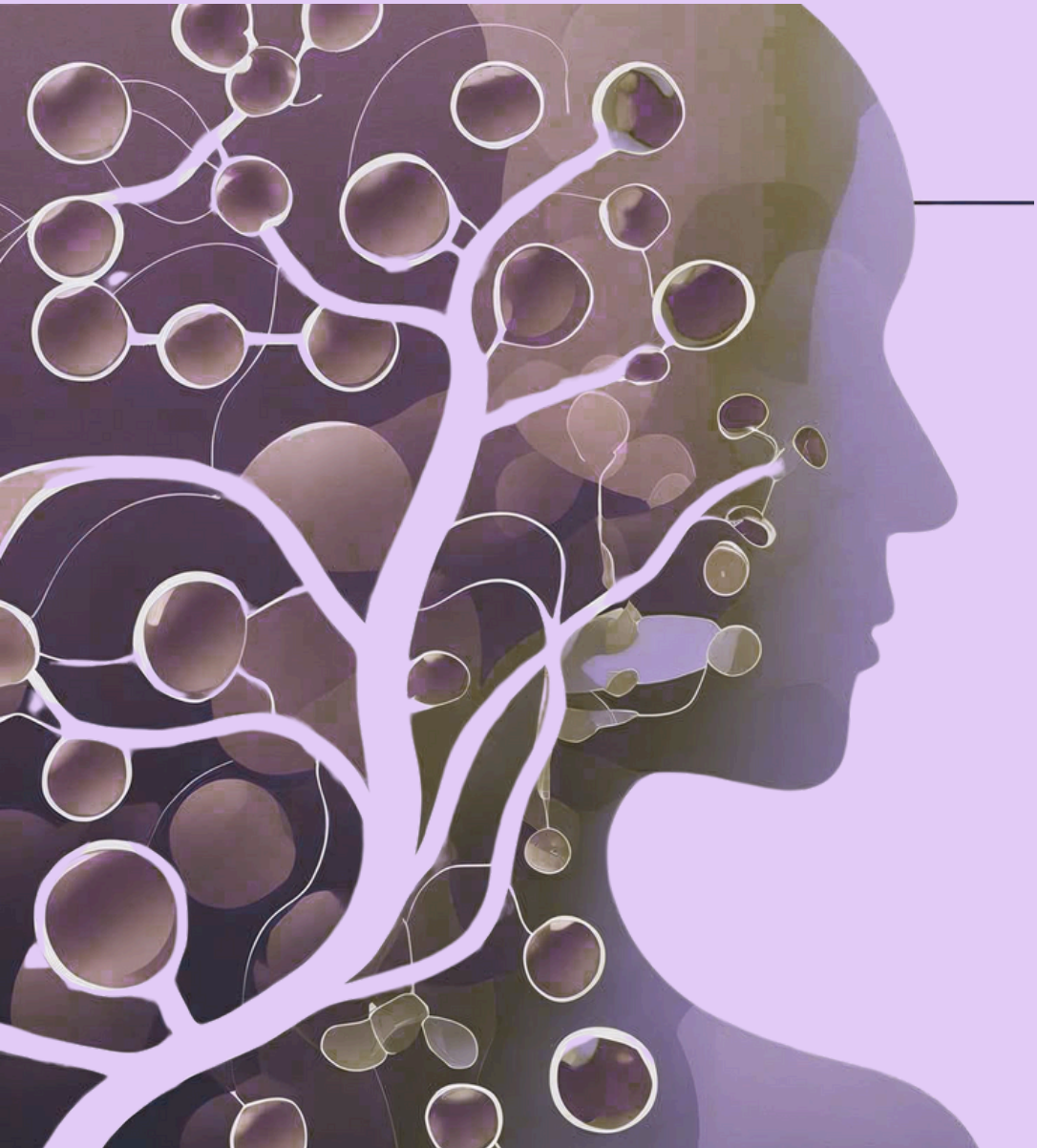
WOREC

UNDERSTANDING INFERTILITY THROUGH SRHR:

Trends and policy obstacles in Assisted Reproduction "

Feminist Participatory Action Research



UNDERSTANDING INFERTILITY THROUGH SRHR: Trends and policy obstacles in Assisted Reproduction

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This research is not just a document – it's a testament to what we can achieve when we come together with purpose and compassion. Thank you all for being part of this remarkable journey.

Table of Content

ABBREVIATIONS

FPAR: Feminist Participatory Action Research
SRHR: Sexual and Reproductive Health and Rights
ART: Assisted Reproductive Technology
FGD: Focus Group discussion
IVF: In Vitro Fertilization
NDHS: Nepal Demographic Health Survey
WHO: World Health Organization
WOREC: Women's Rehabilitation Center
MoHP: Ministry of Health and Population
ICPD: International Conference on Population and Development
WHRD: Women Human Rights Defenders
HRD: Human Rights Defenders
RH: Reproductive Health
TH: Traditional Healer

Executive Summary

In the heart of Nepal's Morang District, many stories unfold, but some have one common thread- one that touches upon the deeply personal journey of couples struggling with infertility. Through the eyes of women who stand on the frontlines of human rights defense, we explore how this intimate challenge intersects with broader questions of gender equality, healthcare access, and social justice.

Our research, conducted by the Women's Rehabilitation Center (WOREC) Nepal, delves into a reality many faces but few openly discuss. While Nepal has made strides in reproductive healthcare, infertility remains a shadow in the corner—acknowledged but rarely addressed. Through conversations with women human rights defenders (WHRDs), we uncover how this silence affects lives, particularly those of women who bear the weight of social expectations and stigma.

The picture that emerges in this research is complex and often heart-wrenching. We found that even those who champion women's rights sometimes struggle to recognize infertility as a crucial reproductive health issue. This gap in awareness reflects a broader pattern where women's reproductive health needs often go unaddressed, leaving many without the information and support they desperately need.

Perhaps most striking is how infertility becomes a lens through which gender inequality comes into sharp focus. Women facing infertility often find themselves navigating a maze of social judgment and sometimes even violence. When a couple cannot conceive, it's frequently the woman who faces blame - even in cases where medical issues lie with her partner. This burden becomes even heavier for women from disadvantaged backgrounds, who find themselves caught between the high costs of fertility treatments and the social pressure to bear children.

The challenges extend deep into Nepal's healthcare and legal systems. The absence of clear regulations around assisted reproduction and surrogacy creates a dangerous void where exploitation can flourish. Women seeking fertility treatments often walk a dangerous path, with neither legal protections to shield them nor emotional support to guide them. For those from marginalized communities, these barriers can seem insurmountable, creating a two-tiered system where reproductive justice becomes a privilege rather than a right.

Our findings compel us to move beyond simply identifying problems to proposing concrete solutions. We envision a comprehensive approach that includes:

- Making fertility treatments and family counseling accessible to all, regardless of economic status

- Developing clear legal frameworks to protect women undergoing assisted reproduction or surrogacy
- Creating support systems that address not just the medical aspects of infertility but also its emotional and psychological impact
- Challenging the patriarchal mindset that places the burden of reproduction solely on women's shoulders

Looking ahead, we see the path to change requiring action on multiple fronts. It's not enough to merely medicalize infertility - we must transform how society views and supports women facing these challenges. This means ensuring that reproductive healthcare policies are grounded in principles of equality and justice, with particular attention to those who have been historically excluded from these conversations.

The story of infertility in Nepal is, at its core, a story about power, gender, and justice. Our research shows that actual progress will only come when we address all three elements. We call for a future where women have not just the medical resources they need but also the social support and legal protections to make informed choices about their reproductive health without fear or constraint.

This journey toward reproductive justice requires us to reimagine healthcare systems, challenge deep-rooted social norms, and create spaces where women's experiences are heard and valued. Only then can we build a Nepal where reproductive rights are not just written in policy documents but lived in the daily experiences of all women, particularly those who have been pushed to the margins of society.

In sharing these findings, we hope to spark a broader dialogue about reproductive justice in Nepal - one that recognizes infertility not just as a medical condition but as a human rights issue that deserves our full attention and commitment to change. The path forward requires collective action, sustained commitment, and a willingness to challenge the status quo in pursuit of a more just and equitable future for all women

CHAPTER -I

1.1 Introduction:

Picture a woman's life in Nepal: Before marriage, her identity is anchored to her father's family; after marriage, it shifts to her husband's. At each stage, society's expectations follow her like a shadow. In such circumstance, the inability to conceive doesn't just represent a personal challenge – it can trigger a cascade of consequences:

- Social isolation from family and community
- Stigma that affects every aspect of daily life
- Risk of emotional and physical abuse
- The constant fear of abandonment or divorce
- Deep psychological distress, including depression and anxiety

While modern medicine offers solutions like IVF, these remain out of reach for most Nepali women, locked behind the doors of private clinics with prohibitive costs. This creates a cruel reality where help exists but remains inaccessible, leaving many women to bear their burden in silence.

When we talk about infertility in such a context, we're talking about more than medical definitions – we're discussing a deeply human experience that touches millions of lives worldwide. Yet, to understand this journey, we must first understand what infertility means in medical terms:

The World Health Organization (WHO) defines infertility is a disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse. Infertility may occur due to male, female, or unexplained factors[1,8]. In the male reproductive system, infertility is most commonly caused by problems in the ejection of semen, absence or low levels of sperm, or abnormal shape (morphology) and movement (motility) of the sperm. Similarly, in the female reproductive system, infertility may be caused by a range of abnormalities of the ovaries, uterus, fallopian tubes, and the endocrine system, among others. Infertility can be primary or secondary. Primary infertility is when a pregnancy has never been achieved by a person, and secondary infertility is when at least one prior pregnancy has been achieved. Fertility care encompasses the prevention, diagnosis, and treatment of infertility. Equal and equitable access to fertility care remains a challenge in most countries, particularly in low and middle-income countries. Fertility care is rarely prioritized in national universal health coverage benefit packages[1].

Behind this clinical definition lies a complex web of human stories. For some, it's about a body that won't produce enough sperm or healthy eggs. For others, it's about reproductive systems that face various challenges – from ovarian issues to endocrine imbalances. Each story is unique, yet all share a common thread of hope and struggle.

The numbers tell us that this isn't a rare experience – globally, as WHO put forward, between 10 to 15% of people (around 80 million individuals) face infertility at some point in their lives. That's roughly one in every six people of reproductive age. In Nepal, while the 2022 Demographic and Health Survey shows that 3.9% of women without children are considered infecund, we suspect these numbers only scratch the surface of a deeper reality.

Historically, our approach to reproductive rights initiatives have generally overlooked infertility treatment and care, focusing instead on issues like birth control, abortion, and maternal well-being. It is crucial to recognize that reproductive rights encompass infertility, as emphasized by the International Conference on Population and Development (ICPD) Program of Action and the National Reproductive Health Strategy 1998[2,3].

The study done by WOREC showed that addressing infertility requires comprehensive surveys and research to better understand its landscape in Nepal. Women facing infertility often encounter harsh social stigma, branded with hurtful labels like "bhaji" or "aputali." The journey becomes a maze of challenges: Couples frequently experience psychological distress due to infertility, compounded by financial hardship and familial pressure, leading many to seek traditional healers instead of modern medical treatments. Those who pursue biomedical methods may struggle with multiple treatment failures, leading to withdrawal due to perceived ineffectiveness and prolonged duration of treatment[5].

In many societies, including Nepal, the ability to have children carries profound social and cultural significance. When natural conception isn't possible, some turn to assisted reproductive techniques like surrogacy – where a woman agrees to take a pregnancy for another family. Yet this solution brings its own complex web of ethical, social, and personal considerations [1].

1.2 Diverse Viewpoints on Surrogacy:

The conversation around surrogacy adds another layer of complexity to this already complicated narrative. Some view it through a critical feminist lens, raising concerns about potential exploitation. Others see it as a powerful expression of women supporting women. These contrasting viewpoints reflect broader debates about motherhood, bodily autonomy, and mutual support in our modern world. The impact of surrogacy on cultural notions of motherhood and kinship also takes center stage, leading to a range of positions that either advocate for or oppose surrogacy[5,6].

1.3 Rationale to work on Surrogacy rights

In Nepal's complex social fabric, a woman's journey through infertility reveals deep-rooted challenges that go far beyond medical considerations. Her worth in society, shaped by patriarchal structures, often hinges on her ability to bear children. This cultural expectation creates a painful paradox: when facing infertility, women find themselves caught between modern solutions they cannot afford and traditional values they cannot escape.

Surrogacy emerges in this landscape as both a potential solution and a source of new ethical challenges. In discussions of infertility, surrogacy becomes a pertinent subject. Surrogacy offers a reproductive avenue for women to have a child and potentially avoid the discrimination and violence associated with childlessness. Nonetheless, it's crucial to acknowledge that the exercise of reproductive rights in surrogacy by intended mothers can clash with the reproductive rights of surrogate mothers. This results in one woman's oppression or exploitation occurring in the pursuit of another woman's reproductive aspirations. Commercial surrogacy mainly involves economically disadvantaged women, particularly from the global South, bearing babies for wealthier women, primarily from the global North, due to the high cost of surrogacy in Western countries. In this process, surrogates often face exploitation as intermediaries coerce and compel them into carrying and delivering babies for foreign individuals in exchange for payment. Therefore, creating awareness within communities and enacting robust laws to regulate surrogacy are necessary steps to ensure the sexual and reproductive health rights of all individuals and reduce the vulnerabilities faced by surrogates[4,9,13].

Surrogacy was halted by the Nepal Supreme Court on August 25, 2015, and officially banned by a Cabinet decision on September 18, 2015, using the Supreme Court's decision date as a cutoff point. The Supreme Court's final ruling was declared on December 12, 2016, stating that surrogacy is legal for infertile married Nepali couples but illegal for single men or women, transgender couples, and foreign nationals. Despite its illegality in Nepal, the regulations pertaining to surrogacy remain unclear[14]. Consequently, the absence of well-defined laws and mechanisms has heightened the risk of violence, exploitation, and human trafficking, directly infringing upon the rights of surrogates.

However, from a rights-based perspective, surrogacy is viewed as a woman's right to make decisions about her own body and reproductive choices. A woman possesses the right to self-determination over her own reproductive body. A significant aspect of reproductive rights is the ability to make independent choices regarding one's reproductive life and body without facing violence and coercion. This pertains to the right to choose whether or not to have children, when, how, and with whom, as well as access to contraception. The act of making one's body available for another person's reproductive needs may raise the same concerns from the viewpoint of reproductive rights. Hence, if surrogacy is a woman's voluntary decision, it can be seen as the exercise of her sexual and reproductive health rights. However, if it is not her choice, it becomes an exploitation of her SRHR.

To guarantee that surrogacy becomes a genuine option for women from the perspective of addressing infertility and to work for assisted reproduction, advocacy for the establishment of comprehensive laws to regulate the practice and fight social stigma related to women's bodies is imperative. To achieve this, it's necessary to conduct community awareness efforts, as surrogacy isn't widely recognized under Sexual and Reproductive Health and Rights (SRHR). Women should have the right to make choices regarding their reproductive health free from coercion, pressure, or discrimination. This includes the option to engage in surrogacy, whether as an intended parent or

a surrogate. Robust legal frameworks should be in place to safeguard the rights of women involved in surrogacy arrangements. Further, in a society like ours, there is a stigma that surrogacy is violence against women as women's bodily autonomy is beyond reality. Therefore, by raising awareness within the community and gathering the data, a consensus can be developed, leading to a community that demands rightful entitlements of women[5,8,14,15,16]. These efforts will contribute significantly to advocating for policy change.

1.4 Government Initiatives Addressing Infertility in Nepal:

The government of Nepal has taken steps to improve access to infertility treatment services, particularly in response to the growing demand for reproductive healthcare. Several initiatives have been introduced over the years, aiming to expand infertility services, improve awareness, and provide financial assistance. However, despite these efforts, implementing such programs has faced challenges, particularly in reaching underserved populations and ensuring the quality of services in federal hospitals. Through the Ministry of Health and Population (MoHP), the Nepalese government has tried to extend infertility treatment services to government-run hospitals, particularly at the federal level. In line with its commitment to improving reproductive health services, the government has aimed to introduce Assisted Reproductive Technologies (ART) such as In Vitro Fertilization (IVF) and Intrauterine Insemination. However, the initiative has faced issues regarding full implementation and coverage[9]. Furthermore, certain aspects of infertility treatment, such as surrogacy, remain neglected in the comprehensive framework of reproductive health services.

In this context, this study aims to explore perceptions and experiences among the community-based front-line women workers who are trained and oriented to community empowerment in a based approach to ensure infertility, assisted reproduction (AR), and surrogacy are the components of sexual reproductive health rights of women in assigned communities. This cadre is named Women Human Rights Defenders (WHRD) and Human Rights Defenders (HRD). With their deep commitment to women’s rights and understanding of local contexts, WHRDs are crucial agents of change, working to protect reproductive health and promote gender equality. Their advocacy contributes not only to individual empowerment but also to the broader movement for social justice and human rights.

1.5 Objectives

1.5.1 General Objective:

To explore infertility within the context of Sexual and Reproductive Health and Rights (SRHR), assisted reproduction (AR), and surrogacy, focusing on the experiences and perceptions of individuals and couples seeking these services, with an emphasis on accessibility, affordability, trends, and barriers within the community through the lens of Women's and Human Rights Defenders (WHRDS/HRDs)

1.5.2 Specific Objectives:

1. To explore the experiences and perceptions of Women's and Human Rights Defenders (WHRDs/HRDs) regarding infertility and Assisted Reproductive Technologies (ART).
2. To explore the problems and barriers faced by individuals and couples seeking assisted reproduction services, including social, cultural, and economic factors as seen through WHRD/HRDs.
3. To explore trends in the utilization of assisted reproductive services in the community, including the increasing demand for AR and surrogacy.

CHAPTER-II

Methodology

2.1 Design/ Our Approach

To understand the complex landscape of women's reproductive rights in Nepal, we chose to listen to those who witness these struggles firsthand - the frontline women's rights activists working with WOREC Nepal. Through their eyes and experiences, we sought to uncover the realities faced by women in the Morang district, using an exploratory qualitative approach that allowed us to dig deep into personal stories and community perspectives.

2.2 Study sites:

This study was conducted at the intervention site of the Women's Rehabilitation Center in 12 different urban metropolitan areas and municipalities of Morang District of Koshi Province of Nepal. Morang is a diverse district encompassing a mix of rural, urban, and peri-urban populations.

Morang lies in the Outer Terai region of Nepal, bordered by Jhapa to the east, Dhankuta and Panchthar to the north, Sunsari to the west, and Bihar, India to the south. It is one of the major districts in the province, home to a significant portion of the population of Koshi Province. The district is characterized by its varied demographic composition, with one metropolitan city, eight urban municipalities, and eight rural municipalities. We carefully selected 12 different areas within Morang's urban metropolitan regions and municipalities. This choice wasn't random - we wanted to capture the full spectrum of experiences:

- Urban communities with their greater access to medical facilities
- Semi-urban areas where traditional and modern practices often meet
- Rural settings where resources might be more limited

This variety allows us to understand how location and urbanization influence:

- Access to SRHR services

- Available educational resources
- Community attitudes and support systems
- Economic opportunities and constraints

By working within WOREC Nepal's existing intervention sites, we could tap into established networks of trust and understanding, allowing for deeper, more authentic insights into these communities' experiences.

This methodological approach, grounded in the real experiences of women's rights activists and the communities they serve, helps us paint a comprehensive picture of how reproductive rights and healthcare access play out across different settings in Morang. Through their stories and insights, we begin to understand not just what challenges exist but how they manifest differently across urban and rural landscapes.

The municipalities where the study took place include:

1. Biratnagar Metropolitan City
2. Sundar Haraicha Municipality
3. Belbari Municipality
4. Pathari-Sanischare Municipality
5. Urlabari Municipality
6. Rangeli Municipality
7. Letang Municipality
8. Ratuwamai Municipality
9. Sunawarshi Municipality
10. Kerabari Rural Municipality
11. Miklajung Rural Municipality
12. Kanepokhari Rural Municipality

2.3 Institutional Profile of Women's Rehabilitation Center (WOREC)

The Women's Rehabilitation Center (WOREC), a national non-government, non-profit organization in Nepal, has been working in the region for over three decades, focusing on women empowerment actions focused on women's sexual and reproductive health (SRH) through various programs. WOREC's extensive presence and local engagement have played a pivotal role in women's capacity development to access the SRHR services in the Morang District. The women's empowerment in the SRHR program is mainly organized at the community and family levels by mobilizing trained local frontline women rights activists and human rights activists. The women's health program is one of the WOREC programs. The main objective of WOREC's women's health program is to make sexual and reproductive health services, including SRHR information,

accessible, affordable, and acceptable to women for 24 hours. The three decades of community-level SRHR promoting women's health and rights have contributed significantly to the district's social development, empowering women to exercise control over their reproductive health and rights.

WOREC is dedicated to empowering Women Human Rights Defenders (WHRDs/HRDs)) and advocating for women's rights, particularly in the realm of sexual and reproductive health (SRH). Through its community-based actions, WOREC mobilizes WHRDs and local communities to address pressing issues like infertility and ART. However, through different campaigns and programs that are implemented in coordination with the Women Human Rights Defenders Network, WOREC has been working for the people throughout the country. These efforts include capacity-building initiatives that equip WHRDs with training on human rights, gender equality, and SRH issues, enabling them to advocate for women's reproductive rights. Local WHRDs are also actively involved in community-based research, gathering data on infertility and ART, which informs both advocacy campaigns and policy recommendations. WOREC leads awareness campaigns to reduce the stigma surrounding SRH while also engaging in grassroots mobilization through door-to-door efforts, focus groups, and peer-support networks. Additionally, WOREC collaborates with local health and legal services to improve access to reproductive healthcare and push for necessary policy reforms. The outcomes of these efforts include increased awareness and knowledge of SRH within communities, reduced stigma, and stronger advocacy for policies that ensure access to reproductive healthcare. Furthermore, WOREC strives to influence policy and legal reforms that improve the accessibility of reproductive healthcare services. Over time, these actions result in long-term achievements, including reduced stigma, improved reproductive health outcomes, and the empowerment of local leaders. WOREC has created stronger, more sustainable networks supporting women's health and rights, particularly in underserved rural areas where reproductive health issues are often marginalized.

Additionally, WOREC's working paper addresses the intersection of infertility, childlessness, and healthcare-seeking behaviors, emphasizing the challenges faced by marginalized communities in Nepal, which highlights the importance of integrating infertility and assisted reproduction into broader SRHR frameworks while advocating for policy changes to ensure that these issues are addressed within the healthcare systems.

The diversity of Morang District, coupled with WOREC's long-standing initiatives, provided a robust context for understanding the intersection of socio-economic factors, geographical location, and gender norms on women's SRHR status. By focusing on both urban and rural municipalities, this study aimed to capture a comprehensive view of the challenges and opportunities in advancing women's sexual and reproductive health and rights in the district.

2.4 Qualification, experiences of facilitator of FGD, and Orientation to field researcher

The facilitator of the Focus Group Discussions (FGDs) was a young researcher who had received training in FPAR (Feminist Participatory Action Research**)**. Additionally, a pre-research consultation in Morang district involved 26 Women Human Rights Defenders (WHRDs) and youth leaders, all female, aged between 20 and 49 years, with the young researcher leading the co-researcher team. The young researcher had experience facilitating FGDs and Key Informant Interviews (KIIs) and also provided virtual orientation sessions on the guidelines for conducting FGDs. This orientation ensured that the young researcher was well-prepared and aligned with the research objectives and ethical standards before engaging with the community.

In this role, supported by a co-researcher, who was responsible for note-taking during the discussions. To maintain privacy and confidentiality, the audio recordings of the FGDs were transcribed. The locations and timing for the FGDs were carefully selected in consultation with the co-researchers and WOREC staff, ensuring that the sessions were both accessible and relevant to the participants.

These co-researchers played an essential role in engaging with the local community, collecting data, and ensuring the research process accurately reflected the voices and concerns of the community.

2.5 Study participant's profile

Women Human Rights Defenders (WHRDs/HRDs) play a central role as study participants and active contributors, especially in approaches like Feminist Participatory Action Research (FPAR). WHRDs are deeply rooted in their communities, giving them a unique ability to identify and articulate the specific reproductive health needs and challenges that woman face. Their lived experiences and expertise in human rights advocacy enable them to provide insights into the social, cultural, and economic factors influencing reproductive health, particularly in areas such as infertility and access to ART. As active participants in FPAR, WHRDs are directly involved in data collection through focus groups, ensuring that community members' perspectives are accurately represented. Their participation guarantees that the research remains grounded in the reality of women's experiences, especially those who are most marginalized or silenced.

2.6 Data collection method:

A total of twenty focus group discussions (FGD) were conducted, with each group consisting of 7-12 participants among community frontliners (WHRD and HRD) to explore Sexual and Reproductive Health and Rights (SRHR), infertility, assisted reproduction (AR), and surrogacy.

The FGD was focused on exploring the perspectives of WHRD and HRD related to SRH issues, barriers to accessing services, and the community's demand for solutions.

2.7 Sample size was decided until data saturation of in-depth insights was achieved. Each FGD were conducted after receiving written consent for participation and audio record.

2.8 Data analysis process: Each Audio records were transcribed and analyzed by applying inductive methodology (Grounded theory) to develop codes for emerging themes and categories in the dataset regarding patterns of knowledge, perception, problems, and felt needs on SRHR related to Infertility; assisted reproductive service and surrogacy. Then, the codebook was developed and manually analyzed, reviewing each FGD data set using the process of coding, sorting, and summarizing to process for thematic analysis in the framework using the Excel software.

2.9 Ethical Considerations

The study adhered to ethical considerations by respecting the human dignity, privacy, confidentiality, and anonymity of respondents. Participation was voluntary, with minimal risks, allowing participants to skip questions or opt-out at any time without consequence. Questions were equally framed in a generalized way to increase the comfort level of participants surrounding sensitive issues.

Additionally, the draft findings were shared with field researchers and participants of FGD for validation of data. At the heart of our research lay a fundamental commitment: to honor and protect the dignity of every participant who trusted us with their stories. This wasn't just about following rules – it was about creating a safe space where voices could be heard without fear or hesitation.

CHAPTER -III

Finding

3.1 Profile of FGD participants (WHRD/HRD)

A total of 20 FGD focus group discussions (FGDs) were conducted with frontline women human rights defenders in the communities of Morang Districts, Nepal. The total number of participants was 309 across these discussions, with an average of 12 participants per FGD. Out of the total participants, 297 (96%) were female, three were male, and nine identified as LGBTQIA++.

Regarding age distribution, approximately 83% of participants were from the reproductive age group of 20-49 years, while those over 50 years old comprised about 14%. In terms of caste and ethnicity, 51.4% identified as Brahmin/Chhetri, 39.8% as Janajati, 6.8% as Dalits, and around 2% were from other groups. This data reflects the diversity within the total number of participants in 20 FGD.

3.2 Coding based on emerged themes and categories

Themes	**Categories**	**Codes**
Perception on Infertility as SRHR	The perceived meaning of infertility	A1
	Infertility as a component of SRHR	A2
Perception of assisted reproduction (AR)	The perceived meaning of Assisted reproduction	L1
	The perceived meaning of Surrogacy	L2
	Opting for alternatives to infertility treatment	L3
	Knowledge of service availability for infertility	L4
Need and difficulty of AR including Surrogacy	Financial Constraints	N1
	Man-forced compromised relations	N2
	Insufficient knowledge regarding the treatment process	N3
	Addressing Surrogate (Third Party) requirements	N4
	Male acceptance issues	N5
Problems faced due to Gender-Based Violence	Discrimination	I1
	Emotional, Psychological, and Social Consequences (Mental Health)	I2
Perception on Government Roles and Responsibility of the Government	Importance of Family Counselling	R1
	Availability and accessibility of RH services	R2
	Financial support	R3
	Ambiguity of Law	R4
Felt needs	Government Accountability and Services Parity	R1

	Women Empowerment	R2
	Need for Information Dissemination and Program Awareness	R3

3.3 Perception on Infertility through SRHR

3.3.1 Infertility as a Component of SRHR

Most of the participants were not aware that infertility is a component of SRHR and expressed confusion about the inclusion of infertility services in government policy despite being familiar with the condition and its impact.

As one of the participants said, " *We have been working on different components of SRHR such as family planning, safe abortion, etc., but not aware of infertility. But we know what infertility is." (FGD: Biratnagar)*

3.3.2 Perceived meaning of infertility/Childlessness

All participants were familiar with the definition of infertility and used local terms such as "Bhajopan," "Bhaji," and "Bahili" in the community. Also, they also could mention the possible causes of infertility in women. They mention that chronic disease, uterus problems, irregular menstruation, etc., could be the causes of infertility. Likewise, the possible cases of male infertility are listed as unhealthy habits such as smoking, alcohol consumption, low sperm count and quality, and hot weather.

As one of the participants said, " *If there is no child even after marriage, that is childlessness. It refers to a problem with a woman or a man who does not have children, whether due to miscarriage or difficulty in conceiving.*

- (FGD: Urlabari)

3.4 Perception of assisted reproduction (AR)

When discussing possible causes of infertility, most of the participants perceived women's problems in the reproductive system.

Regarding assisted reproduction and surrogacy, most of the participants were not aware about it and some had incomplete knowledge.

As one of the participants said, *there is no information about new assisted technology. (FGD, Biratnagar)*

3.4.1 Perceived Meaning of Assisted Reproduction

Some participants defined assisted reproduction as giving birth through technology, such as test-tube procedures or IVF. As one of the participants said, *AR is giving birth to a child through technology like test tubes and IVF. (FGD: Kerabari)*

3.4.2 Perceived Meaning of Surrogacy

The majority of participants did not have knowledge of surrogacy. Few participants had partial knowledge of surrogacy.

As one of the participants said, *I have heard that if the husband is fine, but the physical condition of the wife's reproductive system is defective, then she might hire another person to give birth. It is not necessary to have physical relations with that woman. (FGD: Letang)*

3.4.3 Knowledge of service availability for infertility

Most of the participants were concerned about the issues of SRHR, infertility, assisted reproduction, and surrogacy, expressing that if such technologies and laws existed in Nepal, many infertility-related problems could be minimized. They mentioned that there is no information about the treatment center to address infertility problems at the community level.

The participants shared their observation that very few couples reach out to the service center, and its treatment cost is expensive. They do not know about a better place with a low-cost treatment center and service provider (doctor). There is no government service with a subsidized cost, and they are facing social criticism about their infertility issues.

> As one of the participants said, *one should be able to connect with such new technology, and it should be convenient. People here say to go to Dr. Bhola Rijal in Kathmandu, but it's difficult and expensive technology; the government should provide assistance and subsidies. The biggest issue is that women should not have to endure torture. They should not have to face criticism from their village community*. (*FGD: Kerabari)*

3.4.4 Opting for alternatives to infertility treatment

Most of the participants perceive that there is gender bias regarding the consequences of infertility in the family. They mentioned that if the infertility were due to the husband, the wife would often compromise according to the husband's wishes. However, if the issue lay with the wife, husbands might pursue another marriage with full family support, often blaming the wife as a childless woman. Additionally, some participants preferred seeking help from traditional healers, "Dhami chakra," for infertility issues.

As one of the participants said, *what is said in the village/society is not even heard. They opt for dhami. (FGD: Kerabari)*

3.5 Need and difficulty of AR, including Surrogacy

Some of the participants perceived that there is a tendency for surrogacy by childless couples. The couple who desperately want a child is approaching through brokers both out of the country and within Nepal. However, surrogacy is still illegal in Nepal.

> *Nowadays, some Hindi cinemas and celebrities have had children through surrogacy, applying for Assisted fertility services using technology. There is a law in India. India's law has been recognized. An anecdotal report shows that many couples want a child without a physical relationship. However, there is no law for surrogacy in Nepal. Women from Nepal go to a place called Anand, where the middle person (dalal) takes a fixed amount of 10 Lakhs from the couple while the surrogate mother receives only 1 lakh, which is big exploitation. (FGD: Letang)*

As one of the participants said, *there was a case 9-10 years ago where a couple used surrogacy services using the couple's egg and sperm because the wife had cancer, and she couldn't be pregnant. They received surrogacy services from India since this type of service is still illegal in Nepal.* (*FGD: Biratnagar*

Additionally, there are anecdotal reports regarding the practice of surrogacy in informal settings due to the lack of legal provisions by some individuals seeking treatment and serving as surrogates in neighboring India as well as Nepal.

"In our village, the couple had been separated because of financial issues, but now they are together again because of money. The person who took the child gave 10 lakhs, but the middleman took 3 lakhs from her. It is said that this happened somewhere in Kathmandu, though it's unclear where exactly." (FGD: Pathari)

There would be no fear if there was a proper law. The desire to become a parent could have been fulfilled with a bit of expense. (FGD: Biratnagar)

3.5.1 Insufficient knowledge regarding the treatment process

Except for some, all the participants had some awareness about the different treatments that existed (traditional method, Ayurveda, and Modern treatment). Although most of the couples sought infertility treatment, few participants did not know where to go for treatment. They are searching for a better place for treatment and planning to visit a doctor. However, they were not sure they could afford better treatment and receive good service from the specialist doctor. All of the couples expressed that the treatments were expensive. As one of the participants said, *It's very difficult for women. They are questioned about why they cannot conceive at home but can at the hospital. While it doesn't hurt or impact when outsiders say things, it is excruciating when it comes from within the family.* (*FGD: Kanepokhari)*

3.5.2 Man-forced compromised Relation

Participants expressed that when childlessness is due to male infertility, then patriarchal power relations are seen promptly; suddenly, the husband or family doesn't need a child and wants to continue life as it is. What about the right of women to embrace motherhood? Her wish and decision have not been mentioned anywhere. Everything goes normal when it comes to men, and the whole situation changes when it comes to women. As one of the participants said, *it has been 11 years of marriage, and the couple doesn't have children, so the family started pressuring the son to get married again. But the husband knows that he has a problem. That's why he didn't get married, and they are still living together. And says that whatever happens is enough for me. (FGD: Rangeli)*

Throughout the discussion, there is an absence of male accountability in the case of infertility. Participants discussed the societal tendency to blame women for childlessness, even when the male partner is the one with infertility issues. The reluctance to acknowledge male infertility and the social pressure on women to bear children reflects the more extensive societal norms that prioritize male authority in reproductive matters.

3.5.3 Addressing Surrogate (Third Party) Requirements:

The majority of participants voiced women's right to decide to be a surrogate for intended parents (individual or couple) if they decide to earn via this process. However, the Nepal Government should ensure all the rights of surrogates by developing laws and policies.

Giving one's womb is not wrong, but clear laws need to be made, and there should be regulation. (FGD: Letang)

As one of the participants said, *Money is also needed, and the lives of oneself and children have to be managed. If a woman with the desire for children could have been provided, those children could also be raised...Yes, it could be given in that way, but still, it becomes difficult if there is no law. (FGD: Kanepokhari)*

3.5.4 In-acceptance by Male:

There is no acceptance from men that they are responsible for infertility. They even discontinued the treatment and moved to different countries/places to escape from all the insecurity and left women behind with families. There is no self-realization regarding male infertility.

Everything was normal since the woman couldn't conceive, so the service provider asked to bring her husband for a check-up and found the husband's sperm count very low. After that, the doctor said they should take medicine for 3 months and the possibility of the next child. Husband also agrees but, immediately returning from the hospital, says, "I don't feel anything. I'm fine". First, you need to treat me and move to work. Day and night." The whole family uses words that we can't even hear." (FGD, Biratnagar)

3.6 Problems Faced Due to Gender-Based Violence

Most of the participants (community front liners) expressed that infertile women are facing different forms of violence due to infertility and are not able to come forward and file the case. Women, who are not the reason behind infertility, are also suffering violence from family and society. The patriarchal mindset (Men can't be the reason for infertility) is established strongly for infertility and the reason behind violence against women. As one of the participants said, *since violence due to childlessness is dealt with by law so, they are not taken outside, but there is violence in the village. (FGD: Rangeli)*

3.6.1 Discrimination:

While we talk about infertility, we only imagine women, not men. We need to eradicate this mindset through awareness events regarding infertility. As one of the participants said, *after not having children, women have to cry. They cannot say it to men; They demean them, saying they are just women. This is the patriarchal thinking and belief; they say whatever comes to their mind. Even the husband talks about getting remarried, and the neighbors in the village speak ill, calling her barren, making it difficult to live. The entire family uses offensive and derogatory words, making it hard to stay. It has been three years since her marriage; she has no children, and the people in the village keep mentioning she cannot have children. (FGD: Biratnagar)*

What I want to say is that after childlessness, it becomes difficult for women to live in society. Those who do not have children are accused of being barren, witchcraft allegations, and many other kinds of accusations. (FGD: Biratnagar)

3.6.2 Emotional, Psychological, and Social Consequences (Mental Health)

Due to different forms of violence and lack/insufficient family support directly affecting women's mental health. While analyzing the recommendation from FGD, Partner and family understanding and support play a vital role in decreasing violence against women and improving mental health. Also, if there is a change between individual and family, we assume society's perspectives towards infertile individuals/couples change progressively.

As one of the participants said, *not having a child has caused her mental problems, and her husband has to take her everywhere. One day, there was a discussion at work about money issues. They insulted her, saying," What does she know? She's barren. Even if you're a good person, what is the use if you have no children? Who will take care of you later anyway?" That made her cry a lot. They spoke harshly, hitting her where it hurts the most for her. (FGD: Biratnagar*

Participants repeatedly describe the mental health struggles of women dealing with infertility/childlessness. Societal pressures, family rejections, verbal abuse, and lack of support heighten the emotional toll.

3.7 Perception on Government Roles and Responsibility of the Government

Government negligence in infertility within SRHR is prominent in the community. They haven't realized the pain, violence, emotional factors, and psychological distress to women due to infertility/childlessness. Intended parents and surrogates have the right to make decisions about their reproductive rights; the government should provide a favorable environment by developing comprehensive laws and policies, including child's rights and awareness programs.

Others should not have to experience the same pain as hers. Many people desire to have children… The government should consider their needs, introduce policies and awareness programs, and be able to educate the public. (FGD: Biratnagar)

As one of the participants said, *the mother needs to be cared for. There should be no pressure or exploitation; it is their right to be allowed to do surrogacy by one's own will. Everything has its own advantages and disadvantages… Surrogacy should be given legal recognition. This way, it can become a means of earning for some, while, on the other hand, women who cannot have children can have children. (FGD: Kanepokhari)*

3.7.1 Financial aspect:

Suppose women decide she wants to support an infertile couple or an individual to become a parent; it's her earning source for her family. Then, bodily autonomy rights are an individual choice. The Government should provide the environment if she wants to support an infertile couple or an individual to become a parent. In that case, it's her earning source for her family, and then bodily autonomy right is an individual choice. The Government should provide an environment without discrimination.

Infertile couples/individuals are unable to seek and afford AR treatment and technology due to high financial constraints and only limited private health facilities. Treatment costs have not been transparent, and there is a lack of information sharing and counseling by service providers regarding the AR process for infertile couples/individuals. Due to this, many couples/individuals have to discontinue the AR process due to financial issues. Though the Government of Nepal has presented the policies and programs for the upcoming fiscal year 2080/081 (2023-24) at the joint meeting of the House of Representatives and National Assembly regarding the major policies and programs related to health. Infertility and childlessness treatment services will be extended to federal hospitals in all seven provinces, and access to reproductive health services will be ensured for all. Also, the maternity centers in all the municipality wards will be upgraded.

If you teach them all the things and remind them that they should have medicine regularly, then they will follow, but it is not like that in Nepal. How is it here, a service provider thinks of earning, and suddenly, after 1 month, they will explain another process which is more expensive? And childless women/couples get confused and unable to proceed further due to economic crisis. (FGD: Ratuwamai)

The government of Nepal should make arrangements for all couples to be treated openly, and this should be done free of charge. Otherwise, only those who have money will get service, and it will be difficult for others. Every local level should be made a safe space where women can open up and be able to raise problems related to infertility. (FGD: Letang)

3.7.2 Importance of Family Counseling

The majority of participants focused on family counseling, as different forms of violence are due to childlessness within the family as well as in society. When the family begins to blame the woman, subsequently society, too, starts taunting her through different forms, which degrades women's mental health and quality of life. Change should begin with the individual/family, and gradually, we can think of a violence-free society due to infertility/childlessness.

A budget needs to be allocated for awareness. The first issues is, who will convince the family. …. The government of Nepal needs to take several initiatives, like family counselling. The family won't listen to the women (FGD: Ratuwamai)

Violence is from the family. The mother-in-law's words started coming out, saying she had not brought me a grandchild. The words "kasti ki Chori" came first from the family, from there to society, and from society too far away. So, family counselling is the most important. (FGD, Biratangar)

3.7.3 Ambiguity Law/ Law of Uncertainty

Women are not clear about surrogacy within assisted reproduction. Terminologies like kokh bhada, bacha kinae, etc., stigmatize the community from a negative perspective. Participants shared that women are not aware of the existing laws and it's their right to approach services.

She doesn't have a child now. There are many things that can happen. Even if she buys, she will still get arrested. Whether she has stolen or how she has brought it, she will be put in jail. (*FGD: Biratnagar)*

Surrogacy is needed. I thought it would be good for childless women if the Nepal government gave it legal recognition. Because it is being approached and done secretly by service providers even though there is no law. (FGD: Letang)

3.8 Felt Needs:

The lack of attention to infertility in the government's SRHR policies is a recurrent theme in the discussions. Participants believe that the government is not adequately addressing the emotional, financial, and psychological burdens of infertility. The introduction of new policies to extend infertility treatment services to federal hospitals and upgrade maternity centers at the local level is a step forward. Still, there are concerns that it will not be enough to address the wider needs.

The government's focus on improving access to reproductive health services is promising, but infertility treatment is often neglected within this framework. The government needs to ensure that infertility services are included in the broader SRHR policies and implemented well, are made affordable, and that access to these services is equitable across all regions, especially rural areas. In addition, the government should take a proactive role in raising public awareness about infertility and reproductive technologies to reduce the stigma and encourage early diagnosis and treatment.

CHPATER-IV

Discussion:

The finding of this study is to explore understanding and perception of Infertility through SRHR and trends and policy obstacles in assisted reproduction with community front liners. Studies have shown that participants are familiar with infertility yet unaware of its inclusion in SRHR and the disconnect between awareness at the community level and describe infertility as “Bhajopan,” “Bhaji,” and “Bahili” in the community. In this study, participants identified various causes of infertility in women, including chronic disease, uterus problems, irregular menstruation, etc.. In contrast, in men, infertility was attributed to unhealthy habits like smoking, alcohol consumption, low sperm count and quality, and hot weather. The present study's findings correspond with the working paper prepared by WOREC and the clinical study on infertility [5,7.]

The findings of this study highlight several critical issues surrounding infertility within the context of Sexual and Reproductive Health and Rights (SRHR) in Nepal, particularly regarding societal perceptions, knowledge gaps, and policy barriers. The participants in this study demonstrated a general awareness of infertility. Still, they were largely unaware that it is a component of SRHR policies, reflecting a gap in public education and communication. This disconnect between the recognition of infertility as a medical condition and its inclusion in SRHR programming presents a significant challenge to addressing the issue effectively. The present study findings show that males are not as responsible for infertility as women, and the social pressure on women to bear children reflects larger societal norms. These findings were similar to the working paper prepared by WOREC participants who expressed feelings of social pressure to conceive.

The mental health impacts of infertility and childlessness are significant yet often overlooked in infertile couples shared by participants. This finding is similar to the working paper prepared by WOREC[5.] Participants believe that the government is not adequately addressing the emotional, financial, and psychological burdens of infertility and neglected infertility treatment, especially in rural areas. This finding reflects the study by Gautam M et al. in Nepal, which generally seems to show that the infertility problem has been given less attention by concerned authorities[3].

The study revealed that societal views about infertility are deeply gendered, with a tendency to place the blame on women, even when male infertility is the root cause. This aligns with wider patriarchal norms where reproduction is often seen as a woman's responsibility. Such attitudes contribute to stigma and discrimination, particularly against women who face immense societal pressure to conceive. The study corresponds with findings from previous research, including WOREC's work, which also points to how societal expectations around childbearing affect women's mental health, self-esteem, and social status[5].

Another key finding is the limited awareness and understanding of assisted reproductive technologies (ART), including surrogacy. While participants were familiar with traditional

concepts of assisted reproduction like IVF, there was confusion and lack of awareness about the complexities of these technologies and their legal, ethical, and emotional implications.

Financial constraints emerged as a major barrier to seeking infertility treatment, with many couples unable to afford the high costs associated with ART. The study highlighted that while some couples sought treatment, they often struggled to find affordable and accessible options, especially in rural areas. The high costs, coupled with a lack of government support, mean that many individuals are left with limited choices and may resort to unregulated, informal, or even illegal practices, such as seeking surrogacy services through brokers. This is a serious issue, as it exposes individuals to significant risks, including exploitation and health hazards. The study corresponds with findings from previous WOREC research that most couples experiencing infertility visited hospitals or clinics within 9 months to 4 years of marriage, often prompted by family pressure to have children. While some couples were unsure of which doctor to approach, the majority had undergone treatment. Female partners primarily underwent various tests and checkups, while male partners' health checks were secondary, typically limited to sperm analysis. In many cases, treatment involved injections or oral medications for both partners. Women received treatments like vaginal examinations, hysteroscopy, and sperm injections, while men used oral medications to increase sperm count, though many stopped due to cost and lack of effectiveness[5].

CHAPTER-V

Conclusion:

This research reveals the deeply interwoven nature of infertility challenges in Nepal, where social, economic, and cultural dynamics create layered experiences particularly affecting women's lives and choices. Our findings illuminate how traditional beliefs and modern healthcare practices intersect, often reinforcing existing gender inequities in reproductive health experiences.

The study exposes critical gaps between medical understanding and community awareness of infertility. While local terms like "Bhajopan," "Bhaji," and "Bahili" demonstrate community recognition of infertility, they also reflect deeply embedded social attitudes that often place undue responsibility on women. This gendered experience of infertility manifests in various forms of discrimination, from family pressure to social isolation, revealing how reproductive challenges disproportionately impact women's social status and emotional well-being.

Economic barriers to infertility treatment further compound these challenges. The high costs associated with assisted reproductive technologies create particular hardships for women, who often lack financial autonomy or access to resources for treatment. This economic dimension intersects with gender dynamics, as women frequently bear the social consequences of childlessness regardless of the medical causes.

The absence of comprehensive legal frameworks for assisted reproduction and surrogacy creates vulnerabilities that often affect women most directly. Whether as intended parents or surrogates, women navigate these arrangements with minimal legal protection, highlighting the urgent need for rights-based approaches to reproductive healthcare.

Our research demonstrates that addressing infertility in Nepal requires understanding it not just as a medical condition, but as a complex social issue deeply intertwined with gender relations, economic access, and cultural norms. The emotional and psychological impacts of infertility, particularly on women, reflect broader societal pressures and expectations surrounding reproduction and motherhood.

The findings emphasize how infertility experiences are shaped by intersecting factors of gender, economic status, and social position. This understanding reveals the necessity of approaching infertility not solely as a medical challenge, but as a reproductive rights issue that affects individuals' dignity, autonomy, and well-being. Recognition of these complex dynamics is essential for developing responses that address both the medical and social dimensions of infertility while promoting gender equity in reproductive health. Comprehensive policies that include family counseling counseling, financial support, and educational campaigns could help mitigate the

stigma, discrimination, and violence associated with infertility in Nepal. Success will require a coordinated effort across healthcare, policy, and community domains.

CHAPTER-VI

Major Findings and Recommendations:

- There is a need for better communication and integration of infertility into existing SRHR programs and policies. This could include educating communities about infertility as a medical issue that deserves attention and ensuring that fertility services treatments are covered within the SRHR framework.
- There is a tendency to view women as primarily responsible for reproduction, which leads to stigmatization, particularly when they cannot conceive. This highlights a need for comprehensive education and campaigns that challenge these stereotypes and are aware that infertility can affect both men and women.
- The high cost of ART and the lack of legal framework surrounding surrogacy led to risky and informal practices. Surrogacy and ART could be significantly improved if there were clear regulations and affordable options within Nepal. Establishing clear regulations, affordable treatment options, and legal protections for those pursuing surrogacy could significantly improve the situation.
- The lack of clear laws regarding surrogacy and ART in Nepal, alongside ambiguity surrounding the legal rights of individuals pursuing these options, is a major concern. While some participants suggest that surrogacy could be a source of income for women, they also point to the absence of legal protections and risks posed by unregulated practices.

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