problem. All that caused me to fear (p.3)

Participants lived experience of fear was due to embarrassment buying contraception method at young age as stated.

...I felt bad as a young child going to buy pills, I was feeling ashamed. I was 16 years.... (P.9–18 years old)

They also feared that if their parents found out as mentioned;

**Table 9** Themes and Categories

Van Manen Existential Themes	Emerging Themes	Category
Corporeality	Fear	- Side effects - Complications - Embarrassment - Fear of parent
Relationality	Communication gap	- No information - Unclear information - Unsupportive husband - Unsupportive family member - Unsupportive health workers
Spatiality	Helplessness and frustration	- Unplanned pregnancies - Lack of sexual satisfaction
Temporality	Ingenuity	- Avoidance of the husband - Alternate protection

I have ever used a condom and it's the one I use. I have not found any problem with it .... except I feel ashamed buying it in a pharmacy. People may look at you as a prostitute (P.13-23 years old)

They had told me you have a heart disease so you can't get pregnant.... I feared so much and was thinking about my parents, I knew they would beat ...if they find them in my bag.... (P.9-18 years old)

## Lived Relations (Relationality)

The theme describes how the interaction with the concerned different people in their lives explain create an experience with contraception utilisation.

## Thematic Category of Communication Gap

The theme emerged from no information from health worker and unclear explanation. The lived experience of communication gap was due to lack of information from health worker. Participants claimed that they concentrate on the heart problem and not on contraception as indicated below;

Initially doctors are not open with these family planning issue... they concentrate on your heart, medications, food for those swallowing warfarin. I feel these other issues have been ignored. (P.8)

...I did not get any teaching about...family planning... injections.... ...it's the one I had been using before I was told I have a heart disease. I knew it would work the same way it was working before I got heart disease. (P.5)

The participants noted that they experienced unclear information as noted below in their excerpts

Me I thought, us who swallow warfarin, you can't conceive... they told me... that when your swallowing warfarin you can't conceive.... Because I was taking warfarin and with heavy menstrual bleeding, I knew I wouldn't conceive... found later I was pregnant. (P.4-25 years)

Participants lived experience was lack of family members support, being attached as noted below in their excerpts

...Family of the man treat me bad, they keep talking that the woman you married does not produce..... My relatives keep asking me, how are you staying with the man without children.... am sick and it really frustrates me... At one time I was tempted to remove it and produce... Those things stress me, that's why am always sick, stressed, in and out of the hospital. It hurts me a lot. (P.10,P.11)

Furthermore, lack of support was experienced among health care workers as noted in their excerpts below;

I went to kawempe... told them I wanted IUD, they asked me how many children do you children before putting IUD! To me it looked like it's not good. So I had to explain to them about my heart disease. (P.10)

I went to the family planning person and I told her i wanted IUD, So she was like why are you putting an IUD when your still young, you should be giving birth. (P.6)

## Lived Spatiality

Lived space refers to the way individuals experience and relate to the space around them, even before they can describe what is seen, heard, or felt, according to van Manen.<sup>46</sup>

## Thematic Category of Helplessness and Frustration

The theme of helplessness and frustration emerged from unplanned pregnancy while on natural family planning, and this led to being scared of their heart disease conditions and aborted as noted in their excerpts below;

...Used withdrawal method and counting days.... I got unwanted pregnancy while using withdrawal and counting days... I was completely helplessness.... ..I got scared and aborted, I was worried of my heart disease. (P.1, P.2)

...Withdrawal and I conceived. let me use pilplan, because. ....When i stopped pilplan like this, hardly a month. (P.2)

Participants were conceiving unknowingly as noted by one of the participant's quotes

I was pregnant, after conceiving unknowingly I was dying, I got heart failure, admitted in ICU, I was in and out of hospital. I got heart failure... I felt all alone in this. (P.2)

The lived experience of helplessness and frustration was also due to lack of sexual satisfaction as the methods like condom would make them dry and would not enjoy sex. They claimed also the man would be weak,

...Used a condom. would make you dry and things he would say that my wife, why should I use a condom, He would not enjoy what he would be doing. both do not enjoy sex. (P.12)

...The man complains because they say that one affects them. It makes the man weak he will lose his sexual strength as a man if he continues to use withdrawal. (P.1)

...Why should I use a condom, He would not enjoy what he would be doing both do not enjoy sex. (P.12)

...The man complains because they say that one affects them. It makes the man weak ....he will lose his sexual strength as a man if he continues to use withdrawal.... (P.1)

## Lived Time

Lived time is a person's interpretations of the time dimension; the past, present and future containing memories, future hopes influenced by the present.

## The Thematic Category of Ingenuity

The lived experience of ingenuity emerged from two categories, avoidance of husband and alternate protection. Lived experience of ingenuity was to avoid the husband to prevent pregnancy as noted;

Currently am not using any method, when am in fertile days, I try to ...avoid.... husband. (P.1)

Alternate protection by being secretive was another way of protecting self as this was not discussed with the husband as mentioned below

I would just keep quiet and insert...tablets down..., wait, for the time they told me and then I would give him time and allow him to touch me. (P.12)

## Integration of Findings

The mixed-methods design helped to integrate quantitative and qualitative findings to provide a more comprehensive understanding of contraceptive utilization among women with RHD. Quantitative data showed that only 29.7% of women were using contraception, with a high reliance on contraindicated methods such as pills and injections, and 34.6% discontinuation due to side effects. These results were reinforced by qualitative accounts in which participants described fear of heavy bleeding, palpitations, and weight gain as reasons for stopping methods.

Furthermore, the quantitative finding that 78.6% of women had not discussed contraceptive safety with a health worker was strongly supported by the qualitative theme of *communication gap*, where women reported receiving little or no counselling about family planning in the context of their cardiac disease.

Qualitative themes of *helplessness and frustration* explained the high proportion of unplanned pregnancies captured in the quantitative data, particularly among those relying on traditional methods. Similarly, the theme of *ingenuity* (like secretly using or avoiding sex) contextualized the quantitative observation that some women were not using any modern method despite the risks of unplanned pregnancy.

Overall, the integration of findings demonstrated convergence and complementarity between the two strands of data. Quantitative patterns of low and inappropriate contraceptive use were illuminated and deepened by qualitative narratives,

which explained the fears, communication barriers, relational pressures, and coping strategies influencing women's decisions. This triangulation strengthened the credibility of the findings and highlighted the urgent need for guideline-based, multidisciplinary contraceptive counselling for women with RHD.

## Discussion

### Contraceptive Utilisation Among Women with RHD

The study found only 29.7% of the respondents were using modern method of contraception. These findings differ from earlier finding reported by Chang, Nabaale<sup>10</sup> where 14% of women living with RHD were using a modern method of contraception. These findings could have been different due to different sample size of 50 that was used and the contraceptive use was reported in women who were taking warfarin only. Still, in a study done in twelve African countries Uganda inclusive, 3.6% of women were found using contraception. The study did not report country-specific use.

Objective one also assessed the commonly used methods of contraception and these included hormonal short-term methods (34.7%) comprising pills and injections though literature revealed that methods of contraception should be chosen with careful consideration to avoid aggravation of the heart disease.<sup>8</sup> According to WHO medical eligibility criteria for contraception use, combined oral contraceptives are contra-indicated in people with a valvular heart disease. Furthermore<sup>47</sup> reported that DMPA injection, which was among the commonly used method among women with RHD causes changes in lipid profile of users, which may further complicate the heart disease. Celik<sup>48</sup> reported that these methods are commonly used by women in Uganda because they are accessible and readily available. This emphasizes the need for specific counselling tailored to women with RHD taking in consideration their clinical status.

The study found the commonly stopped methods of contraception was pills and injections due to side effects (34.6%) and the desire to conceive (23.8%). The most reported side effects were heavy menstrual bleeding, weight gain, and palpitations. While not life-threatening, these effects were distressing and created fear of worsening heart disease, consistent with the qualitative theme of fear. Method failure was most common with traditional methods (withdrawal and calendar), which participants often chose for cultural or accessibility reasons. These methods' low effectiveness led to unplanned pregnancies, as reflected in qualitative accounts of helplessness and frustration. Desire to conceive was largely driven by family and spousal pressure, compelling women to discontinue contraception despite medical advice. This finding aligns with the qualitative theme of relational pressure. These findings agree with a study by Lindley, Madden<sup>49</sup> who reported that women with heart diseases were using pills, injections, condoms and calendar method which were less effective and resulted in high rates of unwanted pregnancy.

Furthermore, this study found 78.6% (See Table 8) of the women did not know the safety contraceptives for use with RHD. Pills and injections are sold at the counter and easily accessible to women as a choice of method based on their own liking due to convenience. It should be noted that, among women with RHD, hormonal methods subjects them to severe side effect such as thrombosis<sup>50</sup> or bleeding disorders as commonly reported in qualitative interviews. This could be the contributing factors why women stop the method.

Although Wald, Colman<sup>7</sup> argues that method of contraception in a woman with heart disease should be carefully selected with the guidance of a multidisciplinary team including cardiologist, physician, obstetrician to avoid weighing the risks versus benefit of use. It is imperative that the women with RHD are guided on the right methods. In addition, to have clear guidelines that are referred to by all providers about contraception utilization among women these women to increase continuation rates. It can be argued that the above findings of this study answered the research question one; What percentage of women with RHD use contraception and what methods do they use.

### Exploration of the Lived Experience Contraceptive Utilization Among Women with RHD

Qualitative study employed in-depth interviews involving 13 respondents who were in the age range of 18–39 years and the mean age 28.5 years. Most women were married.

The study revealed the lived experiences of women with RHD on contraception were related to Van Manen's existential themes that explain lived experiences of phenomena of lived body, live space, lived relations and lived time. The derived

themes of fear, communication gap, helplessness and frustration and ingenuity were experienced in the lived world of women with RHD while using contraception. These findings answered objective two and the research question two.

### Lived Body (Corporeality)

The fear impacted on daily life of the women living with RHD due to side effects, complications, Embarrassment and fear of parents. The finding of fear concurs with other studies; Mwizerwa and Rozzano<sup>1</sup> in a study on hormonal contraception utilisation, they found women had discontinued use due to fear, however these women did not have any threatening medical condition and stopping use did not threaten their lives. This implies emphasis should be put on contraception use in risky populations including women with RHD.

The findings are consistent with the conceptual framework, the health belief in that women perceive threat to their lives and use contraception, however poor utilisation was related to a number of barriers that need careful attention to enable continuous use. Therefore, appropriate identification of the right method is paramount.

The finding of shame and embarrassment were feelings of irritability, anger and depression towards early engagement of contraceptive methods at younger age. Furthermore, with uncertainty of being punished if their parents found out and fearing to be labelled prostitutes. These findings agree with a study by Celik<sup>48</sup> which reported that young people faced negative attitudes with inadequate information regarding contraception.

### Lived Relations (Relationality)

The theme of communication gap describes how the interaction of the women with the concerned different people in their lives contributes to an experience of contraception utilisation. Communication gap due to no information by health worker and unclear information on how to use contraception mirrored the lived relations. Appropriate communication improves understanding of contraceptive utilisation and is critical in ensuring the right choice of methods to prevent unplanned pregnancies.

The finding of communication gap concurs with<sup>11,48</sup> who found there were communication gaps regarding contraception utilization between physicians and clients with medical conditions frequently leading to negative experiences.

The study also, found uncaring attitudes among the husbands, family members and the health care workers. These could influence the lived experience of these mothers negatively.

### Lived Space (Spatiality)

Lived space also refers to the experience of the space that surrounds a person before words can describe what is seen, heard, and felt. This was revealed in the thematic category of helplessness and frustration. The women felt let down by family planning method leading to unplanned pregnancy as well as lack of sexual satisfaction. Other studies also found unplanned pregnancy occurring among women with heart disease<sup>1,49</sup> which led to frustration.

Helplessness and frustration were dissatisfaction with contraceptive use and disappointments. These findings should be addressed collective to achieve the optimal wellbeing.

### Lived Time (Temporality)

This life world was experienced in the theme of ingenuity under categories of avoidance of husband and alternative / personal protection. Women avoided their husbands during their fertile days in order not to conceive. Also, women were using family planning methods secretly to avoid pregnancy. This finding is in agreement with Mwizerwa et al and Celik<sup>48</sup> who found ingenuity among women in rural Uganda who discontinued hormonal contraception. These finding clearly points out that women are in search of on an appropriate method that suits them without disabling side effects.

### Triangulation of Qualitative and Quantitative Findings

The qualitative findings strongly supported the quantitative results, showing that only 29.7% of participants were using contraception. The main reasons for discontinuation were side effects, desire to conceive, and method failure. Emerging themes such as fear of side effects, fear of worsening heart disease, and frustration with method failure further explained women's reluctance or discontinuation of contraceptive use, as illustrated in the participant excerpts below.

I had just started using family planning injection, it treated badly.... I was bleeding too much,3 months ended and I was still bleeding.... (P.5)

...when you use family planning, sometimes they make you big. And they tell us a heart patient should avoid being big because it may worsen the heart disease. Me what the doctor told me scared me most... (P.3)

Another emerging theme was communication gap and women mentioned that health workers had not given them clear and full information about family planning. This theme is supported by quantitative finding where 78.6% of the participants said had not discussed with health workers about the safety of contraceptive methods.

Initially doctors are not open with these family planning issue... they concentrate on your heart, medications, food for those swallowing warfarin. I feel these other issues have been ignored (P.8)

...I did not get any teaching about...family planning... injections.... it's the one I had been using before I was told I have a heart disease. I knew it would work the same way it was working before I got heart disease (P.5)

In the quantitative study, it was found that women commonly stopped hormonal short-term methods, which included pills and injections. This finding was still supported by the qualitative findings where who had used pills and injections admitted to have stopped taking them because of the side effects they had experienced. This can be explained in their excerpts below;

I had just started using family planning injection, it treated badly....I was bleeding too much,3 months ended and I was still bleeding....(P.5)

...I tried to use pilplan, haa I was dying ...I got other complications because our lives are fragile.... I could be walking and feel my heart is beating too fast, I have to hold on something and sometimes it is beating too low I cannot even feel it (P.2, P.9)

The findings of this study highlight the urgent need for integrating reproductive counseling into the routine care of women with RHD to reduce preventable maternal morbidity and mortality. Failure to anticipate and manage high-risk cardiovascular conditions has repeatedly been shown to result in sudden and often fatal outcomes.<sup>51</sup> Similarly, women with RHD require proactive counseling and safe contraceptive options to prevent unplanned pregnancies, which can further aggravate their cardiovascular risk.

## Limitations of the Study

The findings of the study cannot be conclusive given that the target sample size was not achieved. The investigator had proposed to recruit 113 participants for the quantitative study but only 84 were accessible to participate in the study, and the majority were above 18 years. This was largely attributed to the school calendar and the month that data was collected, most teenagers were at school.

Additionally, the cross-sectional design used in this study has inherent limitations, such as the inability to establish causality, difficulty in assessing changes over time, and potential for selection and recall bias, which may have influenced the findings.

The qualitative component involved only 13 participants, with sample size determined by redundancy (data saturation). While this number generated rich insights, the small size may limit the generalizability of findings to all women with RHD in Uganda. Therefore, results should be interpreted with caution.

Self-reported contraceptive use may be affected by social desirability bias, with participants potentially overreporting or underreporting use.

The study was conducted in a single-country setting, limiting the generalizability of the results to other regions.

## Implications of the Study

The study highlights the need for multidisciplinary contraceptive counseling, where cardiologists address medication risks, gynecologists recommend safe contraceptive options, and nurses provide continuous education and follow-up. This integrated model ensures that reproductive counseling becomes part of routine RHD care.

We recommend the development of institutional frameworks and national guidelines that adapt WHO/ESC/AHA recommendations to the Ugandan context, to standardize and strengthen contraceptive counseling in RHD clinics.

## Recommendations

Appropriate guidelines on contraceptive use that are specific to women with RHD need to be formulated to enable giving of clear consistent information to enable them make choices on contraception.

Contraception utilisation among women with RHD needs further research to assess the health care workers on the information given to women due to a large communication gap that was found.

## Conclusion

Contraceptive utilization among women with RHD in Uganda remains low, with unsafe methods commonly used and poor counselling support. Integrating structured contraceptive counselling into RHD care pathways, developing context-specific guidelines, and involving partners and families are essential to reduce unplanned pregnancies and improve maternal and fetal outcomes.

Experiences of contraception composed of fear of side effects of contraception, complicating heart disease and embarrassment for the young ones. Communication gap was also experienced as women said they lacked information regarding contraception with their heart disease. Helplessness and frustration were experienced as a result of method failure and unwanted pregnancies and lastly ingenuity which was due to concealing of information about the methods women were using from their unsupportive partners. Guidelines that clearly stipulate use of contraception among women with RHD in different stages of disease will enable women to choose a right method that enables continuity and avoidance of unpleasant experiences.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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