



**UNIVERSITY OF NAIROBI**

**INFORMATION AND DECISION MAKING ON ASSISTED REPRODUCTIVE  
TECHNOLOGIES AMONG FAMILIES EXPERIENCING INFERTILITY IN  
KENYA**

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**A RESEARCH PROJECT SUBMITTED TO THE SCHOOL OF JOURNALISM  
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## DECLARATION

This Research Project is my original work and has not been presented in any form in either this university or any other university for examination

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This Research Project has been developed under my guidance and submitted with my approval as the university supervisor

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## **DEDICATION**

To all women suffering infertility, may they find something valuable in this study

## ACKNOWLEDGEMENTS

I would like to acknowledge the unwavering support I received from my supervisor Dr. Samuel Ngigi right from inception to the end of this study; Dr. Ngigi went beyond the call of duty to ensure that this work got completed. His insightful comments made the topic an interesting one to study and added great value to the work.

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## ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AMH	Anti-Mullerian Hormone
ART	Assisted Reproductive Technologies
ET	Embryo Transfer
GIFT	Gamete Intrafallopian Transfer
hCG	Human Chorionic Gonadotropin
HIV	Human Immuno-Deficiency Virus
ICMART	International Committee for Monitoring Assisted Reproductive Technology
IVF	In-vitro Fertilisation
STIs	Sexually Transmitted Infections
STDs	Sexually Transmitted Diseases
TET	Tubal Embryo Transfer
WHO	World Health Organization
ZIFT	Zygote Intrafallopian Transfer
ICSI	Intracytoplasmic Sperm Injection
OHSS	Ovarian Hyperstimulation Syndrome
KNBS	Kenya National Bureau of Statistics
MoH	Ministry of Health
MoE	Ministry of Education

## ABSTRACT

This study sought to explore the information on infertility and information on Assisted Reproductive Technologies available in Kenya and how it was packaged and disseminated; to find out whether those suffering infertility had fertility awareness; and also find out how the different levels of infertility and Assisted Reproductive Technologies information influenced decision to take up in-vitro fertilisation among families experiencing infertility in Kenya. To achieve the objectives the study adopted a case study research design for which qualitative data was collected using in-depth interviews with participants and key informants in Nairobi County. The target population for the study was individuals who had suffered infertility and had taken up in-vitro fertilisation treatment; and key informants who come into contact with couples in infertility situation as they journey towards in-vitro fertilisation. Ten female participants were interviewed as primary respondents, and four experts drawn from four categories of key informants were also interviewed: a gynaecologist; a fertility expert; a counselling psychologist; and a legal expert. To tie the study into theory and strengthen the work, two theoretical frameworks; the Health Belief Model and the Bio-psychosocial Theory were used. The qualitative data was then subjected to thematic analysis from which relevant information was extracted and findings interpreted by focusing on the research objectives. The results obtained indicated that there was not adequate information on infertility out there though information on Assisted Reproductive Technologies was noted to be available especially in the last 5 years; however, packaging and dissemination in both cases was found to be poor, with no standardised packaging of the information for dissemination. Another notable finding was that there was generally lack of fertility awareness, with actions taken and/omissions by the participants coupled with lack of information during their youth having detrimental effects on their future fertility. The study also found that lack of biomedical information and delayed diagnosis caused a subsequent delay in decision to take up Assisted Reproductive Technologies; while psychosocial consequences served to hasten the decision making on Assisted Reproductive Technologies. Finally, the study found that there was no legal framework to guide implementation of Assisted Reproductive Technologies in Kenya, and also that the legal and ethical issues in Assisted Reproductive Technologies were not considered in decision making on in-vitro fertilisation, though after the successful uptake of in-vitro fertilisation the legal and ethical issues came to light especially with regard to the right of the child born out of in-vitro fertilisation. The study recommends that more efforts be made in hastening the passing of the Assisted Reproductive Technologies Bill 2019 for proper regulation of Assisted Reproductive Technologies, fertility awareness creation among the youth, and incorporation of fertility awareness programmes in the Ministry of Health and Ministry of Education.

# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 Overview**

This chapter begins by looking at the background of the study then continues to state the research problem under investigation. The research objectives and ensuing research questions are also brought out herein after which the justification of the research is given. The chapter also highlights the scope and limitations of the study and finally the key terms used in the study are operationalised.

### **1.2 Background of the Study**

Infertility is a health problem that affects men and women of reproductive age the world over. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and World Health Organization (WHO) give the clinical definition of infertility as a disease of the reproductive system characterised by failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse (ICMART and WHO, 2009).

Research has shown that infertility affects millions of people worldwide. The rates of infertility globally are estimated to be at least 15% in women of childbearing age, with an estimated 48.5 million couples suffering infertility (Mascarenhas, et al., 2012; Obeidat, et al., 2014). Even with the advancement in reproductive technology, the annual incidence of infertility is expected to increase to 7.7million by 2025 (Obeidat et al., 2014). In Kenya, the overall rate of infertility was 26.1% among gynaecology consultations, with 50% attributed to tubal factors and 15% due to male factors (Murage, et al., 2011).

The prevalence of infertility varies from continent to continent as well as from country to country (Kamau, 2011), with low resource setting having a higher prevalence of the disease (Daar and Merali, 2002; Dyer and Pennings, 2010). The high prevalence in low

resource setting corresponds with the high incidence of preventable conditions leading to infertility. Infectious diseases and subsequent damage or blockage of fallopian tubes; undiagnosed or poorly treated genital tract infections; Sexually Transmitted Infections (STIs); post-delivery or post abortion infection; and infections resulting from scarring caused by genital mutilation rites of passage are touted as major contributors to infertility (Evens, 2004). Additionally, Human Immuno-deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) which are also rampant in Sub-Sahara Africa have also been associated with infertility (Evens, 2004; Mascarenhas et al., 2012).

Despite the high incidence rate of infertility, it remains an under recognized public health issue receiving minimal attention in health programs due to limited resources and other issues such as maternal health, child mortality and HIV /AIDS which are seen as more critical health issues especially in the African context (Evens, 2004; Ndegwa, 2014).

Infertility has been attributed to serious social and psychological consequences on those affected with women bearing the greatest burden despite infertility being a problem associated with male and female genders in almost equal proportions. Daar and Merali (2002) classified the psychosocial consequences of infertility on a six-level continuum of increasing severity for those suffering involuntary childlessness. Across the continuum infertility is seen to transform from an acute private agony affecting the individual at a personal level into a harsh public stigma with complex and devastating consequences (Daar and Merali, 2002; Dyer and Pennings, 2010). At level 1 feelings of guilt, self-blame and fear manifest at the individual level advancing with time to level 2 where marital stress kicks in coupled with economic stress, helpless and depression; at higher level 3 mild marital violence and social violence is registered alongside serious economic hardship and social alienation of those affected by infertility (Daar and Merali, 2002). Level 4 sees the consequences escalate further to severe levels of marital and social violence and abuse; severe economic deprivation; social isolation and abuse leading to loss of social status. At Daar and Merali's levels 5 and 6 on the continuum the

consequences reach alarming levels that could lead to starvation and disease; death; or even violence-induced suicide for the afflicted, at level 5, and finally at level 6 there is lost dignity in death where funeral rights are invoked with the infertile being treated differently from other people in death (Daar and Merali, 2002; Dyer and Pennings, 2010). The consequences have been touted to be at lower levels 1 and 2 in the Western Countries and almost always above level 3 in African and Asian communities (Dyer and Pennings, 2010).

Interventions for infertility in the form of Assisted Reproductive Technologies (ART) exist, giving hope to families in situations of involuntary childlessness. ART treatment however, comes at a premium; the associated costs bringing about the issue of inequitable distribution of access to treatment for patients of different demographic characteristics. Ndegwa (2014) emphasises the need for affordable ART services which is likely the only true hope for most Kenyans struggling with unintended childlessness. Training of embryologists, as well as integrating ART into the public health sector through government support and subsidies is cited as key in achieving low cost ART (Ndegwa, 2014).

Serious legal and ethical issues that are associated with ART cannot be overlooked. Information to patients on the possible legal and ethical issues is critical for decision making in adoption of an infertility management regimen. Issues of In-vitro Fertilisation (IVF) with donor gametes; engaging of gestational carriers also known as surrogate mothers; issues of multiple births with or without gestational carriers; rights of the child in cases where gestational carriers with donor gametes are used also arise, the ensuing legal and ethical issues surrounding such instances cannot be overemphasised. From an ethics front again, the issue of disposal of excess embryos where more than required for implantation are available is also quite thorny. All these issues coupled with the fact that there is no guarantee of getting a child after a cycle of IVF treatment makes it imperative

for information to be availed and shared with the patients prior, during and after the decision to undergo ART treatment has been made.

The decision to undergo ART is not a walk in the park. Individuals who find themselves in situations of involuntary childlessness ought to be well equipped for the decision to undertake IVF. Shared Decision Making, a model that focuses on providing information and supporting deliberation to enable intending parents make informed choices becomes imperative.

### **1.3 Statement of the Problem**

Studies from several African Countries have documented the importance of childbearing and the suffering caused by infertility in these societies, with women bearing the greatest weight of the infertility burden (Daar and Merali, 2002; Dyer and Pennings, 2010; Dhont et al., 2011; Ndegwa, 2014). Children are seen to provide their parents the very valuable opportunity of participating in the continuity of family, culture, and community. Most cultures, especially in developing countries, are designed to rely on children for the future care and maintenance of older family members causing children to have a central and critical role in their parents' later days (Even, 2004; Obeidat et al., 2014). According to Mburugu and Adams (2005), infertility, whether primary or secondary, is not anticipated by couples who decide to marry in Kenya; and it is generally viewed that the main objective for marriage, not only in Kenya but in other African societies, is to have children and a woman who cannot or decides not to have children is an object of pity in the family and the society at large (Daar and Merali, 2002; Mburugu and Adams, 2005; Dyer and Pennings, 2010; Obeidat et al., 2014).

In Kenya, the overall rate of infertility was 26.1% among gynaecology consultations, with 50% attributed to tubal factors and 15% due to male factors (Murage et al., 2011). Interventions for infertility in the form of assisted reproductive technologies (ART) exist,



giving hope to families in situations of involuntary childlessness, however little or no information is availed to the affected.

This study therefore, endeavoured to analyse availability of information on fertility awareness; information on infertility; and information on infertility interventions with specific emphasis on ART; how the information is packaged and disseminated and finally how this information influences decision making with regard to the up-take of ART among families experiencing infertility in Kenya.

## **1.4 Research Objectives**

### **1.4.1 General Objective**

The general objective of this study was to investigate the level of information on infertility and ART and how the information influenced decision making on adoption of IVF among families experiencing infertility in Kenya

### **1.4.2 Specific Objectives**

- i. To find out whether information on infertility and ART exists, and how the information is packaged and disseminated in Kenya.
- ii. To investigate the relationship between fertility awareness and decision making on ART in Kenya.
- iii. To explore the extent to which biomedical and psychosocial information on infertility influences decision making on IVF in Kenya.
- iv. To find out the level of knowledge of legal and ethical aspects of ART in Kenya and how it influences decision making on IVF in Kenya.

## **1.5 Research Questions**

### **1.5.1 General Research Question**

The overall research question for this study was; what is the level of information on infertility and ART and how does it influence decision making on adoption of IVF in Kenya?

### **1.5.2 Specific Research Questions**

- i. What information on infertility and on ART exists in Kenya, and how is it packaged and disseminated?
- ii. What is the relationship between fertility awareness and decision making on ART in Kenya?
- iii. How does biomedical and psychosocial information on infertility affect the decision to undergo IVF in Kenya?
- iv. How does legal and ethical information on ART influence the decision to take up IVF treatment in Kenya?

## **1.6 Justification of the Study**

Infertility is a disease of the reproductive system characterized by failure to achieve pregnancy after a period of twelve months or more of unprotected, regular and well-timed sexual intercourse (ICMART and WHO, 2009). Infertility has also manifested as a problem that affects 15% of women of childbearing age across the globe with serious psychosocial consequences for those affected (Mascarenhas, et al., 2012; Obeidat, et al., 2014). Thus, causing it to have a significant importance in health programmes in Kenya and by extension the need for provision of information on infertility and also information on infertility interventions to those affected.

The study was therefore important in that it identified existing gaps on infertility and ART information in Kenya. These gaps could inform policy makers on strategies that can be utilised in improving packaging and dissemination of information on infertility and infertility interventions as well as having programmes for fertility awareness creation among the youth to mitigate future infertility.

### **1.7 Significance of the Study**

In this study the provision of information on infertility and information on ART in Kenya manifested as important for mitigating future infertility as well as ensuring uptake of existing interventions for those affected by involuntary childlessness.

The study also illuminated the value and significance of shared decision making in clinical practice in assisting individuals in involuntary childlessness' circumstances gather as much as is possible information on infertility and information on ART while receiving support from clinicians, counselling psychologists and legal experts in their decision-making process.

This study could be useful for policy makers and legislators in Kenya to encourage the speeding up of the process of enacting the ART Bill 2019 which is the proposed legal framework for implementation of ART in the country

This study findings contain useful information for families experiencing infertility on existing mitigating factors and the necessary information in guiding decision making for adoption of ART.

The study findings could also be useful in encouraging behaviour change and creating fertility awareness among the youth in Kenya.

## **1.8 Scope and Limitation of the Study**

This study was limited to families experiencing infertility and specifically females as the male partners were not willing to share their sensitive infertility information; the study was also limited to the service providers of ART including medical professionals, legal experts and counsellors within Nairobi County.

This study had a challenge in availability of information from respondents due to the sensitive nature of the topic under investigation and the stigma associated with infertility in the African context and more specifically in Kenya. The researcher was however able to create rapport with ten (10) participants and four (4) key informants who provided adequate and sufficient qualitative data for the study. The data was collected between the months of August and October 2019 with the first interview which was with a participant conducted on 1<sup>st</sup> August 2019 and the last one conducted on 2<sup>nd</sup> October 2019 with a key informant.

Time was also a limiting factor in this study given that infertility is a problem that manifests over time and the interventions also bear fruits over a period of time. However, for the ten (10) participants interviewed all of them had been married for a period longer than 5 years and therefore they had had quite a long period with their infertility situation hence provided data that was comprehensive for the study. The key informants had also been in practice for reasonable periods of time mostly more than ten years of professional practise for each of them and thus they had had quite a wealth of experience with individuals and families suffering infertility.

## **1.9 Operational Definition of Terms**

### **Assisted Reproductive**

**Technologies:** Procedures utilised in handling of human oocytes, sperms or embryos for the purpose of establishing a pregnancy. In this

study the terms assisted reproductive technologies (ART) and *In-vitro* Fertilisation (IVF) assisted reproductive technologies (ART) have been used interchangeably

**Fertility Awareness:** Knowledge and facts about factors that would influence the fertility of an individual

**Gametes:** Human reproductive genetic material it could be male spermatozoa or female oocytes

**Infertility:** Refers to a disease of the reproductive system where a clinical pregnancy has not occurred after 12 months or more of regular unprotected sexual intercourse

**Information:** Facts about infertility and Assisted Reproductive Technologies

**Intending Parents:** Two individuals who have an intention of starting a family through assisted reproductive technologies either using their own gametes or donor gametes

**In vitro Fertilisation:** Manipulation of human oocytes and sperms outside of the reproductive system with the objective of achieving pregnancy. In this study the terms *In-vitro* Fertilisation (IVF) and assisted reproductive technologies (ART) have be used interchangeably

**Involuntary**

**Childlessness:** A situation in which a family lacks an offspring of their own due to circumstances beyond their control

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Overview**

This chapter will look at available literature that is related to the area of study. Fertility awareness and infertility including causes, consequences and related information will be explored and discussed. Information on infertility and on ART will also be reviewed on the basis of biomedical, psychosocial, legal and ethical perspectives. Decision making in clinical settings will be highlighted and more specifically the shared decision-making model. The theoretical underpinnings that influenced this study will also be discussed while the conceptual framework that guided the research will be presented as well.

#### **2.2 Fertility Awareness and Infertility Information**

In their study on fertility-awareness, knowledge, attitudes and practices of women seeking fertility assistance (Hampton et al., 2012) posit that several female patients lack knowledge of fertility yet they imagine that they have got the knowledge. Their study found that 68.2% believed they had always had intercourse at the right time when the female partner was fertile as they tried natural conception, yet only 12.7% could precisely recognise the period when the female was fertile. This brings in a major disconnect between fertility awareness which is key in increasing chances of natural conception and the infertility incidence which has been documented to range from as low as 5% up to 30% in different areas across the globe. Women having trouble conceiving were more receptive of fertility information paying particular attention to issues that had a bearing on their fertility as they worked towards accurately identifying the period during which to have intercourse for improved chances of natural conception. (Hampton et al., 2012).

In a United States (US) study of students taking their first degree on their knowledge of fertility aspects and their feelings towards parenting; results indicated that those

interviewed wanted to get their first-born child while the female partner was still fertile. However, the same interviewees lacked knowledge of when the female fertility starts to go down; were not familiar with the chances of conception with unprotected sex; and did not have a clue on *in-vitro fertilisation* (IVF) success rate in case they experienced infertility (Peterson, et al., 2012). In the same study by (Peterson et al., 2012), 67% of women and 81% of men had an incorrect understanding of decline in female fertility which sets in at 35 years and confused it with the onset of menopause which takes place after the age of 44 years.

These findings are further reinforced by Sabarre et al., (2013), in their study of Ottawa University students where they assert that, the participants in the study were willing and ready to take up IVF but overestimated the success rate of ART and also were not clear about the age at which fertility for the female plummets which is said to be at age 35 and confused it with the onset of menopause at 44 years, yet according to Centre for Disease Control and Prevention (2010) success rate per cycle of IVF is only 3.2% at age 44 which is a tenth of the general IVF success rate of about 30%.

Fertility awareness and provision of information manifests as a key factor in reducing the risk of future infertility among members of the population; with those keen on understanding their fertility increasing their chances of natural conception and thus staying away from the likelihood of experiencing involuntary childlessness in their lifetime. Conversely, as literature has clearly brought out, misconceptions and lack of information and awareness on infertility causes women to delay childbearing as they confuse fertility decline with menopause. The role of information thus, becoming very critical right from an early age.

Infertility on the other hand, has been defined as a condition in which pregnancy has not occurred after one year of unprotected, well-timed intercourse without contraception (Raphael-Leff, 2005; ICMART and WHO 2009). According to ICMART and WHO

Revised Glossary of ART Terminology (2009) infertility is further distinguished in two ways, the first one being primary infertility which refers to infertility experienced by those who have never contributed to conception before and the second type being secondary infertility which signifies infertility in couples who have contributed to conception at least once (ICMART and WHO, 2009).

World Health Organization (WHO) recognises infertility as a public health concern, with the requirement that those suffering infertility get the problem addressed having been a consideration under Sustainable Development Goals (SDG) number 3 (WHO, 2017). Infertility is considered a reproductive health pointer, among others such as maternal death rates and contraceptive prevalence rate. It is a critical global issue considered a tragedy especially for women who suffer ostracism and stigma in their sociocultural environment (Daar and Merali, 2002; Evens, 2004; Dyer and Pennings, 2010; Obeidat et al., 2014).

Research has shown that infertility affects millions of people worldwide. Infertility rates across the world are estimated at about 15% in women between ages' 15-49years, and there is a projection of about 48.5 million couples suffering infertility (Mascarenhas, et al., 2012; Obeidat et al., 2014). Despite there being advancement in medically assisted reproduction, the annual occurrence of infertility is expected to grow to 7.7million by 2025 (Obeidat et al., 2014). While Murage et al., (2011), indicated that the infertility rate in Kenya was at 26.1% among gynaecology consultations, of which 50% was due to tubal factors and 15% was attributed to male factors.

The prevalence of infertility varies from continent to continent as well as from country to country (Kamau, 2011), with low resource setting having a higher prevalence of the disease (Daar and Merali, 2002; Dyer and Pennings, 2010). The high prevalence in low resource setting corresponds with the high incidence of preventable conditions leading to infertility. Infectious diseases and consequent disheveling or clogging of fallopian tubes; diseases of the genital track that go undetected or untreated; sexually transmitted



infections (STIs); post-delivery or post abortion infections; and infections resulting from scarring caused by genital mutilation rites of passage are touted as major contributors to infertility (Evens, 2004). Additionally, HIV and AIDS which is also rampant in Sub-Saharan Africa has also been associated with infertility (Evens, 2004; Mascarenhas et. al., 2012).

Despite the high incidence of infertility, it receives minimal attention in health programs due to the culture of contraceptive use which indicates reproductive control (Raphael-Leff, 2005) and other issues such as maternal health, child mortality and HIV /AIDS which are seen as more critical health issues in the African context (Ndegwa, 2014).

The biomedical concept of infertility distinguishes between barrenness that is associated with total damage of the reproductive system, infertility which could be due to treatable conditions, and limited fertility relating to a specific cause or a number of issues in either or both partners, or a combination of conditions in a couple (for instance cervical mucus mismatch), which causes interference at any stage before or after the successful meeting of sperm and ovum (Evens, 2004; van Balen, 2009).

The actual diagnosis of infertility will often be preceded by investigations once a couple in involuntary childlessness situation take a step towards treatment, in other instances it may be due to an emergency where a female patient suffers an ectopic pregnancy (Raphael-Leff, 2005). A diagnosis of infertility for many is a hard slap on self-esteem, more so today when the culture of contraceptive use elucidates reproductive control; the very assumptions, implicitly assumed since childhood, that just like our kin we all have the natural ability to procreate, are suddenly put to doubt (Raphael-Leff, 2005). With infertility identified, an individual's inability to propagate is out rightly exposed. The family tree grinds to a halt, as those in involuntary childlessness see themselves as the end as opposed to the middle of the family tree continuum. The effort that those with infertility

employ towards seeking help with their infertility situation is guided by their life long belief that they have got natural ability to procreate (Raphael-Leff, 2005).

Viewed with a psychosocial lens, it is generally agreed that involuntary childlessness presents a very trying and distressful situations for a couple in their personal history (Robaina, et al., 2008). Irrespective of what brought about the infertility, women encounter the burden of invasive procedures in the journey towards diagnosis and management of childlessness (Centre for Disease Control and Prevention, 2010; Obeidat et al., 2014). While these feelings are evoked in the patients the health care providers look at barrenness as a medical condition as opposed to giving it an all-round outlook while handling couples with infertility (Grinion, 2005; Obeidat et al., 2014). To make it easier for individuals and families suffering infertility an atmosphere where information is made available would go a long way in preparing the couples for the courses of action and interventions available for dealing with their different circumstances.

### **2.3 Consequences of Infertility**

According to Read (1995), among the commonest reactions that couples with infertility endure include: *State of shock*, infertility for many who suffer it is a truth that is impossible to accept, and some people take it with feelings of disbelief. While at a state of shock couples experience deep emotional reactions and even feelings of emotional numbness; *Denial* is another reaction that sets in, the couple imagine the outcome of their diagnosis is mistaken, and usually go ahead and see other doctors expecting varying and different opinions that would disapprove the initial prognosis; *Guilt-blame* feelings also set in for the infertile. As they grapple with the cause of their childlessness, one member of the couple may start to imagine that actions they had taken or avoided in their earlier days could be the cause of their infertility. In many instances the infertile individual in the union starts to imagine they are denying their partner an opportunity to have children;

yet others blame each other for their infertility manifesting hatred and rage towards their partner (Read, 1995; Robaina et al., 2008; Obeidat et al., 2014).

A fourth reaction that sets in with infertility is *Loss of control*, the diagnosis of childlessness in the couple shatters their emotional state of control over their own lives, with other parts of their personal and shared lives being completely set aside to concentrate on treatment alone; infertility also evokes *Social seclusion*, here the affected isolate themselves in an effort to shield themselves from feelings of rage or envy towards relatives or friends who have got children of their own (Read, 1995; Robaina et al., 2008; Obeidat et al., 2014).

Daar and Merali (2002) further classified the psychosocial consequences of infertility on a six-level continuum of increasing severity as shown in Figure 2.1.

<b>Continuum of the consequences of infertility</b>	
Level 1	Guilt, Self-blame, fear
Level 2	Marital Stress, economic stress, helplessness, depression
Level 3	Mild marital and social violence and abuse, serious economic hardship, social alienation
Level 4	Moderate to severe marital and social violence and abuse, severe economic deprivation, social isolation and abuse culminating in loss of social status
Level 5	Death, violence-induced suicide, starvation/disease
Level 6	Lost dignities in death

*Figure 2.1: Continuum of the consequences of infertility*

**Source:** Daar and Merali (2002)

According to Daar and Merali (2002), the effects of childlessness hardly went past level 2 in developed countries, while on the contrary the consequences were higher than at level 3 in African and Asian countries. Studies from Asia and Africa demonstrate verbal and physical abuse (level 3 and 4) after infertility has been confirmed; Social seclusion and loss of social status (level 3 and 4) have also been reported. Given that social status in the

African and Asian communities is linked to having children especially sons', childlessness automatically evokes (level 5) as loss of social status may cause further abuse, violence and deprivation; infertility also prompts high-risk sexual behaviour in an effort to fight infertility. Infertility could also influence funeral rites where the infertile people are treated differently in death (level 6) (Dyer and Pennings, 2010).

Couples in this situation could turn to ART in search of solutions to their infertility and minimise the psychosocial consequences of their circumstances where resources and their specific situations allow (Robaina et al., 2008). With the onset of infertility intervention, the nature of sex in the union becomes complicated. A third party, the medical expert or team, now become party to the couple's bedroom affairs in their concerted effort towards looking for a child. Test after tests for which reports have to be produced are done; post-coital tests, sperm counts and temperature charts get into the private space of the couple and various invasive procedures illuminate their shortfalls. Sexual disturbances are often experienced with studies reporting up to 67% of males with infertility having transient impotence for periods of up to three months, following the discovery of male factor infertility (Raphael-Leff, 2005).

In the entire course of treatment, emotional conflicts and imaginations become part of their lives, including idealisation of the Godlike medical specialists who, like the childhood parents, can produce babies and resentment at their own infantilisation and dependence on the control and interference of these powerful authoritative strangers who take over their lives (Raphael-Leff, 2005). The helplessness and desperation of the couple is palpable, their point of no return can be touched, like one pushed to corner with no escape route in sight is what the treatments evoke.

Couples experience difficult moments, they have to endure treatments that are physically and emotionally draining, the heavy financial burden of the assisted reproduction notwithstanding. Similarly, while engrossed in the struggle for a precious baby to be born

out of IVF, the very procedures employed in the treatment process may be the very reason the couple drifts further apart (Raphael-Leff, 2005). A male IVF patient had this to say about his experience with IVF treatment:

*“It seems so offensive that our beloved baby will initiate in a petri dish from a combination of my wanking off in the clinic toilet and her egg “harvested” up by a pipette” (Raphael-Leff, 2005).*

To endure the emotional turmoil that comes with the treatments couples either opt to play along as they emotionally swing in the roller-coaster of IVF treatments or sustain a situation of contending with questions as they debate whether or not to continue with the next phase of treatment (Raphael-Leff, 2005; Grinion, 2005; Robaina et al., 2008). Some realize that they should get engrossed in social activities just to keep sane in the treatment journey. Others concentrate on the treatment with the focus and drive of making a baby of their own flesh and blood (Raphael-Leff, 2005). The drive to beat infertility surely goes beyond a call of duty.

With ART treatment, sexuality and baby making grow more and more apart and coitus is denied the joy and fantasy it brings as the hope for and obligation to achieve fertilisation are allocated in another place. Denied its very critical role of procreation coitus could be seen as worthless and thus not desired (Raphael-Leff, 2005). A frustrated lady who had had several rounds of failed IVF treatment had this to say:

*“Our whole sex life has shut down’, ‘When he wants to make love, I feel absolutely angered. What is it for? It cannot get us anywhere. We cannot make a baby ourselves. I can’t bear him to touch me yuck! - It’s a reminder that we are useless. As each period approaches, I plunge down again. Such a long expensive haul getting nowhere. We have blown another chance. I dreamed I had left the front door ajar and trespassers were taking over our flat. I was trying to shout but there was no voice I woke my partner shouting “No! No! No!” I know I am furious with him for putting me through the humiliation of IVF because of his low-motility sperm. We are both such downright failures. I presume I’m worse than him. My uterus is not good enough and I think I destroy the fertilised embryos as soon as the doctors put them back into the womb Life is so pointless. I hate myself. I hear this voice inside rebuking me with such repugnance -*

*“you are stupid! Incompetent! Barren! It builds up inside me like electric power waiting for discharge and I turn on my partner screaming: ‘why can’t you even do what any animal can do?’. We can’t take control of our lives - - we lie there in bed, just he and I together - - awake, not touching each other, trapped, separate, wretched, sick with frustration; and sex, the very thing that once brought us comfort, is the very last thing we can consider” (Raphael-Leff, 2005).*

Couples in the situation clearly encounter feelings that could have detrimental effects on their union. (Robaina et al., 2008; Peterson, 2015). The pain she bears is palpable, it is the lowest moment in the relationship, and nothing seems to work or even make sense. Their relationship is in limbo.

Thus, for some couples in involuntary childlessness, pronouncement of infertility can kick off a challenge that goes beyond infertility and into other aspects of their life including their relationship. The nature of the union before the pronouncement of infertility is key in cushioning the possible enormous emotional effect of the prognosis (Pash and Christensen, 2000; Peterson, 2015). Other aspects that help cushion couples and individuals emotionally are personal attributes to include the “resilient” personality type or social support systems the couple has got from family and from friends (Obeidat et al., 2014; Peterson, 2015).

#### **2.4 Information on Assisted Reproductive Technologies**

Assisted Reproductive Technologies (ART) have emerged as some of the most successful and widely accepted and utilised medical interventions in the last half of the 20<sup>th</sup> Century and continues to advance in the 21<sup>st</sup> Century, creating opportunities for millions of families in involuntary childlessness across the world. Taking cognisance of the need for standard definitions as critical for benchmarking the outcomes of ART procedures, ICMART and WHO revised the glossary of ART terminology in 2009. They defined ART as all treatments or procedures that include the *in-vitro* handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy. This would include, but not limited to, *in-vitro fertilisation* (IVF) and embryo transfer (ET); gamete intra-

fallopian transfer (GIFT); zygote intrafallopian transfer (ZIFT); tubal embryo transfer (TET); intracytoplasmic sperm injection (ICSI); gamete and embryo cryopreservation; oocyte and embryo donation; and gestational surrogacy. This definition of ART however, was not to include assisted insemination (artificial insemination) using sperm from either a woman's partner or a sperm donor (ICMART and WHO, 2009).

*In-vitro Fertilisation* (IVF) was a breakthrough for infertility with the first IVF child Louise Brown born slightly over four decades ago on 25<sup>th</sup> July 1978 (Magarelli, et al., 2008), by the year 2008 more than 1,000,000 IVF cycles were performed each year the world over for a population of about six billion humans then (Magarelli et al., 2008). IVF involves manipulation of human gametes outside of the human body with a sole objective of establishing a pregnancy. During IVF the female egg/oocyte is fertilised in a petri dish using spermatozoa that will have been harvested from the male partner or from a sperm donor. Once fertilised the resultant embryo is implanted in the intending female parent's uterus for a pregnancy to occur.

#### **2.4.1 Gametes (oocyte/ human egg and sperm) and embryo donation**

The advancement of assisted reproductive technologies has created many options for infertile couples to include gamete and embryo donation; oocyte, spermatozoa and embryo donation treatments have been associated with increased success rates of ART pregnancies and live births (Borrero, 2002; Kenny and McGowan, 2014).

Successful donation of oocyte as a treatment for infertility was first reported in 1984, while donor sperms have been used for more than a century (Borrero, 2002; Kenny and McGowan, 2014). For both egg and sperm donation a series of medical examinations are recommended to ensure the genetic material collected is of sound health; with sperm donation the spermatozoa are frozen and can only be used after the donated material has been subjected to repeat test for infectious diseases such as HIV usually after a period of six months since they were first harvested (Borrero, 2002; Tournaye, 2002).

With advancing age in women, the volume and quality of oocytes diminish; this however, occurs at varying degrees for different women with research showing that the decline plummets in the late 30's and deteriorates further in the 40's. The quality of the oocytes and the capacity to produce genetically viable embryos from those eggs are a key pointer to success with IVF treatment (Borrero, 2002; Tournaye, 2002; Kenny and McGowan, 2014). Young women (under 35) therefore, have a super opportunity at conceiving with their own oocytes through IVF, but by the mid 40's the rates of successful pregnancies diminish, hence requiring donation of oocytes.

Human eggs donation takes two females, the donor who gives the oocytes and the woman who wishes to get pregnant. Recipients will usually have a choice between a known donor such a sister, relative or a friend or an anonymous donor (Borrero, 2002; Kenny and McGowan, 2014). The procedure involves screening of the donor preferably women aged below 30 years for medical and psychological profiles to establish that the female individual is fit to donate eggs. The donor then receives fertility injections to mature the eggs, after which Human Chorionic Gonadotropin (hCG) injection is given to force discharge of the eggs from the ovaries after which an egg retrieval to harvest those eggs just before they are released is done (Borrero, 2002; Tournaye, 2002; Kenny and McGowan, 2014).

In the early days of ART, intervention for couples where the issue was with the male partner especially sperm abnormalities was problematic as the low-quality sperm were often incapable of fertilising the eggs. This problem has since been minimized with technology in which case, sperms are harvested from ejaculated male spermatozoa for use in intrauterine insemination (IUI), in-vitro fertilisation (IVF) or for intracytoplasmic sperm injection (ICSI). The spermatozoa ejaculate could be from the male partner or from a sperm donor (Tournaye, 2002).



ICSI, developed in the early 1990's, is a procedure for fertilising oocytes at IVF to improve chances of fertilisation which was a major bottleneck in male infertility (Tournaye, 2002). ICSI has to do with direct injection of single sperm into an egg, and is efficacious with all except the most abnormal sperm. With the emergence of ICSI, the primary impediment to positive IVF treatment now became egg quality, hence, couples with only male factor infertility could expect successful outcomes from IVF.

Embryo donation for ART is encouraged where infertility affects both the male and female partner. A large number of embryo donations are of cryopreserved embryos sought from couples who have completed their families through IVF. Donor embryos are also derived from separate oocyte and sperm donation that are taken through the IVF process to form embryos. The embryo donors must sign an informed consent allowing the use of their embryos and also relinquishing all rights to the embryos and/or off springs that may result from the transfer of these embryos (Borrero, 2002).

Screening of the embryo donors for hereditary and communicable illnesses is mandatory to prevent spread to the recipient or offspring; the recipient couple must receive the screening results before the donation takes place. The recipient couple must also be evaluated fully including their medical history, their physical wellbeing and must also receive psychological counselling (Borrero, 2002).

#### **2.4.2 Gestational Carriers/ Surrogacy**

The final stage in successful baby making, be it the natural way or through assisted reproduction treatments such as IVF, is for the embryo to implant in the uterus. There are cases where the intending parents are able to produce viable gametes that fertilise and embryos form but the female partner may not be able to carry a pregnancy. This may be occasioned by lack of a uterus for instance in women with Rokitansky Syndrome or other genetic disorders, or it could be as a result of a hysterectomy for the female partner. Scar tissue within the uterus from prior surgeries could also cause difficulties in carrying a

pregnancy; yet other females are unable to conceive or hold on to a pregnancy, despite having genetically viable embryos transferred back. The treatment for these types of "uterine" issues is usually via IVF with a gestational carrier which then introduces a third party in a couple's relationship.

The gestational carrier's cycle starts with recruitment of potential surrogates who are then screened for medical, physical and psychological wellbeing, the surrogates may be known to the infertile couple or may be recruited through an agency or a fertility clinic. The process of engaging surrogates requires specialised legal professionals as the legal status of children born from IVF with surrogates (including the parents listed on the birth certificate) differs from state to state (Jadva, et al., 2003).

To kick off IVF with a surrogate the commissioning parents meet with the fertility expert and/or staff at the fertility clinic. The female then undergoes the necessary tests and selects a carrier. The fertility clinic team then synchronises 'dates' for the carrier and the (genetic and intended) mother using medications such as leuprolide and birth control pills. This ensures that when the patient's eggs are ready, the surrogate's uterus is also ready for implantation as well (Jadva, et al., 2003).

The intending mother receives fertility injections to make her oocytes grow, once the eggs are mature a hCG injection is administered to force the eggs to release and an egg retrieval to harvest those eggs just before they are released is done. The normal IVF process is followed where the oocytes are fertilised with the intending male partner's spermatozoa. The resultant embryos are then transferred to the gestational carrier's uterus, and if successful, the carrier will give birth to the child/children of the intended parents (Jadva et al., 2003).

### **2.4.3 Multiple Pregnancy and Multiple Births with ART**

IVF highly correlates with multiple pregnancy and multiple births; the high incidence of multiple pregnancy is associated with the practice of transferring several embryos into the uterus in a bid to increase chances of conception with IVF (Ozturk and Templeton, 2002). Multiple gestations are highly connected with increased risk of miscarriage, preterm delivery, low birth weight, congenital malformation and foetal and infant deaths (Fathalla, 2002).

Studies have shown a direct relationship between pregnancy induced hypertension and (pre) eclampsia with multiple pregnancy with clinical presentation in these cases manifesting much earlier and with more severity in multiple pregnancies as compared to singleton pregnancies (Ozturk and Templeton, 2002). Besides complications of pregnancy and birth, twins, triplets and higher order children are more likely faced with medical problems that cause them to be hospitalised for longer periods in their neonate and infant life as compared to singletons (Fathalla, 2002; Ozturk and Templeton, 2002). It is therefore imperative that information on the increased chances of multiple pregnancy with IVF and risks associated with multiple gestation and multiple births is made available to prospective parents as they embark on the decision to undergo ART.

### **2.4.4 Other Options of handling involuntary childlessness**

Families in fertility crisis require information on other existing options of handling involuntary childlessness. Information on how and when to stop further IVF treatment cycles where such interventions fail is key. Rauprich et al., (2011) found that majority of patients requiring assistance with reproduction in Germany did not have information on the various aspects that were critical for decision-making regarding their treatment; the patients, overcome by their desire for a child were lost in their situation and were unable to decide when to end unsuccessful treatment (Evens, 2004; Rauprich et al., 2011). A roadmap for halting ART and boarding on alternative vehicle for purposes of coping with

infertility ought to be part of the initial discussion as couples embark on treatment (Rauprich et al., 2011).

Where ART fails, adoption as a family building option exists and would go a long way in assisting couples in coping with their childlessness. While couples could also be assisted in accepting a life of childlessness (Peterson, 2015). These options however are only viable where the infertile couples are taken through a series of counselling sessions to assist them in accepting their circumstances and accepting to either adopt a child or resign to childlessness (Peterson, 2015).

## **2.5 Information on Legal and Ethical Issues in ART**

Assisted Reproductive technologies have been well embraced, and consequently assisted treat millions of infertile couples around the world successfully (Brezina and Zhao, 2012). ART today creates new definitions of parents and children, and subsequently for families facing infertility decisions about having children get complicated. With these complexities a myriad of legal and ethical issues arise for which information sharing with the intended parents is not only integral but also critical.

All IVF cases have got a legal aspect right from the fertilisation *in vitro* which involves ovarian hyper stimulation to mature as many as is possible oocytes for fertilisation with either a partner's sperms or donor sperms. Harvested oocytes are fertilised and as many as are viable embryos are available for implantation on a ready uterus where usually a maximum of three embryos are implanted, while the excess embryos are cryopreserved for later use (Borrero, 2002; Tournaye, 2002; National Health and Medical Research Council, 2017). The cryopreserved embryos belong to the patients but are stored in a fertility centre, the couple must sign consent forms determining how they would like their frozen embryos treated. This legal requirement must be communicated to the intending parents ab-initial.

Though many of the frozen embryos are eventually utilised in IVF cycles through embryo donor programmes, many remain unutilised with an estimate of about 600,000 cryopreserved embryos in the United States in 2011. Often couples who successfully undergo IVF and have excess embryos are not certain of what to do about any excess embryos that are cryopreserved once their families are complete (Dickens, 2002). Some couples just stop paying the storage fees or lose contact with the clinics; this leaves the clinics in a difficult position on how to handle the embryos as they cannot dispose them without the couples consent for ethical and legal reasons. Donating for research of the excess embryos also gets complicated due to varying laws and restrictions in different jurisdictions and lack of legal framework in other jurisdictions (Dickens, 2002; Brezina and Zhao, 2012).

Introduction of third parties in a couple's reproduction where another person enters in their baby-making scenario is an ethically confounding issue. The overall safety of gametes; the ethical recruitment of donors and surrogates to ensure that there is no coercion or exploitation; the high risk of commodification of the baby making process where large amounts of money is involved in paying the third parties such as donors and surrogates are issues that raise a myriad of concerns (Fadhalla, 2002; Kuhse, 2002; Brezina and Zhao, 2012). Information should be availed to these third parties as they also run a risk of endangering their own lives especially the oocyte donors where there could be Ovarian Hyperstimulation Syndrome (OHSS) which was estimated to range between 0.6 -14% after IVF due to superovulation protocols (Kuhse, 2002).

Conflict of interest is also common place in third party procreation, the rights of the child to know the truth in cases where they are conceived out of IVF with donor gametes and/or born through surrogate arrangements, issues of the right time to make such a disclosure to the child are critical for the intending parents. This ensures that all parties are treated in a considerate way including the child who had no role in the ART decision (Kuhse, 2002; Jadvá et al., 2003).

Physicians running the fertility clinics and centres providing treatment are usually also entrepreneurs cognisant of and focussed on profits. The vague and often unclear way that the ART success rates are presented while obscuring the likely complications that come with it are showcased to patients is of great concern (Kuhse, 2002; Brezina and Zhao, 2012; National Health and Medical Research Council, 2017). In some instances patients are denied relevant and critical information or do not grasp the technicality of the ART information; in such cases they could be unintentionally or deliberately misguided on the chances of success and the likely risks associated with the treatment; such patients will therefore not be said to have freely consented to an ART procedure. Many fertility clinics however, feel pressure to produce statistics that show potential patients the highest possible pregnancy and birth rates with minimal or no risks mentioned just to attract as many potential clients as possible (Kuhse, 2002; Brezina and Zhao, 2012). This inadvertently influences the choices of treatment and fertility clinic albeit unethically; where truthful and accurate information is available the decisions taken will be well thought out and evaluated by the intending parents.

Transfer of multiple embryos, to minimize the chance of repeated ovarian hyperstimulation is practiced regularly giving rise to increased rates of multiple pregnancies. Multiple pregnancies pose threats to the health of pregnant women as well as that of their unborn baby and also a difficult early childhood for twins, triplets and higher order babies born out of IVF. Despite having been a consideration for minimizing physiological and psychological burden borne by women in cases of repeat IVF cycle; the practice of multiple embryo transfer becomes an ethical issue where there are cases of multiple gestation and multiple births (Kuhse, 2002).

Where women carry an excessive number of foetuses' pregnancy reduction, a technique that introduces several issues both physiological and psychological to the patient, and that may also bring about foetal loss and miscarriage is done (Kuhse, 2002). This practice involves, abortion of healthy foetuses which is in certain instances considered ethically

wrong and also illegal where abortion is outlawed for instance Kenya. Given the considerable burden that ART imposes on women the role of information becomes critical in preparing individuals on what to expect as they make choices regarding the uptake of the technology.

## **2.6 Decision Making**

Decisions about health care issues including those on ART, ought to be taken autonomously; a concept that is drummed up for by the notion of informed consent. To be independent, consent requires that it is driven by adequate and accurate information at the very least, as well as clarification of the associated risks and benefits of alternative courses of action, and that it be voluntary (that is, free from coercion and undue inducement) (Rauprich et al., 2011). When it comes to making choices about ART, it has been recognized, that it may be very difficult, if not impossible for individuals to autonomously choose to enter ART programs. Therefore, adequate information ought to be provided to enable those suffering infertility take decisions on ART.

With decisions on ART, one area that has elicited considerable attention is the unstructured and sometimes confusing way in which the success rates of various treatments, and any potential risks associated with them, are brought forth to would-be parents and how this projection of information may rush decision making without comprehensive ART information. Where individuals and couples do not adequately understand the relevant information (or are inadvertently or intentionally misrepresented with information about potential risks and the chances of a successful pregnancy by commercially driven fertility clinics), then they cannot autonomously consent to an ART procedure.

Patient decision making therefore, becomes an increasingly important area of research (Peddie et al., 2005) and Shared Decision Making is seen as a route to improved

informational communication and power distribution between the doctors/ clinicians and patients for enhanced decision making (Peddie et al., 2005).

Shared Decision Making (SDM) has been touted as an ideal model in medical encounter (Peddie et al., 2005). In SDM decision making shifts more towards informed choice as opposed to informed consent (Peddie et al., 2005). The concept of informed consent grants the clinicians' autonomy of information with patients only required to give consent to what the clinicians have thought and approved as the best courses of action; while informed choice presupposes comprehensive provision of information to the patient for facilitation of making informed choices. The SDM process allows for patients to gain support from medical personnel in deliberating about decisions and choices that are well aligned with their informed preferences (Elwyn et al., 2016).

In achieving SDM, cultivating a good relationship in the clinical encounter is critical as it ensures that information is given correctly and patients are supported to deliberate and communicate their preferred options and views during the decision-making process (Elwyn et al., 2012). SDM is based on three steps, namely choice talk, option talk and decision talk with an overall objective of providing information and supporting deliberation (Elwyn et al., 2012; Elwyn et al., 2016). Choice talk ensures that the patient knows that there exist rational options; option talk refers to availing further detailed information about options; and decision talk refers to walking the patient through the rational options to facilitate deciding what is best (Elwyn et al., 2012; Elwyn et al., 2016).

Where the infertile couples are supported in the decision-making process through provision of all the necessary information by the clinicians, psychological counsellors and legal experts, it can be deemed that they are able to freely make an ART decision that will be most appropriate and autonomous in their specific situation.



## **2.7 Theoretical Framework**

The theoretical framework helps in bringing out theories that underpin the area of study; in this case the health belief model and the bio-psychosocial theory are the two theories that were used. The health belief model was used to describe and explain how information can be utilised to change/ manage behaviour of the individual in infertility situation to take action while the bio-psychosocial theory brought out the interaction of the various levels of information and how it influences cues to action on ART for the infertile persons.

### **2.7.1 Health Belief Model/ Health Communication**

Health Belief Model (HBM) also referred to health communication is a model developed to clarify and forecast health-related behaviours, specifically in relation to the uptake of health services. The model indicates that what people believe about their health issues, what they are likely to achieve or lose by taking action; and their self-efficacy influences their engagement or lack of it in their choice for health-promoting behaviour (Becker et al., 1974; Rosenstock et al., 1988; Brindis et al., 2005). A kind of cost benefit analysis takes over whereby, an individual evaluates opposing choices; on the cost side are vulnerability and harshness factors while likely gains of taking action and the ability to override obstacles stand on the benefits side. A personal drive, or cue to action, is also necessary in order to prompt the health-promoting behaviour (Becker et al., 1974; Rosenstock et al., 1988; Brindis et al., 2005).

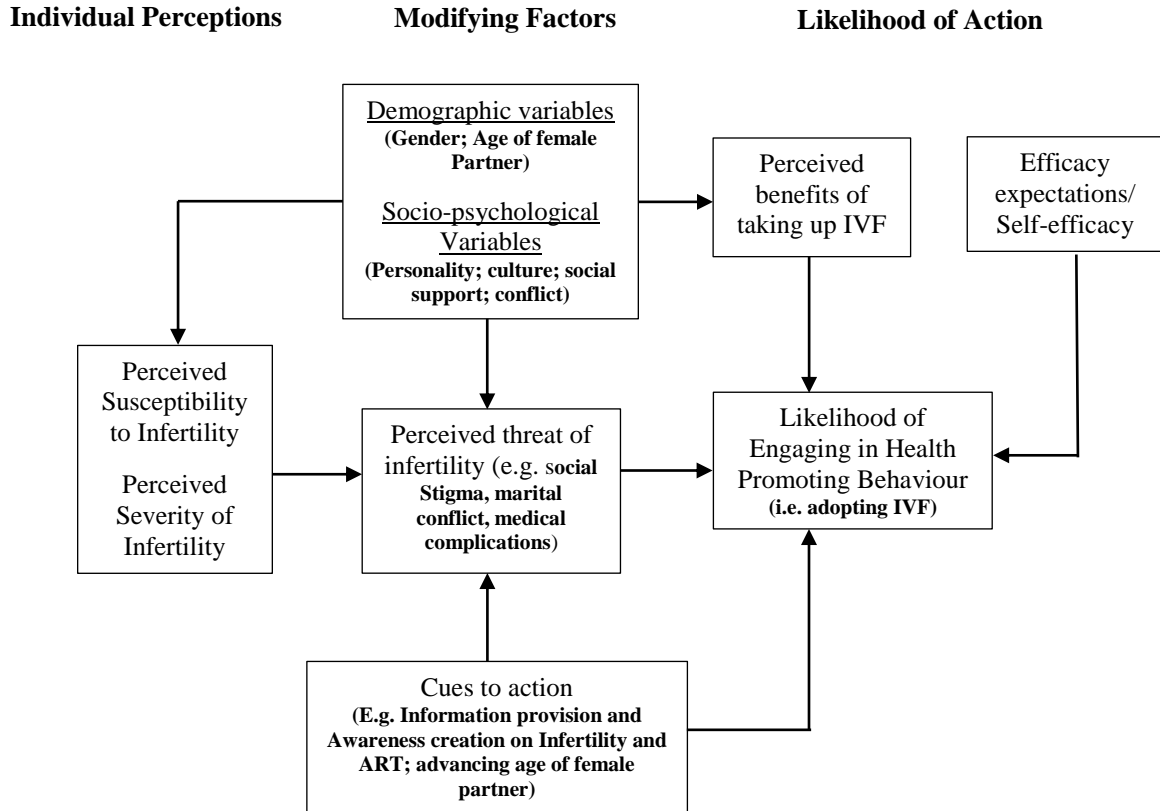


Figure 2.2: The Health Belief Model  
**Adopted from:** Becker et al., (1974)

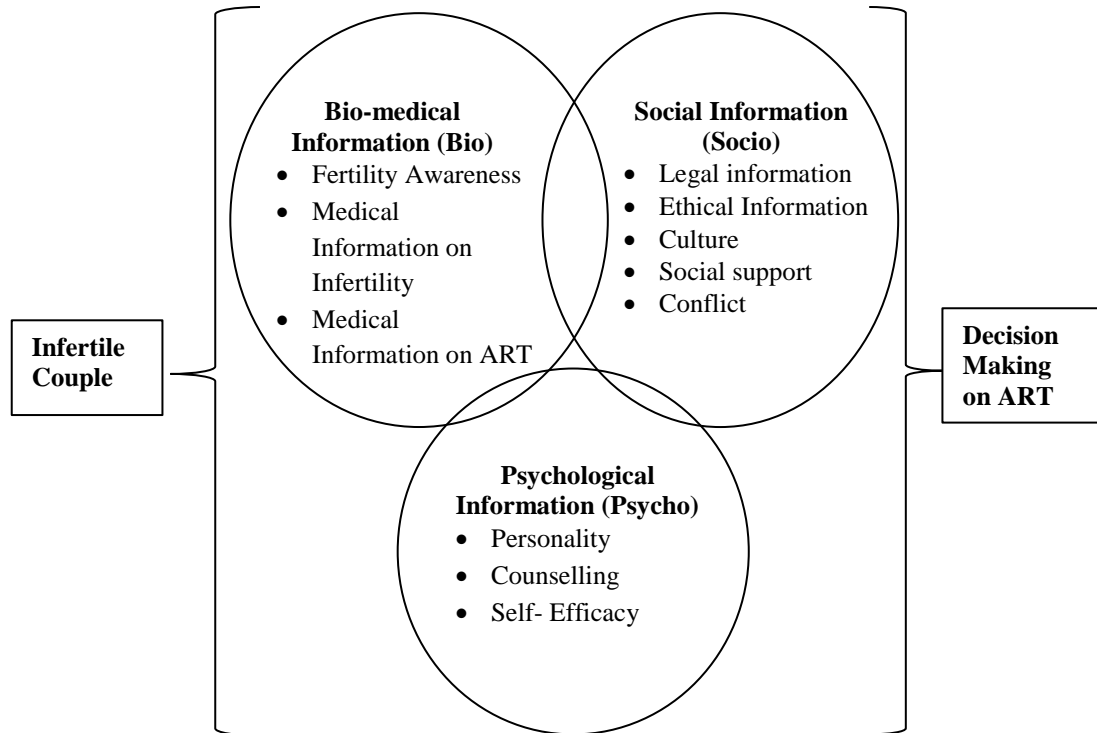
In this study the health belief model becomes relevant in that infertility as a health condition triggers the four constructs representing the perceived threat and net benefits: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers. These notions were seen to directly influence people's "readiness to act." The higher the perceived severity of infertility, the higher the cue to action; the higher the perceived susceptibility (information about the risk of engaging in risky behaviour), the higher the cue to action. Where the perceived benefits of adopting ART are high the individual will likely take up the treatment regimen and conversely where there are barriers such as lacking social support; cultural impediments and low self-efficacy the likelihood to take up the ART treatment will be low.

Modifying variables in the model also termed as the intervening variables as shown in the conceptual framework covered under section 2.8 include culture, personality, self-efficacy, social support and conflict. These variables have a bearing on perceived benefits and/or barriers, all of which have an influence on decision making in adoption of ART.

### **2.7.2 Bio-psychosocial Theory**

In his paper '*The need for a new medical model*', published in the Science Magazine in 1977, George Engel, specialist in internal medicine and psychiatry, saw a short fall in the available biomedical models and conceptualized a new bio-psychosocial model with which he advocated the integration of biological, psychological and social factors in the study, prevention and treatment of disease (Engel, 1977; Havelka et al., 2009).

The Bio-psychosocial Theory proposes the integration of biological, psychological and social factors in the study, prevention and treatment of disease (Engel, 1977; Havelka et al., 2009). In the Bio-psychosocial theory, interactions of the biological, psychological and social aspects of disease take place within one unique system specific for each individual, a system within which all three major subsystems closely interact by integrating and coordinating information, energy and other substances (Engel, 1977; Grinion 2005; Havelka et al., 2009; Obeidat et al., 2014). The key area of focus in bio-psychosocial model is the sick individual as opposed to the disease itself. The model vouches for team work and interdisciplinary approach in both medical research and practice, feeding the more rapid and successful development of medicine itself (Grinion 2005; Havelka et al., 2009). It is therefore critical that couples experiencing infertility receive information in all aspects of infertility, these are, biomedical which has to do with the illness itself; psycho which has to do with the individual's psych or frame of mind; and the social aspects which have to do with the individual and their social set up to include immediate and extended family, the society, culture, religion, as well as legal and ethical issues surrounding infertility.



*Figure 2.3: The Bio-psychosocial Model of Infertility and ART Information*  
**Adopted from:** Obeidat et al., (2014)

The Bio-psychosocial Theory is relevant to this study in that infertility as a disease has got information from the three facets of the theory namely bio-medical, psychological, and social information which are all at play in an individual and/or family suffering infertility. These three aspects are necessary in decision making on ART.

An infertile couple or individual who receives information from the biomedical and social facets of infertility and ART will internalize and be influenced cognitively at the psychological level to make a decision on the uptake or rejection of ART.

## 2.8 Conceptual Framework

The conceptual framework for this study focuses on information on infertility including fertility awareness, biomedical information and psychosocial information that individuals

are exposed to as they deal with their infertility circumstances. Similarly, it presents information on assisted reproductive technologies such as medical, legal and ethical information that is necessary in influencing the infertile persons' courses of action regarding their infertility situation.

Couples experiencing involuntary childlessness will be exposed to information on infertility which includes infertility awareness, biomedical information, and psychosocial information. Fertility awareness has to do with information on factors that can improve an infertile individual's fertility and lead them towards natural conception and this may include change of lifestyle and diet for both partners. Biomedical Information on the other hand has to do with an individual's state of health that is contributing to infertility: for the female partner it could be blocked tubes, a damaged uterus, uterine fibroids, polycystic ovarian syndrome, HIV and AIDS among others; while for the male partner it will usually be due to sperm abnormalities, HIV and AIDS among others. Similarly, psychosocial information has to do with an individual's state of mind 'psycho' and their social environment 'social' that will be triggered by their infertility status especially when it is prolonged. Psychosocial situations have been exhaustively discussed under the consequences of infertility section.

In the process of seeking fertility treatment and dealing with the psychosocial circumstances triggered by infertility, couples will come into contact with information on ART. ART information has medical, legal and ethical components. Medical information on ART comprises IVF treatment protocols, requirements for one to qualify for treatment and the different processes that are undertaken during the treatment. Legal and ethical information becomes part of the medical component in that where couples lack viable gametes there are provisions for donor gametes and donor embryos as well as surrogacy for women who may have difficulty carrying a pregnancy to term. In these instances, legal and ethical issues arise and have to be factored in decision making on ART.

Information on infertility and information on ART make up the independent variable of the study and are all critical in decision making on ART. However, an infertile couple at their individual level and in certain instances collectively will be influenced by other factors in their pursuit of ART treatment; these other influencers termed as the intervening variables in the conceptual framework include culture, personality, self-efficacy, social support and conflict which are closely tied to consequences of infertility are also well covered in the theoretical framework. Culture as an intervening variable has been demonstrated by Daar and Merali, (2002) in his six-level continuum of increasing severity of consequences of infertility where he demonstrates that for women experiencing infertility in African and Asian cultures, the consequences are of higher order above level 3 to include violence, physical abuse, violence-induced suicide, starvation and loss of dignity in death; while in the Western Countries the psychosocial consequences are less severe at level 2 and below (Daar and Merali, 2002; Dyer and Pennings 2010).

Social support for the infertile is a key component in their journey to seeking ART interventions. Daar and Merali, (2002) have clearly brought out what individuals suffering infertility go through; with social support from family members and the society the infertile will endure less of the consequences. Personality type which is closely linked to self-efficacy has a great influence on decision making at any level. The Health Belief Model and the Bio-psychosocial theories elaborated earlier have clearly illuminated personality and self-efficacy as influencers of decision making from a clinical perspective and shown that information on infertility and information on ART have to be processed cognitively by the self for self-efficacy to set in and prompt decision making on ART.

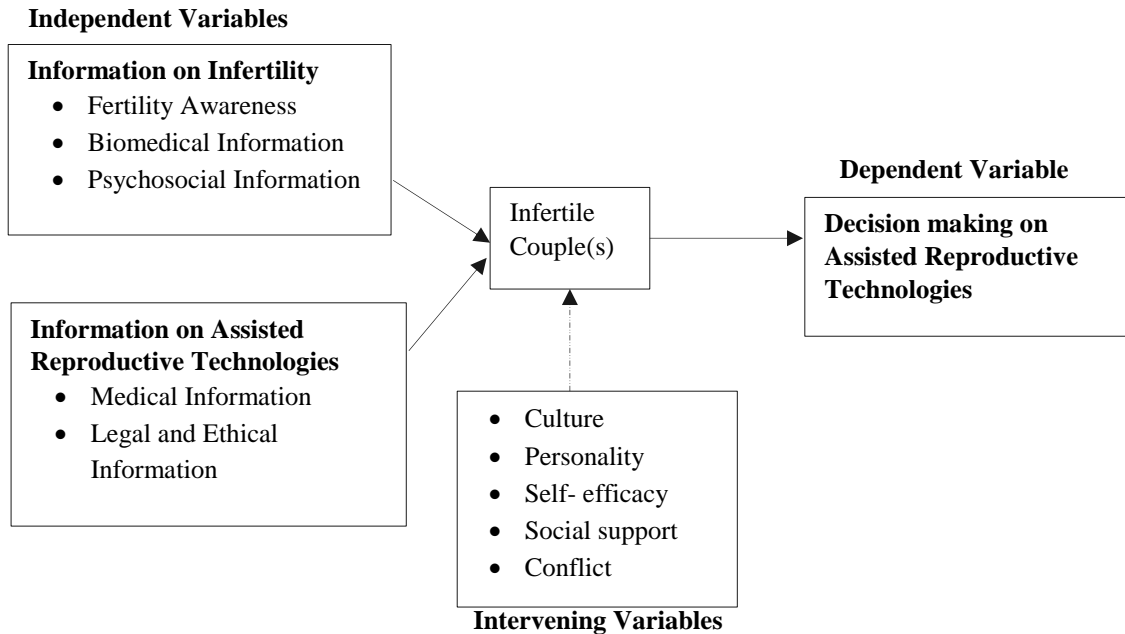


Figure 2.4: Conceptual Framework

Source: Researcher’s Own conceptualization (2019)

The decision to take up assisted reproductive technology is also a key aspect in the conceptual framework. The ensuing discussion as compressed diagrammatically in the conceptual framework clearly indicates that besides being influenced by the information on infertility and information on ART, the decision to adopt or reject assisted reproductive technology will be predisposed to moderating variables including an individual’s culture, personality, self, efficacy, social support and conflict experiences as a result of infertility.

## 2.9 Summary

Chapter two has reviewed the literature that is related to the area of study to include information on infertility and information on ART; with infertility awareness emerging as an important factor in preventing future infertility especially when the awareness is created among the youth. Literature has also shown the consequences of infertility as a key determinant of how individuals deal with their infertility circumstance as the consequences vary from continent to continent and more specifically from individual to

individual. Information on ART has also been exhaustively covered from a medical point of view, psychosocial perspective and also from a legal and ethical front.

Decision making has also been looked at from a clinical approach with the shared decision-making model illuminated as a key component in decision making on assisted reproductive technologies. To tie up information and decision making on ART from a theoretical perspective the Health Belief Model and the Bio-Psychosocial Theory have been discussed and related to the study in this chapter. Finally, a conceptual framework has been developed by the researcher to guide and focus this study.



## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Overview**

This chapter covers the research design, research site, the population, as well as sample and sampling procedure. Information on how data was collected and analysed is also highlighted. The validity and reliability of the study and ethical considerations for the study also form part of this chapter.

#### **3.2 Research Design**

This study employed a descriptive research design within the constructivist paradigm to present, analyse and bring out the meaning making process of individuals in infertility situations as they interact with information on infertility and on ART and how the information influences their decision to take up IVF treatment.

Constructivists insist that truth is relative and depends on one's perspective. Constructivism appreciates the gist of the subjective human creation of meaning (Baxter and Jack, 2008). Social creation of reality is the building block on which constructivism stands and close relationship between the researcher and the participant is critical, this closeness enables participants to tell their stories (Crabtree and Miller, 1999); and in narrating their stories the participants bring out their views of reality giving the researcher an opportunity to grasp the actions of the participants (Baxter and Jack, 2008).

For this study the participants narrations of how the different levels of information on infertility and information on ART influenced their decision making on taking up ART formed data for analysis and interpretation of the study findings.

### **3.3 Research Approach**

This study utilised a qualitative case study research approach for sampling, data collection, data presentation and data analysis and interpretation. According to (Stake, 1995; Yin, 2009) qualitative case study falls under the constructivist paradigm. Stake (1995) describes the case study methodology as a mode of inquiry whereby, the researcher reconnoitres in detail a programme, an event, an activity, a process or one or more individuals. Simons (2009) further affirms Stake (1995) and looks at case study as a detailed detour from multiple perspectives the intricacy and exclusivity of a particular project, policy, institution, programme or system in a 'real life'. Yin, (2009) further proposes several conditions under which case study approach is used and these are: i) when the researcher wants to answer how and why questions; ii) when the behaviour of the participants cannot be tampered with; iii) to cover contextual conditions that are of importance to the phenomena under study; and/or iv) when there is no clear demarcation between setting and phenomena under study. This study fitted into the conditions set out by Yin, (2009) in that; the researcher investigated how different levels of information relating to infertility and ART influenced the participants decision on ART; the question of why they adopted or rejected ART was also explored in the study. Secondly, the behaviour of the participants in the study was difficult to manipulate as those interviewed as participants were women in situations of involuntary childlessness and were either undergoing IVF or had had at least a cycle of IVF treatment and hence they were re-living their experiences in the journey towards infertility treatment.

Baxter and Jack, (2008) further advise that in case study approach, a researcher must be able to determine what their unit of analysis is as this is what constitutes a case; while (Milles and Huberman, 1994) define a case as a phenomenon that occurs in a bounded setting. A case therefore becomes a unit of analysis occurring in a bounded context. In this study the unit of analysis which is my case was decision making on ART and the context within which the case was bound was the different facets of information to include

information on ART; infertility awareness; and information on infertility, that influenced the decision on ART.

### **3.4 Research Method**

The researcher sought to gain insight on the problem by investigating the views of participants on how their levels of information on infertility and ART influenced their decision to undertake IVF. The data collection method used was in-depth interviews conducted with the IVF patients as study participants and key informant interviews with a gynaecologist, a fertility expert, a psychological counsellor and a legal expert. This ensured that the data collected from the participants was corroborated and enriched by the information gathered from the key informants. The researcher also reviewed documents relating to infertility and ART in Kenya to further enrich the data collected from the participants and the key informants.

### **3.5 Research Site**

The research was carried out in Nairobi City County, Nairobi is the capital city of Kenya and one of the 47 counties in the country. Nairobi has a population of about 4,397,073 persons with 2,192,452 males and 2,204,376 females (KNBS, 2019). It is a cosmopolitan city and the heart of educational, socio-economic, political, commercial and industrial activities of the country. Nairobi has the largest teaching and referral hospital in the country the Kenyatta National Hospital as well as other major hospitals including, The Aga Khan University Hospital, The Nairobi Hospital, Nairobi Women's Hospital among others. The concentration of Hospitals in Nairobi avails a large pool of medical specialists and by extension a major location for those seeking medical treatment in the Country and also from the East Africa Region (Bellows, 2017). Nairobi is also one of the counties in Kenya where IVF treatment is available and also has the highest number of IVF clinics in the country, currently there are about seven fertility clinics in Kenya offering IVF with 5

of them being in the capital city. The other counties in Kenya where IVF is available are Nakuru, Eldoret and Mombasa.

### **3.6 Study Population**

The study population comprised infertility patients who had undergone IVF treatment or were in the process of undergoing IVF and these were the primary respondents. Medical professionals comprising of a gynaecologist and a fertility expert believed to have experience in infertility and IVF and thus in contact with infertile couples seeking or undergoing treatment formed part of the key informants for this study. The other categories of key informants interviewed for the study were a psychological counsellor handling IVF patients and a legal expert dealing with infertility and ART issues.

### **3.7 Sample Size and Sampling Techniques**

Purposive and snowball non-probability sampling technique was used since the sampling population could not be precisely defined given that no list of the study population existed and also due to the nature of the problem under investigation. The initial contact was established by getting an individual who was seeking or had sought IVF treatment in any of the clinics in Nairobi after which they were requested to introduce another person and this continued until the researcher had reached the adequate sample size. The researcher interviewed ten (10) female participants who are undergoing IVF or had already had at least one cycle of IFV treatment while at the same time striving to ensure that the qualitative saturation point was reached (Litchman, 2014).

Purposive sampling enabled the researcher reach the targeted key informants for the research with ease and quickly (Webb and Doman, 2008) and hence the key informants for the study were selected using purposive sampling. This study had four key informants drawn from four categories of experts. Coming first was a gynaecologist; gynaecologists are assumed to be the initial contact with individuals or couples struggling with infertility

and are likely to be the first to diagnose infertility for the individual. In the second place was the fertility expert, this is the professional to whom the infertile individual or couple is referred by the gynaecologist, the fertility expert investigates the infertility further and proposes an ART treatment regimen. Coming third and fourth as key informants were a psychological counsellor and a legal expert. These two categories of experts become necessary in a couple's infertility journey owing to the nature of infertility and the circumstances surrounding the treatment as brought out in the earlier chapter of literature review. Consequences of infertility touch the psychological well-being of individuals in which case psychological counsellors' step in; where there is introduction of a third party in the baby making process such as in cases of IVF with donor gametes or donor embryos and/or surrogacy, proper rules of engagement must come into play thus the need for legal experts.

The researcher interviewed one (1) gynaecologist, one (1) fertility expert, one (1) psychological counsellor and one (1) legal expert. This made a total of four (4) key informants for the study, the amount of data collected from the key informants was sufficient to corroborate and reinforce the information gathered from the ten (10) primary respondents/ participants.

### **3.8 Data Collection Tools and Techniques**

Three key case study scholars (Stake, 1995, Merriam, 1998 and Yin, 2003) agree that case study researchers gather data from a multiple of sources to capture the case study in its intricacy and wholeness. Yin, (2003) further posits that there are six (6) major evidentiary sources from which a case study researcher gathers data and these are interviews, documentation, participant observation, direct observation, archival records and physical artefacts; while Stake, (1995) agrees with Yin, (2003) but insists on only three ways of gathering case study data which are documentation, participant interviews and direct observation.

In this study the researcher utilized two of the evidentiary sources proposed by Stake, (1995) and Yin, (2003) namely: interviews and document review. Yin (2009) and Stake (2000) concur that using multiple sources of data then converging it during analysis is crucial to performing a case study reliably. Additional sources of data allow case study researchers to create a story, a story that puts into perspective the participants' meaning-making processes. For this study the researcher used interviews as the primary data collection vehicle, and then enriched the data with additional secondary data from documentation that relates to infertility and ART in Kenya.

### **3.8.1 Interviews**

As a rule, interviews ought to be done carefully for a case study to be dependable. Therefore, purposeful sampling of the interviewees, including the consideration of an individual as opposed to a group focus, should be factored, at the same time, the size of the sample and fitness for purpose of the participants for the interview are critical in the choice of interviewees. The interview is always considered to be a conversation between the interviewer and interviewee, where the interviewer enquires and the interviewee responds appropriately (Esterberg, 2002). For effective interviews, relationships and rapport must be created, and matched up with trust: interviews aim at bringing out what is in and on someone else's mind. Interviews are carried out to bring out what cannot be observed (Patton, 1987). Active listening and non-judgmental character are two of the common practices that should be put into consideration when conducting interviews for case study research.

The researcher chose interviewing as the primary data source for this research for four major reasons': First, qualitative interviewing is aptly used when studying people's understanding of the meaning in their lived world (Kvale, 1996). Second, the purpose of interviewing is to find out what is in and on the interviewee's mind (Patton, 1987). Third, qualitative interviews yield thick descriptions of the subject being studied that make it

possible for readers to make decisions about transferability of study results (Merriam, 2002). Finally, interviews allow for converging of information arising from other sources and, thus, enrich the credibility of study results (Stake, 1995; Merriam, 2002).

For this study the researcher conducted in-depth interviews with the primary respondents using the interview guide developed for this research; a total of ten (10) ladies were interviewed. The researcher also conducted key informant interviews with four (4) key informants for the research; interviewing medical professionals (a gynaecologists and a fertility expert); a psychological counsellor and a legal expert enabled the researcher pick and solicit knowledge from those who Patton (1987) calls, “key informants”. Key informants are people who are predominantly conversant with the inquiry setting and articulate about their knowledge, and whose insights can be helpful in assisting an observer in understanding events that have happened and reasons why those events happened. All the interviews were conducted face to face and at the convenience of the interviewees with regard to time and place. For purposes of being exhaustive the interview with participants took between 45-57 minutes while those with key informants took between 25-40 minutes.

With participant and key informant’s approval, the researcher audio recorded the interviews to ensure accurate transcription (Merriam, 1998). The researcher also took handwritten notes during each interview, this helped in tracking key points to return to later in the interview and also highlighted ideas that were of particular interest and/importance.

At the inception of each interview, participants were reminded of the purpose of the study, research procedures, expected benefits, their right to withdraw from the study at any time, and protection of confidentiality. The researcher also asked participants if they had any questions about the research study or research procedures. The researcher provided

information about herself to establish rapport and gain trust from the respondents and key informants (Patton, 1987).

The researcher used the semi-structured interview approach (Merriam, 2002) and a uniform set of open-ended questions to obtain i) demographic information on the participants, and ii) study specific questions focusing on the availability of information on infertility and information on ART and how it influenced participants' decision to undertake ART. Open-ended questions were used throughout the interviews to encourage participants to respond freely and openly to queries (Esterberg, 2002). Probing and/or follow-up questions were used, when necessary, to encourage participants to elaborate on or clarify a response (Denzin and Lincoln, 2000).

The transcription process began after the first interview. To ensure transcript accuracy, the researcher reviewed each transcript while listening to the audiotapes. Additionally, the transcripts were presented to each interview participant for their further review to ensure accuracy.

### **3.8.2 Document Review**

Document review was used to clarify and/or substantiate participants' statements and to enrich the description of the case (Merriam, 2002). The researcher reviewed binding document from the Ministry of Health (MoH), the National Assembly Legal Directorate and the National Hospital Insurance Fund (NHIF) as these three agencies had documents that were deemed pertinent to the case under analysis for purposes of enriching the study and confirming what the interviews had brought out.

Among the documents that were reviewed included:

- i. Assisted Reproductive Technology (ART) Bill 2019 which was the proposed legal framework for ART practice in Kenya;



- ii. Kenya Ministry of Health Strategic Plan which was the guiding framework for public health under which infertility falls;
- iii. The National Hospital Insurance Fund (NHIF) provisions on Infertility Treatment Insurance, NHIF is the national health insurer

### **3.9 Data Analysis and Interpretation**

In qualitative research data analysis takes place concurrently with data collection and write up of findings (Creswell, 2014); and ultimately due to the density of qualitative data not all information gathered during data collection is used in the write up process (Creswell, 2014). To enable focussing and aligning of data to the research questions and/or propositions it is recommended that the researcher '*winnows*' the data to pick what is necessary and disregard other parts of the data (Guest et al., 2012). Focussing enables the researcher aggregate data into a small number of themes to the tune of five to seven (Creswell, 2014).

Qualitative analysis entails intellectual imagination and creativity, and there is not a specific way of carrying out qualitative research considering that data analysis is basically a meaning making process. It is a creative process, not a mechanical one (Denzin and Lincoln, 2000); a qualitative study exploits the very basic ways of making sense (Stake, 1995). Stake continues to affirm that, "there is no specific time in the research process when data analysis begins. "Analysis," he insists, "basically means taking something apart". Qualitative data analysis, therefore, gives meaning to first imprints and final accumulations; and for this study the researcher was interested in how the information that infertile couples are exposed to influences their decisions on ART and at the same time reinforce their experiences with information from the key informants and data from documents reviewed, to identify patterns that emerged from the participants meaning making process.

Practically, Esterberg (2002) recommends getting very intricate with one's data to store up key concepts that are generated from qualitative data into the researcher's memory to ensure that all thoughts and ideas that respond to the research questions are not ignored. This research followed the data analysis and coding process suggested by Creswell (2014) and Esterberg (2002). Precisely, Esterberg (2002) insists that open coding is where the research intricately goes through the data transcripts line by line picking out themes and categories that are of interest. Creswell (2014) also emphasises the traditional outlook in social sciences that lets codes and themes emerge as one analysis data.

For this study the researcher examined the data collected on the level of information on infertility and information on ART and decision making on IVF in Kenya and utilised the open coding technique to bring out all possible themes. The study followed the Creswell, (2014) six steps process during the data analysis. It is however worth noting that though the steps are outlined in a linear tiered order, Creswell asserts that the steps are intertwined and there is a back and forth kind of interaction with the data during analysis; the process is not simply a static, linear order of analysis.

The first step involved organising and preparing the data for analysis. The researcher reviewed the audio recorded interviews and transcribed them to word documents.

Next the researcher read the transcripts; here the researcher looked at the data with a view of grasping the overall meaning to pick the general sense of the information and idea the participants brought out. This step also corresponds with Esterberg (2002) directive to "get to know your data".

The third step involved coding all the data. The researcher organised the data by classifying sentences into categories and labelling those categories with a term based on the actual language used by the participants.

The researcher then used the coding process to bring out a description of the setting or people as well as categories or themes for the analysis (Step 4). The generated codes were used to describe the case study and generalise to a small number of categories or themes. The researcher then analysed the themes that emerged and gathered the various cases into a general description for this study.

The fifth step involved showing how the descriptions and themes would be embodied in the qualitative narrative. The researcher twined the developing themes into narrative passages, so that the findings of the study emerged sequentially and logically from the participants' responses.

The final step involved interpreting the findings (step six). Creswell (2014) asserts that a researcher's own background plays just as important a part of the meaning making process as a researcher's fidelity to a theoretical lens. Creswell also recognises that interpretation in qualitative research can take many forms, be adapted for different types of designs, and be flexible to convey personal, research-based and action meaning. The researcher in this case interpreted the findings by focusing on the research objectives and how the data analysed fitted into the objectives was brought out by the participants' own meaning-making process and reinforced by the key informants.

### **3.10 Validity and Reliability**

Qualitative research expects a researcher to be wholly engrossed in gathering and interpreting the meaning making of those they study. Credibility of a qualitative researcher goes hand in hand with being good and trustworthy. Qualitative researchers are therefore required to be objective and open minded so that they are able to understand their area of study from the participants' perspective, as opposed to imposing their own assumptions, Stake (1995).

To increase the credibility of the study findings, the researcher worked with approaches endorsed by renowned qualitative researchers. To decrease threats to credibility (Lincoln and Guba, 1985), The researcher: i) used multiple data sources as detailed in the data collection section to confirm emerging findings (Merriam, 2002; Stake, 1995; Yin, 2003); ii) performed member checks (Merriam, 2002) this was achieved by providing the participants a copy of their interview transcript and asking them to validate the accuracy of the information; and iii) requested the supervisor to review the findings as they emerged (Merriam, 2002). To increase dependability of study findings, the researcher provided an audit trail (Merriam, 2002) that is, a detailed explanation of the data collection and analysis methods and how decisions were made throughout the study. Finally, to enable other researchers to make decisions about transferability (Lincoln and Guba, 1985) of results, the researcher used rich, thick description (Merriam, 2002).

Merriam (2002) further defined the approach of ensuring rich description as “providing enough account to contextualise the study so that readers are able to conceptualise the depth to which their situation corresponds with the research context”. Thus, the prominence of Merriam’s strategies in this study’s methodology ensured validity and reliability of this research.

Maximum variation strategy is another of (Merriam, 2002), recommendations for qualitative studies; maximum variation seeks wide-ranging investigation of the sample size to allow for a greater range of application of the findings. For this study the researcher interviewed ladies experiencing infertility as the primary respondents; four different categories of professionals as key informants who interact with the primary respondents during their infertility journey; and also reviewed binding documents that contain critical information relating to the area of study.

This maximum variation strategy, as explained by Merriam (2002), recommends use of multiple sources of data collection methods to confirm findings. Therefore, the

credibility/transferability/dependability/ nature of the research were ensured, and the validity and reliability of this qualitative study was strengthened.

### **3.11 Ethical Consideration**

During the research process the researcher sought informed consent from the informants. Anonymity and right to privacy of the research subjects was guaranteed and mechanism put in place to safeguard the trust and welfare of the participants. The data collected was coded to protect their identity and no name of an informant was used in the write-up.

The participants were asked at the beginning of the interview whether they would like to identify themselves and if the same could be recorded or not. Permission to record the interviews was sought from the participants and they were also advised that they would not have to answer every question and that the right to withdraw from the interview at any time rested on them. The explanation to the informants of their rights helped create a rapport with them. All data collected was kept confidential and subsequently destroyed at the end of the write-up process.

The researcher defended the proposal and only proceeded to the field after approval by the School Post-Graduate Committee and obtaining of a Certificate Fieldwork from the School of Journalism and Mass Communication (see appendix 7). The researcher also applied for a research permit from the National Council for Science, Technology & Innovation (NACOSTI) as required, and was granted the approval on 9<sup>th</sup> September 2019 (see appendix 6). Once the data was collected, analysed and the write up completed the researcher defended the final project, passed and carried out the requisite correction and was issued with a certificate of correction by the School of Journalism and Mass Communication (see appendix 8). The final project was subjected to turnitin originality check by the University of Nairobi on 13<sup>th</sup> November 2019 and passed after which the researcher was issued with a certificate of originality (see appendix 9).

### **3.12 Summary**

This chapter outlined the methodology of this study. Constructivist paradigm was described along with the rationale for the qualitative research method. Case study approach and the conditions that allowed for use of the approach for this study was illuminated as well. The research site, population for the study, the sample size and the method employed in sample selection were also described. Data collection tools to include interviews and document review were well elaborated with the technique employed during analysis and interpretation of the collected data also expounded on comprehensively. The validity and reliability of the study was also outlined and finally, the ethical considerations for the study highlighted.

## CHAPTER FOUR

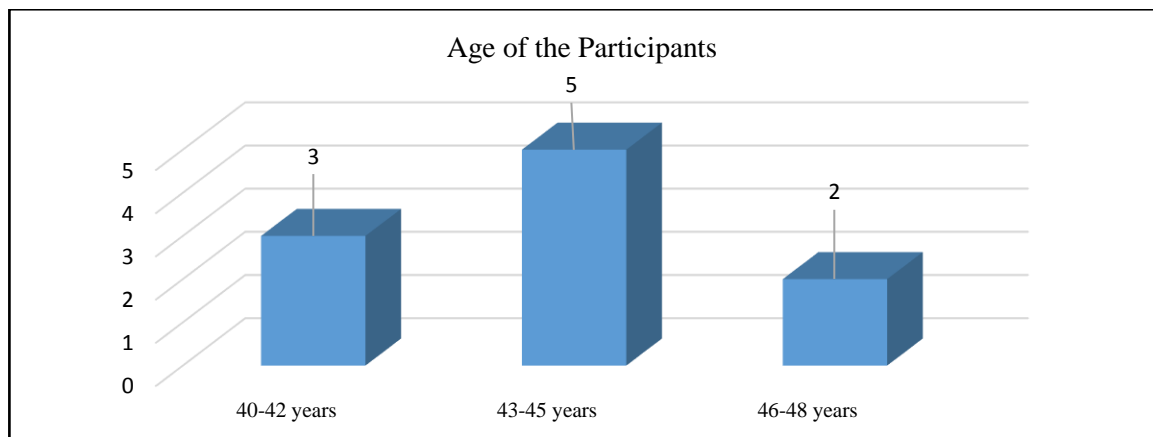
### DATA PRESENTATION, ANALYSIS AND INTERPRATION

#### 4.1 Overview

This chapter covers the organization and analysis of data as well as presentation of the research findings. The study focused on the availability of information on infertility; availability of information on infertility interventions with specific emphasis on IVF; how the information is packaged and disseminated; and finally, how this information influences decision making on the up-take of the ART interventions among families experiencing infertility in Kenya. The study was carried out in Nairobi County which is the Capital City of Kenya and also the county that has the highest concentration of facilities offering ART interventions.

#### 4.2 Demographic Characteristics

The study participants included ten (10) female participants who had undergone at least one cycle of IVF or were in the process of undergoing IVF. The figure below presents the age of the study participants.



*Figure 4.1: Age of the Female Participants*

From the figure above, the age of the ten (10) participants ranged between 40-48 years; five (5) of the female participants forming the majority at 50% were aged 43-45 years; 3 participants (30%) were aged between 40-42 years; and two (2) participants (20%) were aged 46-48 years.

The female participants were also asked for how long they had been married. The findings are presented in Figure 4.2.

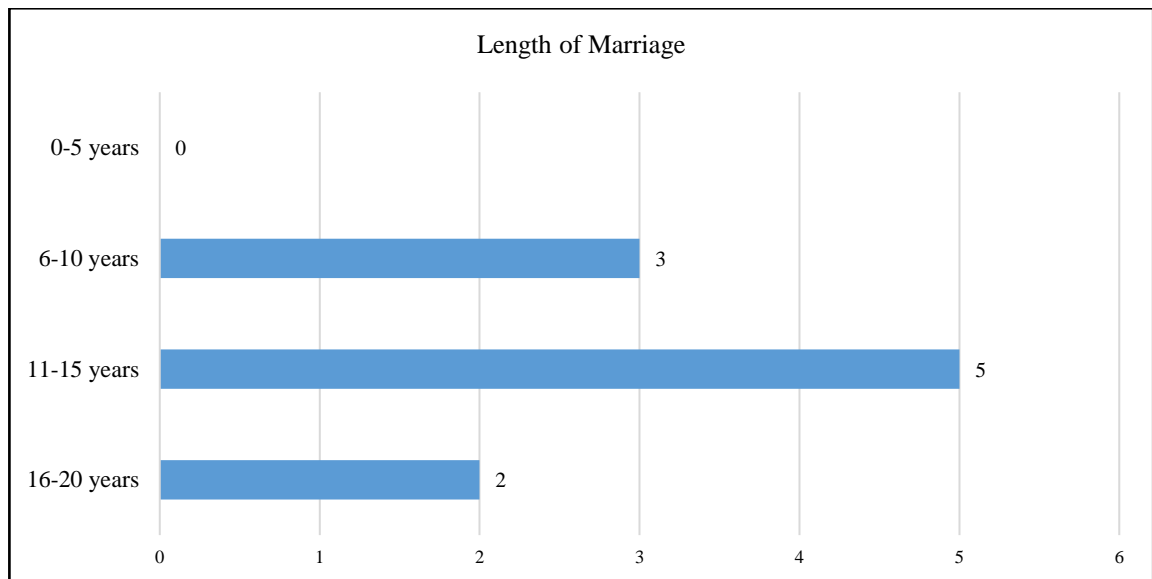


Figure 4.2: Length of Marriage

From the figure above, all the ten participants were married, with five (5) of them who were the majority having been married for 11-15 years, followed by three (3) who had been married for 6 -10 years and two (2) who had been married for between 16-20 years. None of the participants had been married for less than five (5) years.

The participants were also asked whether they had primary or secondary infertility and it emerged that a majority of the participants at 80% had primary infertility whereby they had not had a child at all before attempting ART, while 20% or two (2) participants suffered secondary infertility.



In addition, the researcher also interviewed four (4) key informants among them a gynaecologist, a fertility expert, a counselling psychologist, and a legal expert to enrich and corroborate the information gathered from the study participants.

#### **4.3 Information on Infertility and Information on ART in Kenya; the Information Packaging and Dissemination**

The researcher sought to find out what information on infertility and on ART was available in Kenya and how it was packaged and disseminated. Regarding availability of information on infertility the participants did not have adequate information on infertility, despite having challenges with their fertility. The participants noted that information was not easily available and you would have to do a lot of probing and personal effort to get it as the person suffering infertility. One participant had this to say about availability of information on infertility:

*I can't say it is easy to get that information because, one, for you, by the time you're being identified as infertile, you've passed through several doctors who do not get to diagnose you properly to start with. So, it's something you set to go fishing on your own when you see that the doctor's interventions are not working. (Participant 1)*

Similarly, another participant indicated the personal effort that goes into getting infertility information:

*So, like the gynaecologist won't go right away and tell you that you are infertile. They give you like different treatments first of all. They do not get to the problem quickly. So, most of the information you will get it at a later stage. And mostly it is you digging for that information. (Participant 5)*

Yet another participant affirmed the above sentiments and had this to say:

*No, it does not exist. Information on Infertility, you're kidding me it's not there. So, cause like right now what we have been seeing in the media, they are trying to promote to give a little bit of awareness but it does not exist in a structured way. In fact, I am thinking you get more information from um, social media, you get more information from Facebook, than what you get from your doctor. And of course, you know what this means you get information overload so you have to sift through what makes sense to*

*you. Infertility being a medical issue in your life do you really want to rely on social media sources? (Participant 6)*

On packaging and dissemination of infertility information the participants noted that given the information was scanty the packaging and dissemination was poor. Majority of the participants said that the information was not well packaged. The participants also noted the insensitivity of the medical personnel in breaking the news of infertility. The participants felt that they were not explained to the reasons why they were being referred to the fertility experts or the reasons why they were taken through a myriad of tests. The medical personnel that gave information, did not give it wholesome, but in bits.

Participants were also concerned about gender sensitivity during dissemination noting that there was a general assumption that infertility affected women more yet most fertility experts were male and hence insensitive when disseminating information to the infertile female in the presence of the male partner. One of the participant's sentiments on packaging and dissemination were as outlined below:

*So, the way it is packaged poor. Very poorly packaged, especially if you're encountering it for the first time. Because this doctor will disseminate to you this information without even counsellors being around. So, it is your first interaction and the first time you learn about infertility in your union and you are being told everything there.*

**(Participant 1)**

Another participant also noted the need for sensitivity during dissemination and expressed concern:

*And I'm also thinking the way it is packaged they should be sensitive to the gender. Whom they are addressing because most of the fertility doctors are men addressing infertile women. So, when they're bringing this information to women, in the presence of their husbands, I think they should find out a way of how to do it without it coming out as a...protecting the man ego thing! (Participant 2)*

The gynaecologist interviewed corroborated the findings from the participants and indicated a lack of coordination in availing information on infertility to patients. This she felt was especially because doctors are not necessarily communicators, yet the patients

have got a right to information. The gynaecologist had this to say about availability of information on infertility, its packaging and dissemination:

*The challenge is that there is no standardization of a specific package of dissemination, and so it is provider dependent, every doctor will share information with their patient based on individual, case to case. You know, we're all different some are good communicators some may not necessarily be. Though the patient's rights require that the patient understands their condition, understands the available treatment, understands advantages and disadvantages and expected outcomes of all of them, so that by the time they're making an informed decision, it's very informed.*

**(Key Informant 1)**

Regarding availability of information on ART, the participants felt that there was more information available now than there was 5-10 years ago. Most available information was found online, and on social media sites, with 60% of the participants acknowledging the existence of a particular Facebook page on infertility and ART which is managed by a Kenyan fertility specialist, whereby a forum for sharing experiences and giving solutions is created. One participant shared:

*I see Facebook, a lot of Facebook posts. People talking about their experience and posting links; so I think right now on, online information is much more available than it was, like 10, 12, 13 years ago! (Participant 4)*

All participants indicated having got information on ART from media sources and this was well after they had discovered their infertility. The ART information sources included goggle, Facebook, newspaper articles, YouTube, radio and television talk shows. Information on ART was also available in fertility clinics in the form of brochures and wall branding which meant that one had to visit the clinic to get the packaged reliable information. A participant who got ART information from a hospital having gone for consultation shared:

*Um, another source for me was the hospital. Nairobi hospital itself, ah, linked me to their fertility specialist. (Participant 4)*

Another source of ART information for participants was from word of mouth by people who had either experienced infertility and used ART or just friends and relatives who were familiar with the interventions. One other participant had this to say about her source of ART information:

*I'm trying to think where my sources were. A lot of my information came from friends. Word of mouth from people who've either gone through something so they tell you there is this fertility specialist. (Participant 5)*

The fertility expert made a similar observation on availability of ART Information and access to the interventions while acknowledging that while previously the patients were aged 38 years and above, there are now seeing more of the 20s and 30s seeking fertility help due to availability of ART information:

*I think ART information, it's out there. I think what I am seeing now compared to when I started earlier, when there was really less, much less information, I'd see couples coming in when the woman was 40, or 38. But now that it's available, like especially in Nairobi, patients from here, kind of understand that it's there. And you get 28 year olds and 30 year olds coming in for IVF, eh, especially if you have tubal blockage and you know that there is something that can be done and they come in for IVF very early, which makes a huge difference because somebody who comes in at 28 when one has a whole nice funnel ovarian quality. So, they're most likely, couples who have three children out of one IVF cycle, it really makes a difference that you know earlier as opposed to later. (Key Informant 2)*


The available sources of ART information according to the participants and the fertility experts however disadvantaged those that came from rural areas as the information and the interventions were not so easily accessible for them. The fertility expert had this to say on access to information in far flung areas:


*Like I said earlier ART information, is out there, the unfortunate bit is that there are two centres in Nairobi, and I think one in Mombasa, and one in Eldoret. So, that is the biggest drawback that people in the villages and in other counties do not get the chance to know about it. I'm not sure if I still think that the penetration and knowledge of IVF and that the services available in Kenya are really widespread. But I think it's going in that direction. The penetration to other counties will go a long way (Key Informant 2)*

The legal expert presented the ART information in a very catchy and interesting way through wall branding in her consulting room which is the same place the researcher conducted the key informant interview with the expert. The researcher requested that the expert allows her to also capture the branding as part of data for the study which was gladly allowed. The branding which I share below figuratively shows the surrogacy/gestational carrier journey. Of the two figures one communicated about the requirements to allow an infertile woman take surrogacy as an option, and the second one had a flow-chart indicating the process through which a gestational surrogacy goes from the beginning to the end:

**KEY SURROGACY REQUIREMENTS:-**

1. Genetic Link to Intended Parent(s)
2. Written Surrogacy Agreement in Kenya
3. Medical Clearance for Surrogacy



**HER BODY**  **MY BABY**

**Surrogacy is.....**

- Spectacular journey
- Unreal to most
- Resulting in and
- Reminding us
- Of the
- Greatest Gift
- A person
- Can ever give or receive
- Yielding in Amazing Beauty




Figure 4.3: Requirements for surrogacy as shown in the legal expert's office



*Figure 4.4: Surrogacy stages as shown in the legal expert's office*

Packaging and dissemination of the information on ART was however noted to be a challenge. Participants indicated that they had to visit a fertility centre to get the information. A participant shared their thoughts on packaging and dissemination of ART information:

*No. The way it is packaged! Not in a friendly way! You'd have to go physically to either the fertility centre or a clinic and get a one on one kind of... information, and you have to do consultation. The technical language notwithstanding (Participant 8)*

The gynaecologist was in agreement in admitting that for both information on infertility and information on assisted reproductive technologies there was no standard packaging and also that the medical language would be a limiting factor due to its complexity and its technicality.

*So, we don't quite have a standard package neither on infertility nor in Assisted Reproductive Technologies. So, we always have to start from scratch. And the problem with understanding fertility is that it's very technical. (Key Informant 1)*

These findings therefore beg the need for specialists to find a way of breaking down the information in a language that the patients understand irrespective of their level of education or their background. The patients should understand the specific cause of their infertility to enable them weigh the treatment options available for them. This will enhance informed decision making. The importance of good communication and people skills for the medical practitioners then becomes imperative.

#### **4.4 Relationship between Fertility Awareness and Decision Making on ART**

The researcher sought to find out how fertility awareness influenced the participants' decision to take up Assisted Reproductive Technology (ART). The findings show that the participants lacked fertility awareness with some actions they had taken in their late teens and early 20s affecting their fertility in their 30s and 40s. This initial lack of fertility awareness had them exposed to hormonal contraceptives, such as the Norplant and Depo-Provera as early as age 19 years with some detrimental effects on their future fertility. A participant who had their first experience with contraceptives at age 19 shared her experience:

*So, when I was ready to like have sex, I said contraceptives and I did my research. There was this clinic that we used to go on Kenyatta Avenue I went for the 3 months injection*



*the Depo-Provera; this one [foreign] 'kwanza' won't give me periods so I can have sex anytime I want. I enjoyed not having a period. I read about it later and I never thought it was me. And that thing is bad. I read about how it causes infertility. (Participant 5)*

The participants also indicated that they were not aware of the connection between STIs and infertility; and even as they avoided STIs it was for their immediate health reasons and well-being but not for fear of infertility. The fertility expert confirmed that recurrent and untreated STIs, and misuse of contraceptives especially the morning after pill which was popular among young girls were predisposing factors to future infertility, yet the people were not quite aware. She had this to say:

*You know, people are not scared? I think people are more scared of pregnancy than HIV right now. When you hear of Postinor-2 the morning after pill getting finished in the pharmacies on Saturday and Sunday morning... It tells you that unprotected sex is rampant. They are not worried about STIs and STDs, they are worried about the pregnancy. So, I don't know if they really know what they are exposing themselves to regarding future infertility. Anyway, we can only give information.*

**(Key Informant 2)**

A majority of participants noted that in their twenties they had hormonal imbalances characterized by irregular menstrual cycles, with extended periods of no menses at all; and due to lack of fertility awareness these occurrences did not seem to raise a red flag on their fertility. They actually enjoyed the periods of missed menses not knowing that this was an indication of possible infertility. Some of the experiences shared were:

*For me when I think about it, I did not have fertility awareness. Because I think if I was, if I was aware, I would have done something earlier. I wouldn't, it wouldn't have gotten to that extent where I needed to be assisted. I would have been able to either do hormone treatment, or some other intervention instead of having to be assisted.*

**(Participant 4)**

Another participant also shared and said:

*I would have tested my AMH when I was 15. Because to me I think my (Anti-Mullerian Hormone) AMH went low quite early and it was almost gone when I was 26 years. So, for me I would have tested like a long time ago. In fact, I think the first time that I came across AMH was the day that I was being told I had infertility problem the*

*very first time. And I am a biochemist such that I had not even met it in my studies.*

**(Participant 1)**

Yet another participant who had erratic menses had this to say:

*Um, one of the things, one of the red flags, which I didn't still understand at that time was my period stopped. And I was only 25. So, at first, they became erratic, and because I was so busy working, I didn't I didn't question it. It didn't ring a bell. Then the other thing, once it became erratic for now longer stretches, months would pass I still didn't go to the doctor, which makes you know I had no awareness. In fact, I was thankful because my periods were so painful, and I would bleed heavily so I am like phew! at least this month. But then now, when I started trying to conceive is when it it...dawned on me that that loss of periods was directly linked to ovulation and now therefore can't conceive. So that at that point is when I saw a specialist five years later at age 30 years.*

**(Participant 4)**

In the participants' experiences, they shared about their wish to delay marriage and child bearing to their 30s in pursuit of education and career goals. Even after getting married in their mid-thirties some of the participants were not ready for a child immediately. Thus, they started trying to have a child when the maternal instincts kicked in after the fifth year of marriage as they approached forty. The participants shared the struggles they had in their attempt to get pregnant even without contraceptive use. They believed that they still had a good window for conception as they expected to experience problems conceiving after 44 years. The participants lacked awareness of the fact that there is remarkable fertility decline after 35 years mistaking fertility decline with onset of menopause at 45 years.

These research findings are similar to those of Hampton et al., (2012) who in their study found that women had limited fertility awareness and still overestimated the slight knowledge they had. The findings also echo the study by (Peterson et al., 2012), who found that 67% of women studied inaccurately believed that female fertility markedly declines after the age of 40, with the other one third of women convinced that the decline takes place after the age of 44 years.

The researcher also found that the awareness the participants received in their infertility journey gave them a drive to encourage the youth to try getting children while still in their 20s so that in case of any problem, it can be sorted out while they are still young in their 30s for greater chances at conception with intervention. The participants noted that if they had had fertility awareness, they would have done things differently in their heydays:

*So, as now after going through my journey and researching so much on it and getting to where I am with my children. Now I'm at a point where I can give back and in my giving back, now I'm able to talk to women and realize that most of the time, it's just that we have no information, and people have no information. (Participant 2)*

Another participant who is passionate about sharing their experience and encouraging early interventions as they give awareness says:

*And I would say a lot because, right now, when I speak to, you know, like people between the age of 25 and 30. And I explain to them why you don't have to wait until you're 35 to start trying for child, you can almost see that that information is getting home. And the reason why I say it influences a lot. (Participant 9)*

The gynaecologist emphasized the need for teaching of sexuality education that would provide more information on fertility awareness and factors that may cause infertility in both males and females. Additionally, the gynaecologist noted that most medical personnel attempt do mentorship programmes with University Students, while they give information but this, she noted may not be adequate.

#### **4.5 Biomedical and Psychosocial Information on Infertility and Decision Making on IVF Treatment**

The researcher was keen on finding out what biomedical and psychosocial information on infertility the participants had and how it influenced their decision to take up IVF treatment. From the findings on biomedical information and decision making on ART, the participants shared their experiences of having suffered medical conditions that hindered natural conception. For four of the participants who suffered primary infertility, the information on their specific conditions leading to infertility was not given in good time

thus delaying their decision to take up ART. Among them, a participant who had lost one fallopian tube to an ectopic pregnancy and had a problem with the remaining one shared her experience:

*Even the dissemination after that, where the report clearly stated, that my fallopian tube does not work, it's dishevelled or distorted, there was no spill. A lot of medical lingo; even for him to break that information truthfully to me, it did not happen. So, he still gave me hope to go and try in a situation where the probability of it working was very low. So even from the experts themselves, the medical information is not given wholesome, and they have their own reason. And for me, I can only think of money. Money is why, is what made this guy not just tell me go for IVF right away. He wanted me to keep going for consultation and pay him more and more times; not forgetting the myriad tests you have to do that also cost money. (Participant 10)*

Majority of the participants noted that most of the gynaecologists they dealt with were not forthright in giving them the biomedical information on infertility or they just lacked experience in dealing with infertility issues, and thus delayed referring them to fertility experts where they would get help in good time. The participants felt that they were tossed from doctor to doctor, taken through tests after tests and several years down the line is when suggestions for them to seek help from a fertility specialist would come up. This delayed their decision making on take up of IVF.

*I think I went to six different doctors. I visited almost everywhere, before now I met the one who established the problem who was the eighth one. Several years down the road of course... (Participant 2)*

Additionally, the participants noted that as the gynaecologists ran the tests and asked them to take fertility enhancing drugs, the results from the drug use were more detrimental than helpful, and they wished they had taken up ART earlier than trying fertility enhancing drugs for long periods of time. Five of the participants noted that fertility enhancing drugs diminished their egg quality and egg reserve, sometimes leaving them without eggs resulting in the use of donor eggs for their IVF cycles. One of them had an experience worth sharing:

*They will just keep on telling you now we need to give you a different fertility drug that you need to take. And unfortunately, what I'm coming to learn now. The more you spend time in those gynaecological clinics, the more you're wasting time. That's what I tell people the more. You see, there is something about the fertility drugs that you take in terms of egg quality because they diminish your egg quality and egg reserve. So, the more you continue to keep taking those things, the more you continue wasting time just makes your chances worse. These gynaecologists should release you and send you to the fertility expert when you still have chances to use your own eggs for IVF.*

**(Participant 5)**

These findings indicate that individuals and couples should be given the right and relevant information in good time so that they are not unintentionally or deliberately misled about potential risks of some treatment and are also not delayed in taking the right informed decision.

The gynaecologist interviewed confirmed the need for patients to be given all the biomedical information relating to their specific situation and be given the necessary support so that they are able to take the right decision at the right time.

*So, you must find a way to break it down in a language the patient understands irrespective of their level of education, or whatever the background, because if they can't understand, then it's very difficult to explain to them why the options are being taken. (Key Informant 1)*

But also acknowledges that it is not always the way:

*So sometimes patients walk in and say, I want ART and I am like why? Oh, I have tried to conceive and saw this doctor and they told me that it was the option and then I am like; did they tell you what about your condition qualifies ART? And sometimes you find that maybe we have failed in that, there's a gap! (Key Informant 1)*

On psychosocial issues, participants noted that there was pressure from their spouses and the spouse's families especially the mother-in-law and the aunts and pressure from friends. This resulted in the female participants being stigmatized. The related stigma, the participants noted was due to cultural expectations and societal pressure for a newly married couple to have a child or children. The pressure and expectations were a great

influence for the participants' decision to seek IVF treatment and get a child. A participant who ended up divorcing due to childlessness shared their experience:

*And my family, my parents, my siblings were very supportive. But my husband's family was not so understanding. They put a lot of pressure on him. Yeah, and even though they knew we were having issues, they would still keep on saying, there is no baby, what's going on? So that put a lot of pressure on him and I think it contributed to the death of our marriage (Participant 3)*

The husband would also be under pressure to find another wife who would bear him children. Participants shared their experiences where family meetings would be called to discuss her unwillingness thereof to give her husband a child. Such meetings were distressing and a strain on the marriage. A participant also revealed how the husband's sisters suggested that she allows the brother to marry another wife who would bring forth children for the family. Participants also shared how they received text messages from other females who would claim to be carrying their husbands' children; these females would say your husband made me abort or would be asking for finances for the upkeep of the unborn child.

The participants also described how they lost friends, some who were unsupportive and others who overstepped their boundaries and would speak against them to their husbands. Some participants, decided to take leave from their work, so as to deal with the issues of infertility. The cultural pressure was confirmed by the gynaecologist and the legal expert who asserted that most of the patients were under a lot of pressure from family members and relatives to have children. A participant who lost friends due to infertility shared her experience:

*I lost friends... along the way, very many. And how I lost friends is that by the time we were getting married, we had a group of couples who were very tight. And then two years later, then they have children and I don't. So, what they would do is when we go out, they would leave me with the boys. The girls would go on the side. And tell me they are talking about babies, openly. Like breastfeeding and all that sharing whatever and*

*all those things..... By the way, our world is very cold and cruel to infertile people.*

**(Participant 2)**

According to the findings, infertility evoked emotional and physical turmoil on the affected. The participants shared how they felt incomplete and unworthy members of the society. They felt like they were to blame for the situations they were in and felt helpless. This triggered the decision to take up IVF in a bid to regain their place in society.

*I think there's a lot of embarrassment and stigma from others and from yourself. Sometimes even you can have supportive people. like my family have been very supportive when I was going for the Laparoscopy. Even when I got the ectopic—they have always even when I had the second miscarriage, at least I have always told my siblings and family. So, your environment can be supportive, but you, you know just from deep down and whatever, that you feel shame. (Participant 5)*

Yet another participant said the following:

*I think we are too; we are harsh on ourselves. Because I am telling you knowing who I am, if this was something, I'm not ashamed or embarrassed about, I would be talking, I would have been talking about it. And I would be shouting and that's what my husband wanted. And I told him, weeeeh, no! you know people will start looking at me like this barren woman, some will feel sorry for me. Some will come and ask me what is it? Let it be me who chooses who to tell!! (Participant 10)*

The participants talked of the depressive moods and anxiety they experienced triggered by their childlessness. In some cases, they had to seek medical treatment to prevent becoming clinically depressed. This situation made them seek other forms of getting children with one participant undergoing IVF with a surrogate and two others opting for adoption. A participant who underwent IVF with a gestational carrier shared her experience and had this to say:

*You have such a strong desire for child but now it is killed. You start getting depressed, you start getting -yeah, very, you get disillusioned. You don't know where to start, you feel like you reached the end of the world. It got bad so bad I was, I saw a psychiatrist for three sessions, but he said he didn't need to medicalize so I was able to get over it. But I think what helped me more is the decision now to do the surrogacy. (Participant*

**3)**

The fertility expert noted that despite having psychologists in the clinics and further subsidising them by including the cost of psychologist in the treatment costs, most of the patients were not keen in engaging the psychologists as they felt like that introduces a third party in their children making affair.

*The biggest issue is that patients refuse to see the psychologist. Because they say, this is a now a third and fourth person knowing my problem. So, it is very difficult I will say. We had even actually introduced that it has to be part of the package and you will not pay. And still someone will not pick that appointment. (Key Informant 2)*

Yet the fertility expert emphasized the very critical role that getting the psychosocial information plays in the fertility treatment journey.

*But I honestly think it's a very important thing because we have, we have we're facing a lot of problems now. And some of them can be sorted out by a psychologist because I cannot, as a doctor it's very difficult to be the psychologist, to be the doctor to be the shoulder to cry on... (Key Informant 2)*

The psychologist interviewed confirmed that many of the patients were psychologically affected by the challenge of fertility. A lot of counselling was required as well as psychoeducation. Additionally, the patients were advised to get self-empowerment, healthy coping strategies and were encouraged to join support groups.

The findings presented above correspond with the findings of Raphael-Leff (2005), Grinion, (2005) and Robaina et al., (2008) who noted the emotional turmoil couples especially the woman underwent in their infertility journey and eventual interventions in the form of assisted reproduction. This is also supported by Daar and Merali (2002) who conceptualized a six-level continuum of consequences of infertility; where they state that across the continuum infertility is seen to transform from an acute private agony affecting the individual at a personal level into a harsh public stigma with complex and devastating consequences ranging from marital stress, depression and social isolation among others.



#### **4.6 Legal and Ethical Information on ART and Decision Making on IVF Treatment**

Regarding the legal and ethical issues around ART, the researcher wanted to find out how legal and ethical information on ART influenced the participants decision to undertake IVF. All the participants noted that when they first thought of undergoing IVF legal and ethical issues were not anything they thought about. The greatest drive for IVF for a majority of the participants was desire for a child and the legal and ethical information did not have room to deter them from their decision. Some participants had this to say:

*I am willing to, um, go through any legal document agreement or whatever and have my babies. With the IVF, I have no, I don't have those hang-ups of thinking about I don't know the ethical or whether etc. or anything. I believe that God gave us brains to think and even gifts like scientists have the gift. Let the babies just come then the rest we can handle. (Participant 5)*

Another participant who underwent IVF with a surrogate mother had an experience that also serves to show how legal and ethical information had no room in influencing their decision:

*Because of someone else carrying your pregnancy like with my surrogacy you see! Those are serious legal issues. But like I told you, that desire for child does not allow you to go through the legal and ethical motions, you cannot process this. That desire is such a strong driver. Any legal documents your way you just sign mechanically. (Participant 3)*

With the participants having indicated the mechanical nature in which they dealt with legal and ethical issues, it was worth noting the sentiments of the gynaecologist and the fertility expert interviewed who noted that ART was shrouded with a myriad of legal and ethical issues which were very critical at the point of engagement with the patients planning to undergo IVF. Among the issues raised by the fertility expert that had serious legal and ethical implications was engagement of third parties in cases where donor gametes or embryos were to be utilized in the IVF process and use of gestational carriers or surrogates. The experts felt that proper screening, exhaustive information provision and

consent were key where donors or gestational carriers were engaged. The fertility expert interviewed expressed the sensitivity of what they do and how it can be abused where ethics are not observed:

*IVF can be I mean, what we do can be misused, it can go south, however, I'm trying not to do anything that is unethical for the integrity of the clinic. I have tried in this clinic like my main goal is that we are ethical. But what I'm finding is that people don't care, you know, people are ready like who would do what I want. So, I will gladly send you but it's... It's very sad. And I think, that there should be laws, we have to have laws in place. For this for our own legal framework as a country! (Key Informant 2)*

The researcher also found that religious beliefs and practices had an influence on how legal and ethical issues in ART were handled. The legal and ethics expert noted that for the Muslims, they do not support the anonymous donor programme that is practiced in some of the fertility clinics. The legal expert explained that for people professing the Islam faith and require donor eggs for IVF the female donor has to be a wife of the male partner; so that where the man has more than one wife a donor could be picked from any of the other wives and for instances where the man has one wife who requires donor eggs he would have to marry a potential donor for ART purposes and once the process is completed he divorces her.

*Muslims, for instance, cannot just be donated, cannot take embryos from Christians or Hindus. It has to be another Muslim. And it cannot be anonymous it can't, if she if the woman gets an egg donor, that's like the man sleeping out of the marriage. So, she the donor has to be married to that man before the egg donation process starts and then divorce the man after. (Key Informant 4)*

The researcher also found that according to the participants and also the legal expert, from a legal and ethical perspective, the right of the child born of ART was important. All the participants who had finally conceived with IVF were fretful about when and how to inform their children that they were a product of IVF and this only occurred to them after the procedure had been successful and they had a child. The legal expert noted that in being truthful with the patients it was important to inform them that the ensuing ethical issues with ART could bring about psychological issues in future.

*So, it has to be all information given. Also, you have to give the risks and the benefits. You just do not tell them, ah, it's good, it's whatever. You also have to tell them that later in life, you may even be psychologically affected because of the egg donor program. Your child may turn out to be a thief. (Key Informant 4)*

A participant who underwent IVF with a surrogate had this to say:

*Because my desire was met, I have forgotten these other issues. But these are ethics, these are my children. Have I told them that I didn't get them myself? I have not. What is the right of a child? They may be young right now? Am I planning to tell them? ethically they should know. But, then again, ethically when? Because at what time you tell them, may affect them again. You see! You see! those are counter-ethical issues*  
**(Participant 3)**

Yet another participant who got twins with IVF shared and said:

*From the mother, the parents in terms of informing. And to the child in terms of how will they take it? You know, that information, you know! Because this is a person. Me, I met my desire. Did I think about ethically about how these children will be affected? How selfish! It's me I want, you know? Yeah. So, it's all loaded very loaded ethically.*  
**(Participant 2)**

The legal expert asserted the right of the child and affirmed that they always advise the patients to look into the future and understand that ART is not just about the women but more about the child:

*And you also know that privacy and all that. Are you willing to tell your child that they were conceived by egg donation? Or surrogacy in that matter. How the information and what time, you know, all that. So, they really have to look in the future because you know women when they come here, unfortunately, they think it's them, all these things, and then you're curing infertility and that's it. No, at the end of the day, it's the child ((Key Informant 4)*

The legal and ethics expert acknowledged that there was no legal framework on ART or a strategy for implementation of procedures such as IVF and surrogacy in Kenya. The expert however asserts that assisted reproduction being in sort of a category of its own there is need for consent on every single decision and everything being done. To manage the process and have all parties covered the expert noted that the law does not operate in

a vacuum and there is always a way out in consultation and collaboration with the patients. She put it this way:

*You get enriched by the patients in the process. I will give you the legal expertise, which is basic; then we will manoeuvre on what you are talking about. We will see which law supports you know, people keep saying [Foreign] hakuna sheria! hakuna sheria! but if you look at the sherias, there is no vacuum. You can use the constitution; you can use the children's rights. (Key Informant 4)*

The expert went ahead to site an example of how the existing law can be applied:

*Like if a woman walks in here and she's 65 years. Surely, she wants a baby. Egg donations, you know all that and if unfortunately, she dies in 10 years, 5 years and maybe the husband most likely is like 70 years. You see the child will be an orphan by the time he is like 5 years. So, what's the best interest of the child? You see there's already the children rights to take care of that. So, there are laws in place. [Foreign] kidogo kidogo it's just not a system like direct but if you look closely, you'll find there's something that we can use. (Key Informant 4)*

The expert also indicated that information consent which was required at the various stages of IVF served to incorporate and assure legal and ethical issues are protected:

*Even the information consent. When someone is giving consent, it has to be full, full consent. You know, it has to be informed. It has to be in a language they understand Because not everyone speaks English. Not everyone understands Kiswahili. You get Swahili is not just Kenyans by the way. You get Tanzanians who are deep in Swahili. Yeah so you don't know the correct Swahili word for a particular thing so you have to consult someone. Can you explain this? because it has to be informed consent. (Key Informant 4)*

Regarding legal and ethics framework for ART, the researcher found that the first attempt in coming up with a legal framework for ART was with the IVF Bill 2014 which could not be passed in Parliament because it had several amendments and there were recommendations that a new bill is drafted. A new bill was drafted and renamed 'Assisted Reproductive Technology Bill 2016'. However, this attempt again did not see the light of day as just when it was to be presented to the 11<sup>th</sup> Parliament the campaign fever in the run up to the 2017 general elections had caught our legislators.

Currently there is the ‘Assisted Reproductive Technology Bill 2019’ which has been sponsored by Member of Parliament for Mbita Hon. Millie Odhiambo and appears on the Special Issue of the Kenya Gazette Supplement dated 15<sup>th</sup> April 2019 and stamped received by the National Assembly Legal Services Directorate on 23<sup>rd</sup> May 2019. The main objective of the bill is to regulate rights and obligations relating to ART. The bill also establishes an Assisted Reproductive Technology Authority to regulate the processes, licensing, standards, research and infrastructure relating to ART. The Bill has been modelled in a manner that addresses a balance between the need for regulation of ethics and advancement of modern science and technology.

#### **4.7 Summary**

This chapter presented the findings from the research conducted on the level of information on infertility and ART and how the information influences decision making of adoption of IVF among families experiencing infertility in Kenya. The demographic characteristics were presented first followed by the research findings that were presented according to the research objectives.

## **CHAPTER FIVE**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 Overview**

This chapter presents a summary of the findings, conclusions and the recommendations of the research conducted on the level of information on infertility and Assisted Reproductive Technologies (ART) and how the information influences decision making on adoption of *in-vitro* fertilisation (IVF) among families experiencing infertility in Kenya. The study was conducted in Nairobi Kenya and targeted individuals who had had at least one IVF cycle or were in the process of undergoing IVF. These individuals were interviewed as the primary respondents for this research. The researcher also interviewed four key informants who interact with individuals suffering infertility as they journey through infertility treatment.

#### **5.2 Summary of Findings**

For this study all the participants were female despite infertility being a problem that affects both males and females in almost equal measure. The male spouses were unwilling to participate in the study, this could be due to the stigma associated with infertility and the sensitivity of infertility information sought by the researcher. All the participants were aged between 42-48 years and had suffered either primary or secondary infertility. The information sought from the participants was corroborated and reinforced by information from four key informants that were interviewed and the summary of findings are presented here.

##### **5.2.1 Infertility Information and ART Information; Packaging and Dissemination of the Information**

The first objective for this study was availability of information on infertility and availability of information on ART and how the information was packaged and disseminated. Regarding information on infertility there is not enough information

available and therefore, when one has infertility, they have to search for the information themselves. The major source from which the patients find that information is in online sources in an unstructured manner resulting in information overload and also a challenge of reliability of the information. Infertility information is also sought on a one on one consultation with medical consultants where the patient has to find their way to the specialist's clinics. Where one on one consultation is done the information is presented in a very technical manner which is difficult for the lay people/ patients to understand.

Assisted Reproductive Technology (ART) information is more available now as compared to 5-10 years ago. However, the information is only available for people living in major cities where fertility clinics and fertility experts are and thus disadvantages individuals who come from far flung areas away from major cities where ART clinics and fertility experts are not available. The ART information is also very technical for the patients to decipher.

On packaging and dissemination of information on infertility and information on ART there is no standardized specific way of packaging the information and the dissemination is therefore provider specific where the provider is the medical practitioner. There is therefore need for improved communication and people skills for the medical professionals as well as involvement of communication personnel to help break down the technical information and package it for consumption by the affected. The fact that ART facilities are only available in three counties Nairobi, Mombasa and Eldoret out of forty-seven counties in the country makes dissemination of the information skewed to only those areas where infertility experts are found.

### **5.2.2 Fertility Awareness and Decision Making on ART**

Fertility awareness is the knowledge and facts about factors that would influence the fertility of an individual. Fertility awareness is very limited among those affected with actions that they had taken or avoided in their youth affecting their future fertility.

Individuals are not aware of the fact that use of certain contraceptives such as the Norplant and Depo-Provera; misuse of the emergency contraceptives commonly referred to as the morning after pill; issues of hormonal imbalance characterized by irregular menstrual cycles; incidences of STDs and STIs are closely linked to infertility.

Ignorance and lack of fertility awareness causes delayed decision to take up assisted reproductive technologies yet ART especially for the female partner works best at an early age when the individuals still has a good ovarian reserve and quality eggs for IVF. Having fertility awareness then becomes critical for success of ART. It is therefore important to have fertility awareness created among the young persons in secondary schools and Universities so that they can be aware of what actions to avoid and what actions to take while still young to avoid compromising their future fertility.

### **5.2.3 Biomedical and Psychosocial Information on Infertility and Decision Making on ART**

Biomedical information on infertility has to do with the individual's specific situation that brings about the involuntary childlessness. Psychosocial information on the other hand relates to an individual's frame of mind coupled with family and societal pressure that comes with childlessness.

The initial point of establishing infertility for individuals is the gynaecologists who provide biomedical information to the infertile people on their specific circumstances. The gynaecologists delay in providing the biomedical information and instead engage the patients in running several tests upon tests. The patients in a bid to get second and third opinions also move from doctor to doctor and this causes further delay in seeking assisted reproduction.

While seeking biomedical information the patients also get prescriptions for fertility enhancing drugs from some of the gynaecologist. The use of fertility enhancing drugs has



been noted to have detrimental effects on the patients' ovarian reserve and egg quality. The passage of time occasioned by movement from doctor to doctor, tests after test and use of fertility enhancing drug with the hope of succeeding in natural conception causes delays in decision to take up assisted reproductive technologies and therefore, minimises the chance of getting assisted with own gametes resulting in use of donor eggs during IVF for the females.

The issue of the technical and complex nature of the biomedical fertility information is also an impediment to effective decision making. There is therefore need for the gynaecologists being the initial contact with the patients to be more candid and forthright with information while at the same time breaking it down to a language that the patients understand so that when they make a decision it is an informed decision. The need for communicators to break down and package the infertility information becomes important as well.

Psychosocial information on infertility is provided by psychological counsellors who are usually based in the fertility clinics. A person in infertility crisis will usually suffer a myriad of psychosocial consequences emanating from the self, the immediate family as well as from the society. Psychosocial issues are a constant reminder of the individual's state of childlessness.

The psychosocial issues manifest as the most critical component in influencing decision to take up ART for those affected by infertility. The personal drive for a child from the patients coupled with pressure from family and the society causes them to take up the decision for ART at the quickest opportunity. However, patients are not keen in engaging psychologists as they feel that they do not want to include too many people in their infertility experience due to the stigma associated with infertility and childlessness.

#### **5.2.4 Legal and Ethical Information on ART and Decision Making on IVF**

Legal and ethical information on ART is provided by legal and ethics experts who operate within the fertility clinics. Legal and ethical information is encountered after the decision to take up ART has already been made as this is usually provided in the fertility clinics. Legal information is provided throughout the treatment process and patients are required to sign consent forms for all the procedures undertaken.

Despite the fact that legal information forms part of every process and procedure in ART it does not stand out as key in one's decision to take up ART since it is encountered at a later stage once the decision has already been taken and the process started. Ethical issues in ART however, become alive for individuals who succeed in ART especially regarding the right of the child. The right of the child to know the truth about how they came to the world and the time at which to give such information are a major ethical issue for the parents who go into ART with the overwhelming psychological pressure just thinking about their infertility situation without considering the outcome which is the child.

There is also no legal and ethical framework for implementation of ART in Kenya and legal experts therefore use existing laws such as the constitution and the Children's Rights which they customize to the individual's situation. Where there are religious and cultural practices that have limitations that are in conflict with the standard ART procedures the legal expert has to ensure that they support the client while at the same time operating within the existing laws. A case in point where ART procedures conflict with religious values is ART with donor eggs for female Muslims, the female donor has to be part of the marriage for the procedure to be acceptable; Muslims cannot use anonymous donor programmes which are a mainstay for many fertility clinics.

## **5.3 Conclusions**

### **5.3.1 Infertility Information and ART Information; Packaging and Dissemination of the Information**

The study indicated that there was no sufficient information on infertility yet an individual requires this information to understand what is causing their infertility. Having to search for infertility information online or do one on one consultation with a medical expert usually comes with a fee and this disadvantages individuals who cannot afford the internet or one on one consultation with specialist doctors. Information on ART has been more readily available in the recent years however it is also only available to individuals who are situated in major town in Kenya again disadvantaging those coming from rural areas and smaller towns that do not have fertility centres and fertility experts in their locality.

Packaging and dissemination of both infertility information and ART information is also a challenge as there is no standard package of the information for dissemination. There is therefore need for a proper packaging of the infertility and ART information to make it available in a way that is standardized for the patients. Involving communicators to help in breaking down the technical information and also for translating of the information into local languages will also go a long way in making the infertility and ART information more available to those affected by infertility.

### **5.3.2 Fertility Awareness and Decision Making on ART**

The level of fertility awareness is extremely low among those affected. Individuals lack knowledge of factors that predispose them to future infertility. Actions taken by the youth in their heydays affect their future fertility causing them to require assistance to conceive. At the same time ignorance and lack of fertility awareness causes them to delay taking some necessary actions in their youth and they also end up with infertility thus requiring assisted reproduction. Fertility awareness should therefore be created in the high schools

and Universities so that the youth are aware of situations that may lead to future infertility and hence take the necessary action in good time.

### **5.3.3 Biomedical and Psychosocial Information on Infertility and Decision Making on ART**

Biomedical information on an individual's infertility is an important aspect in decision making on ART. The biomedical information is the major pointer to the causes of infertility and also the determinant of the courses of action in handling an individual's or couple's infertility. The initial source of biomedical information is usually a gynaecologist who does the diagnoses; it is however clear from this study that gynaecologists are slow in giving the biomedical information to the patients causing the patients to visit several doctors in search of other opinions. The specialists also cause the patients to undergo a myriad of tests while also prescribing fertility enhancing drugs that are in certain instances more detrimental than helpful. These actions cause a delay in the patients seeking assisted reproduction minimizing the chances of the female patients to have IVF using their own gametes and thus resulting in use of donor eggs.

Psychological pressure manifests as a major driver for decision making in ART. Psychological information is therefore a critical component of infertility and ART information. The fertility clinics have incorporated psychological counselling in the ART treatment but the patients are however not keen in engaging psychologists in their journey as they see it as involving another party in their infertility journey which they do not want to.

### **5.3.4 Legal and Ethics Information on ART and Decision Making on IVF**

Fertility treatment in the form of ART is a medical intervention that is in sort of a category of its own as it comes with requirements for consent at almost every process and procedure of treatment. Due to lack of a legal framework for ART the legal experts usually utilize existing law and the individual's religious and cultural dispositions to facilitate the legal

and ethical requirements for each case to case. The legal information is encountered once the decision to take up ART has been made and it therefore does not affect the initial decision to take up ART; however, where IVF is successful the ethical issues start to take effect as the parents of children born out of IVF have to balance between the child's right to know and the right time to give information to the child with regard to how they were born. The fact that the parents have to adopt their own child born through a surrogacy arrangement becomes thorny since the law in Kenya recognises the woman who gives birth as the mother of the child. It is therefore very critical that there gets to be a law that regulates ART in Kenya.

#### **5.4 Recommendations**

The research has clearly shown that the different levels of information on infertility and on ART are all important in decision making on assisted reproductive technologies. The need for a standardised packaging for dissemination of Infertility and ART information and simplifying of the technical language cannot be overemphasized. Consequences of infertility as a major driver for decision making stands out and finally the need for a legal framework to guide the implementation of Assisted Reproductive Technologies is needed as a matter of urgency to guide the implementation of the practice which has been with us in this country for over 15 years and over 40 years globally.

With that very strong assertion of the need for infertility information and ART information; the researcher would like to make the following recommendations:

The research recommends that the Ministry of Health gives infertility the priority it deserves so that information on infertility, fertility awareness and ART information is made readily available for those affected. This will help ease the burden on those affected and also ensure that issue of stigmatization of infertility and frowning of ART will reduce.

Fertility awareness creation among the youth is also recommended. The Ministry of Education in collaboration with the Ministry of Health should consider coming up with study material on fertility awareness that could be incorporated in curriculum both at secondary schools and Universities. This would help ensure that the youth do not commit or omit acts that may jeopardize their future fertility and that they are well armed in picking tell-tale signs of infertility in good time.

The study also recommends the engagement of communication experts by the Ministry of Health and the County Governments medical practitioners to assist the medical practitioners in breaking down the technical infertility and ART information for ease of use by lay people suffering infertility. This could be very beneficial in ensuring that the information reaches a larger number of those suffering and that it is also well understood

It is also recommended that the Ministry of Health facilitates development of information, education and communication materials on infertility, fertility awareness and ART to ensure proper standardization and packaging of infertility and ART information for dissemination. Standardization of information could be beneficial for all users of infertility and ART information and especially for guiding patients on best courses of action for their specific circumstances.

Another recommendation for the study is that the National Hospital Insurance Fund opens up the ART insurance cover to all members registered under the insurer; this could help ease the financial burden associated with IVF. Currently the NHIF only covers civil servants and parastatals that have taken a comprehensive medical cover with them.

The researcher also recommends that all possible efforts be put to facilitate passing of the Assisted Reproductive (ART) Bill 2019 to law in parliament this will go a long way in creating a legal framework that would regulate the practice of ART in the Country. The ART bill proposes the formation of an ART Authority which will regulate rights and obligations relating to ART.

## **5.5 Recommendations for Further Research**

Infertility being a disease that affects almost 15% of the population, it a subject in which lots of areas of research can be explored. The researcher would therefore like to recommend the following areas of further research.

The researcher recommends that this research is replicated in other parts of the country especially in the rural areas to see how different demographics perceive information on infertility and ART.

The researcher also recommends that a research on fertility awareness among secondary school and university students to check awareness levels and establish gaps that can be addressed regarding information on infertility with the youth.

Further research on psychosocial consequences of infertility especially on women and how they can be encouraged to take up information on psychosocial issues is also recommended

Research on how legal and ethical information can be incorporated in the earlier stages of IVF is also recommended so that the patients have all the required information ahead of taking the decision on ART.

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## APPENDICES

### Appendix 1: Participants Interview Guide

*“Thank you for accepting to participate in my study and availing yourselves today. You are free to answer only the questions that you are comfortable with and you can choose to withdraw from the interview at any point you wish. I also request your permission to audio record the interview and you will receive a copy of your written transcript for review. I have procedures in place to keep this information confidential and it will be used only for this research project”.*

#### A. Introduction and Demographic Information

1. How old are you?
2. How long have you been married?

#### B. Study Specific Questions

##### **Research Question #1. What information on infertility and on ART exists in Kenya, and how is it packaged and disseminated?**

3. Would you say there is information on infertility and available interventions provided in Kenya?
  - i. In what way is that information provided?
  - ii. Describe the packaging
4. How is the information on infertility and ART made accessible to Kenyans?
  - i. Describe how the information on infertility and ART availed influenced your decision to take up IVF

##### **Research Question #2. What is the relationship between fertility awareness and decision making on ART in Kenya?**

5. What is your understanding of the term fertility awareness?
  - i. Would you describe yourself as having fertility awareness?
6. Are you aware that there are some predisposing factors that could cause future infertility?
  - i. Describe some of those predisposing factors that cause infertility

- ii. Had information on the predisposing factors been availed to you in your youth, are there things you would have done differently?
  - iii. Tell me about it
- 7. At what age did you plan to have your first and last child?
  - i. Are you aware of the age at which female fertility declines?
  - ii. What causes fertility decline in women?
- 8. What is the average IVF success rate for most infertility clinics?
  - i. How did the IVF success rate influence your decision to go for it?

**Research Question #3. How does biomedical and psychosocial information on infertility affect the decision to undergo IVF in Kenya?**

- 9. How did you learn about the infertility in your union?
  - i. How did it make you feel?
  - ii. Is it a female or a male factor infertility/ or a combination of both?
- 10. How did the information on your Infertility trigger your action to take-up IVF?
- 11. Are you aware of the psychosocial consequences of infertility?
  - i. Have you suffered any of those consequences?
  - ii. Please take me through that path

**Research Question #4. How does legal and ethical information on ART influence the decision to take up IVF treatment in Kenya?**

- 12. Are you aware of the legal issues associated with IVF?
  - i. How did the legal issues affect your decision making on IVF treatment?
- 13. Tell me about the ethical issues that surround IVF
  - i. In which way did the ethical issues influence your decision to take-up IVF
- 14. Did the professionals you interacted with and the information they provided influence your decision in any way?
  - i. Give me details

15. Are you familiar with any other ways of handling infertility other than ART?

i. Did you ever consider any of them? Which one and why?

**C. Closing and Thank you**

16. Is there anything else you would like to share in relation to the issue of infertility and ART that we have not has a chance to tackle?

*“Thank you for your time today. As mentioned earlier, I have procedures in place to keep this information confidential and it will be used only for this research project”.*



## **Appendix 2: Key Informants Interview Guide - Gynaecologists**

*“Thank you for accepting to participate in my study and finding time today. You are free to answer only the questions that you are comfortable with and you can choose to withdraw from the interview at any point you wish. I also request your permission to audio record the interview and you will receive a copy of your written transcript for review. I have procedures in place to keep this information confidential and it will be used only for this research project”.*

### **A. Introduction and Demographic Information**

1. How would you describe your work as a gynaecologist?
  - i. What has the journey of handling reproductive health been like?
2. How long have you consulted as a gynaecologist?

### **B. Study Specific Questions**

#### **Research Question #1. What information on infertility and on ART exists in Kenya, and how is it packaged and disseminated?**

3. What would you say about availability of information on infertility and ART interventions provided in Kenya?
  - i. In what way is that information provided?
  - ii. Tell me about how it is packaged and disseminated to Kenyans
4. From a professional perspective does the information on infertility and ART as availed influence how the affected make their decision to take up IVF?
5. How do you make your referral for infertile clients to an infertility clinic?
  - i. Do you have specific clinics that you refer to?
  - ii. What is your consideration for the choice of the infertility clinic to refer to?

#### **Research Question #2. What is the relationship between fertility awareness and decision making on ART in Kenya?**

6. What is your understanding of the term fertility awareness?
  - i. Is fertility awareness created among Kenyans?

7. What are some of the predisposing factors that could cause future infertility to an individual or couples?
  - i. I would like to gather some information on those predisposing factors
  - ii. How are Kenyans made aware of those predisposing factors?
  - iii. At what age is the information provided and is it the ideal time to give the information?
8. What is the ideal age for couples to have their first and last child?
  - i. Female fertility is said to start to decline at a certain age; what age is that? Are women made aware of the imminent fertility decline at the right time? (i.e. at a time when they are still able to make fertility related decisions): if yes, how is it done? If no, what do you think can be done?
  - ii. What causes fertility decline in women?
9. What is the average IVF success rate for most infertility clinics?
  - i. Does the IVF success rate influence how gynaecologists support the infertile couple when deliberating their decision on ART?

**Research Question #3. How does biomedical and psychosocial information on infertility affect the decision to undergo IVF in Kenya?**

10. How do gynaecologists give biomedical information on infertility to couples especially those affected?
11. Do gynaecologists consider the psychosocial effects that the infertility information has on the couple?
  - i. How do gynaecologists help couples navigate the psychosocial effects of infertility?

**Research Question #4. How does legal and ethical information on ART influence the decision to take up IVF treatment in Kenya?**

12. Are you aware of the legal issues associated with IVF?

- i. Do you direct the infertile couples on how to go about the legal issues that may influence their decision making on IVF treatment?
- 13. Are you aware of the ethical issues that surround IVF?
  - i. In which way do gynaecologists guide the infertile couples on how to handle ethical issues that may influence their decision to take-up IVF?
- 14. Tell me about other ways in which infertility can be handled other than through ART?
  - i. Do you talk to your clients who consider IVF about them?
  - ii. How do they react?

**C. Closing and Thank you**

- 15. Is there anything else you would like to share in relation to the issue of infertility and ART that we have not has a chance to tackle?

*“Thank you for your time today. As mentioned earlier, I have procedures in place to keep this information confidential and it will be used only for this research project”.*

### **Appendix 3: Key Informants Interview Guide - Fertility Experts**

*“Thank you for accepting to participate in my study and finding time today. You are free to answer only the questions that you are comfortable with and you can choose to withdraw from the interview at any point you wish. I also request your permission to audio record the interview and you will receive a copy of your written transcript for review. I have procedures in place to keep this information confidential and it will be used only for this research project”.*

#### **A. Introduction and Demographic Information**

1. How would you describe your work as a fertility expert?
  - i. What has the journey of handling reproductive health and infertility been like?
  - ii. How long have you consulted as a fertility expert?

#### **B. Study Specific Questions**

**Research Question #1. What information on infertility and on ART exists in Kenya, and how is it packaged and disseminated?**

2. What would you say about availability of information on infertility and ART interventions provided in Kenya?
  - i. In what way is that information provided?
  - ii. Tell me about how it is packaged and disseminated to Kenyans
3. From a professional perspective does the information on infertility and ART as availed influence how the affected make their decision to take up IVF?
4. Do you run a fertility clinic?
  - i. About how many clients do you see in a year?
  - ii. What would you say is the percentage IVF success rate for the clinic you run?
  - iii. Do you know of any other infertility clinics in Kenya? How many are they?

**Research Question #2. What is the relationship between fertility awareness and decision making on ART in Kenya?**

5. What is your understanding of the term fertility awareness?
  - i. How is fertility awareness created among Kenyans?
6. What are some of the predisposing factors that could cause future infertility to an individual or couples?
  - i. I would like to gather some information on those predisposing factors
  - ii. How are Kenyans made aware of those predisposing factors?
  - iii. At what age is the information provided and is it the ideal time to give the information?
  - iv. Do you think provision of information on predisposing factors would reduce infertility prevalence?
7. What is the ideal age for couples to have their first and last child?
  - i. Female fertility is said to start to decline at a certain age; what age is that? Are women made aware of the imminent fertility decline at the right time? (i.e. at a time when they are still able to make fertility related decisions): if yes, how is it done? If no, what do you think can be done?
  - ii. What causes fertility decline in women?
  - iii. How does female fertility decline affect IVF success rates?
8. What is the average IVF success rate for infertility clinics in Kenya?
  - i. Does the IVF success rate influence how fertility experts deal with clients undergoing ART?

**Research Question #3. How does biomedical and psychosocial information on infertility affect the decision to undergo IVF in Kenya?**

9. How do fertility experts give biomedical information on ART to couples undergoing IVF?

10. Do fertility experts consider the psychosocial effects that the infertility information has on the couple undergoing IVF?
  - i. How do fertility experts help couples navigate the psychosocial effects of infertility?
  - ii. Does your fertility clinic have a psychological counsellor affiliated to it?
  - iii. How do you engage the psychological counsellors?
  - iv. What is the level of interaction between the psychological counsellors and the couples seeking IVF?

**Research Question #4. How does legal and ethical information on ART influence the decision to take up IVF treatment in Kenya?**

11. What are the legal issues associated with IVF?
  - i. How do you direct the infertile couples on handling the legal issues that are associated with IVF treatment?
  - ii. Does your fertility clinic have a legal professional affiliated to it?
  - iii. How do you engage the legal expert?
12. What are the ethical issues associated with IVF?
  - i. In which way do fertility experts guide the infertile couples on how to handle ethical issues that may come up during IVF?
13. Tell me about other ways in which infertility can be handled other than ART?
  - i. Do you talk to couples seeking fertility treatment about them?
  - ii. How do they react?

**C. Closing and Thank you**

14. Is there anything else you would like to share in relation to the issue of infertility and ART that we have not had a chance to tackle?

*“Thank you for your time today. As mentioned earlier, I have procedures in place to keep this information confidential and it will be used only for this research project”.*

## **Appendix 4: Key Informants Interview Guide - Psychological Counsellors**

*“Thank you for accepting to participate in my study and finding time today. You are free to answer only the questions that you are comfortable with and you can choose to withdraw from the interview at any point you wish. I also request your permission to audio record the interview and you will receive a copy of your written transcript for review. I have procedures in place to keep this information confidential and it will be used only for this research project”.*

### **A. Introduction and Demographic Information**

1. How would you describe yourselves as a psychological Counsellor?
  - i. What has the journey of handling people in distress been?
  - ii. How do you deal with the self when the load from others becomes a little heavy?
2. How long have you consulted as a psychological Counsellor?

### **B. Study Specific Questions**

#### **Research Question #1. What information on infertility and on ART exists in Kenya, and how is it packaged and disseminated?**

3. Having dealt with infertile couples, what would you say about availability of information on infertility and ART interventions provided in Kenya?
  - i. In what way is that information provided?
  - ii. Tell me about how it is packaged and disseminated to Kenyans
4. From a professional perspective does the information on infertility and ART as availed influence how the affected make their decision to take up IVF?
5. Do you work closely with a fertility clinic?
  - i. About how many clients do you see in a year from the clinic?
  - ii. What would you say is the percentage IVF success rate for the clinic you work for based on the clients you see?
  - iii. Do you know of any other infertility clinics in Kenya? How many are they?

**Research Question #2. What is the relationship between fertility awareness and decision making on ART in Kenya?**

6. What is your understanding of the term fertility awareness?
  - i. How is fertility awareness created among Kenyans?
7. What are some of the predisposing factors that could cause future infertility to an individual or couples?
  - i. I would like to gather some information on those predisposing factors
  - ii. How are Kenyans made aware of those predisposing factors?
  - iii. At what age is the information provided and is it the ideal time to give the information?
  - iv. Do you think provision of information on predisposing factors would reduce infertility prevalence and thus the cases you would have to see with infertility related psychosocial needs?
8. What is the ideal age for couples to have their first and last child?
  - i. Female fertility is said to start to decline at a certain age; what age is that? Are women made aware of the imminent fertility decline at the right time? (i.e. at a time when they are still able to make fertility related decisions): if yes, how is it done? If no, what do you think can be done?
  - ii. What causes fertility decline in women?
  - iii. How does female fertility decline affect IVF success rates?
9. What is the average IVF success rate for infertility clinics in Kenya?
  - i. Does the IVF success rate influence how fertility experts deal with clients undergoing ART?

**Research Question #3. How does biomedical and psychosocial information on infertility affect the decision to undergo IVF in Kenya?**

10. How do fertility experts and gynaecologists give biomedical information on ART to couples with infertility?



11. Do fertility experts and gynaecologists consider the psychosocial effects that the infertility information has on the couple undergoing IVF?
  - i. How do you deal with couple's psychosocial issues related to infertility?
  - ii. Are you affiliated to any fertility clinic?
  - iii. What value in your opinion do fertility clinics attach to psychological counselling?
12. In which way do you recruit/get clients suffering infertility related psychosocial issues?
13. What is the level of engagement with the clients suffering infertility?
  - i. At what point in their infertility journey do you get to see them?
  - ii. How many times do you see them?
  - iii. What is the level of information they have on the psychosocial consequences of infertility?
  - iv. Are they aware of coping strategies they could adopt?

**Research Question #4. How does legal and ethical information on ART influence the decision to take up IVF treatment in Kenya?**

14. What are the legal issues associated with IVF?
  - i. How do the legal issues associated with infertility affect the psychological well-being of those affected?
  - ii. In which way do you counsel couples on dealing with legal issues?
15. What are the ethical issues associated with IVF?
  - i. How do the ethical issues associated with infertility affect the psychological well-being of those affected?
  - ii. In which way do you counsel couples on dealing with ethical issues?
16. Tell me about other ways in which infertility can be handled other than ART?
  - i. Do you talk to couples seeking fertility treatment about them?
  - ii. How do they react?

### **C. Closing and Thank you**

17. Is there anything else you would like to share in relation to the issue of infertility and ART that we have not has a chance to tackle?

*“Thank you for your time today. As mentioned earlier, I have procedures in place to keep this information confidential and it will be used only for this research project”.*

## **Appendix 5: Key Informants Interview Guide - Legal Experts**

*“Thank you for accepting to participate in my study and finding time today. You are free to answer only the questions that you are comfortable with and you can choose to withdraw from the interview at any point you wish. I also request your permission to audio record the interview and you will receive a copy of your written transcript for review. I have procedures in place to keep this information confidential and it will be used only for this research project”.*

### **A. Introduction and Demographic Information**

1. How would you describe your work in legal practice?
  - i. What has the journey of handling legal issues around infertility been like?
2. How long have you consulted as a legal expert?

### **B. Study Specific Questions**

#### **Research Question #1. What information on infertility and on ART exists in Kenya, and how is it packaged and disseminated?**

3. Having dealt with infertile couples, what would you say about availability of information on infertility and ART interventions provided in Kenya?
  - i. In what way is the information provided?
  - ii. Tell me about how it is packaged and disseminated to Kenyans
4. From a professional perspective does the information on infertility and ART as availed influence how the affected make their decision to take up IVF?
5. Do you work closely with a fertility clinic?
  - i. About how many clients do you see in a year from the clinic?
  - ii. What would you say is the percentage IVF success rate for the clinic you work with based on the clients you see?
  - iii. Do you know of any other infertility clinics in Kenya? How many are they?

#### **Research Question #2. What is the relationship between fertility awareness and decision making on ART in Kenya?**

6. What is your understanding of the term fertility awareness?
  - i. How is fertility awareness created among Kenyans?
7. What are some of the predisposing factors that could cause future infertility to an individual or couple?
  - i. Tell me about those predisposing factors
  - ii. How are Kenyans made aware of those predisposing factors?
  - iii. At what age is the information provided and is it the ideal time to give the information?
  - iv. Do you think provision of information on predisposing factors would have an effect on infertility prevalence?
8. What is the ideal age for couples to have their first and last child?
  - i. Female fertility is said to start to decline at a certain age; what age is that? Are women made aware of the imminent fertility decline at the right time? (i.e. at a time when they are still able to make fertility related decisions): if yes, how is it done? If no, what do you think can be done?
  - ii. What causes fertility decline in women?
  - iii. How does female fertility decline affect IVF success rates?
9. What is the average IVF success rate for infertility clinics in Kenya?
  - i. Does IVF success rate influence how legal experts deal with clients undergoing ART?

**Research Question #3. How does biomedical and psychosocial information on infertility affect the decision to undergo IVF in Kenya?**

10. How do fertility experts and gynaecologists give biomedical information on ART to couples undergoing IVF?
11. How do fertility experts and gynaecologists give psychosocial information on ART to couples undergoing IVF?

**Research Question #4. How does legal and ethical information on ART influence the decision to take up IVF treatment in Kenya?**

12. What are the legal issues associated with IVF?
  - i. What value in your opinion do fertility clinics attach to the legal profession?
  - ii. Are you affiliated to any fertility clinic?
13. What is your level of engagement with the clients suffering infertility?
  - i. In which way do you recruit/get clients requiring legal assistance on infertility related issues?
  - ii. At what point in their fertility journey do you engage?
  - iii. What information on legal issues related to infertility do the clients have upon engagement?
  - iv. How do you engage them to unpack all legal aspects on infertility?
  - v. Does your engagement influence their final decision to undertake IVF?
14. What are the ethical issues associated with IVF?
  - i. How are legal issues related to ethical issues in infertility?
  - ii. In which way are the infertile couples guided on how to handle ethical issues that may come up during IVF?
15. Tell me about other ways in which infertility can be handled other than ART?
  - i. Do you talk to couples seeking fertility treatment about them?
  - ii. How do they react?

**C. Closing and Thank you**

16. Is there anything else you would like to share in relation to the issue of infertility and ART that we have not had a chance to tackle?

*“Thank you for your time today. As mentioned earlier, I have procedures in place to keep this information confidential and it will be used only for this research project.”*

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## Appendix 7: Certificate of Fieldwork



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**COLLEGE OF HUMANITIES & SOCIAL SCIENCES**  
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Nairobi, GPO  
Kenya

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Reg. No: K50/7904/2017

Name: GACII SARAH MUTHONI

Title: INFORMATION AND DECISION MAKING ON ASSISTED REPRODUCTIVE

TECHNOLOGIES AMONG FAMILIES EXPERIENCING INFERTILITY IN KENYA

DR. SAMUEL NGIGI  
SUPERVISOR

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26/7/2019  
DATE

Dr Samuel Singi  
ASSOCIATE DIRECTOR  
Prof Ndeth Ndet  
DIRECTOR

Singi  
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7.2019  
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**Appendix 8: Certificate of Correction**



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Reg. No: KSO/7904/2017

Name: SARAH NUTHONI GACII

Title: INFORMATION AND DECISION MAKING ON ASSISTED REPRODUCTION TECHNOLOGIES AMONG FAMILIES EXPERIENCING INFERTILITY IN KENYA

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