

**STRESS AND AFFORDABILITY OF ASSISTED REPRODUCTIVE  
TREATMENT: A COMPARATIVE STUDY BETWEEN THE UNITED  
KINGDOM AND NIGERIA**



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## **ABBREVIATIONS**

ACU- Assisted Conception Unit

ART- Assisted Reproductive Treatment

BAI- Beck Anxiety Inventory

CADAS- Computer Aided Data Analysis Software

CCEMPI- Campbell and Cochrane Economics Methods Group

CCG- Clinical Commissioning Group

DHS- Demographic Health Survey

ESHRE- European Society for Human Reproduction and Embryology

GDP- Gross Domestic Product

HAI- Health Action International

HFEA- Human Fertility and Embryology Authority  
HIC- High Income Countries  
HIV- Human Immuno-Deficiency Virus  
HRP- Household Reference Person  
HRQOL- Health Related Quality of Life  
ICSI- Intra Cytoplasmic Sperm Injection  
IFFS- International Federation of Fertility Society  
IUI- Intra Uterine Injection  
IVF- *In Vitro* Fertilisation  
LIC- Low Income Countries  
LMIC- Low-Middle Income Countries  
MVS- Maximum Variation Sampling  
NHS- National Health Service  
NHIS- National Health Insurance Scheme  
NICE- National Institute for health and Clinical Excellence  
OPP- Out of Pocket Payment  
PPP- Purchasing Power Parity  
PSS- Perceived Stress Scale  
QOL- Quality of life  
SFW- Subjective Financial Well-being  
SPSS - Statistical Package for Social Sciences  
SSQ- Social Support Questionnaire  
STI- Sexually Transmitted Infection  
UBTH- University of Benin Teaching Hospital  
UN- United Nations  
UK- United Kingdom  
US- United States  
WDI- World Development Indicators  
WHO- World Health Organisation  
WHOQOL- World Health Organisation Quality of Life



## **ABSTRACT**

**INTRODUCTION:** This study examined the cost-burden of assisted reproductive treatment (ART), stress patterns, social support and perceived quality of life of sub-fertile women in the UK and Nigeria.

**METHODS:** After obtaining their consents, 116 sub-fertile women from the UK and Nigeria participated in the study. This was a cross-sectional concurrent mixed method research design. Quantitative data was obtained using the socio-economic questionnaire, Beck Anxiety Inventory, Perceived stress scale, social support and the WHOQOL scale while qualitative data was obtained using semi-structured interviews on 15 and 17 of these women in the UK and Nigeria respectively. Descriptive statistics, affordability analysis, correlations and regression analyses were performed on the quantitative data, while a thematic approach was used in the qualitative findings.

### **RESULTS:**

Most of the Nigerian cohort incurred catastrophic expenditures, but not the UK cohort. Interview findings showed that women obtained funds from savings, contributions and loans. Results showed that a cycle of IVF would cost the lowest paid government worker 2 months and 4 days wages in the UK and 3 years 3 months wages in Nigeria. Significant differences were observed in stress levels between both cohorts; with Nigerian cohort experiencing higher levels than the UK. Duration of subfertility and aetiology of subfertility were shown to be significant predictors of stress in Nigerian women. The findings from the UK cohort supported the hypothesis of a moderating role of quality social support in the relationship between stress and quality of life. However, within the Nigerian cohort social support did not buffer stress as most women preferred to keep their infertility diagnosis private.

**CONCLUSION:** The results show that most Nigerian women are willing to acquire financial burdens to pay for ART due to the stigma associated with infertility. Additionally, the psychological management of sub-fertile women should be individualised and cost reducing strategies in this setting needs to be implemented to eliminate the burden of out of pocket payment for ART.

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# **CHAPTER 1: INTRODUCTION**



## CHAPTER 1: BACKGROUND OF THE STUDY

This chapter presents the background and discusses the rationale of the study. The research objectives and the study settings are also presented. The final section presents the thesis structure.

### 1.1. UNDERSTANDING INFERTILITY

A number of terms have been used in the literature to describe infertility. The various descriptions are summarised in Table 1.1.

Table 1.1: Definitions of infertility

Year	Organisation	Definition
2004	National Institute for Health & Clinical Excellence guidelines (NICE)	Infertility should be defined as failure to conceive after regular unprotected sexual intercourse for 2 years in the absence of known reproductive pathology
2008	American Society for Reproductive Medicine (ASRM)	Infertility is a disease defined by failure to achieve a successful pregnancy after 12 months or more of regular unprotected intercourse.
2009	European Society for Human Reproduction and Embryology	Earlier evaluation and treatment may be justified based on medical history and physical findings and is warranted after 6 months for women over age 35year. Infertility is a disease of the reproductive system defined by the failure to conceive after 12 months or more of regular unprotected sexual intercourse
2013	National Institute for Health & Clinical Excellence (NICE) clinical guideline	A woman of reproductive age who has not conceived after 1 year of unprotected vaginal sexual intercourse, in the absence of any known cause of infertility, should be offered further clinical assessment and investigation along with her partner.

Adapted from: Gurunath S, Pandian Z, Anderson RA, Bhattacharya S (2011). Defining infertility: a systematic review of prevalence studies. *Human Reproduction Update*. Sep-Oct;17(5):575-88.

At the moment, the clinical definition of infertility commonly accepted is the one by the World Health Organisation (WHO), which defines infertility as “*a disease characterised by the inability to achieve a pregnancy after 12 months of regular unprotected sexual intercourse*” (p.1062) (Zegers-Hochschild et al., 2009). While most clinicians and epidemiologists use this definition, demographers define infertility as the “inability of a non-contracepting woman to achieve a live birth after 5 years of attempting” (Larsen, 2005). This definition by demographers makes formulating programmatic action almost

inadequate as it is based on a five-year period of exposure. Contrarily the epidemiological and clinical definitions are more useful as it is based on a shorter period of exposure (Okonofua et al., 1997).

Contradicting both epidemiologic and demographic time-frame definitions is that of medical anthropologists. They argue that “infertility is a process that begins when a couple starts to determine its inability to have children as a problem” (Martins, 2012). From their view, it is the absence of the intended conception, rather than the presence of pathological symptoms that underlies the concept of infertility (Greil et al., 2010, Martins, 2012).

In summary, various definitions are used in infertility measurements, as described above. They all incorporate some time dependent measurement of exposure (Mascarenhas et al., 2012a). However, in view of the epidemiological and clinical nature of the studies presented in this thesis, as well as the design of this study, the WHO definition would be used.

### **1.2.1. Types**

Infertility is of two types, primary and secondary. Primary infertility refers to couples (man or woman) who have not been able to conceive after one year of unprotected sexual intercourse, without birth control methods (WHO, 1987), while secondary infertility refers to couples (man or woman) who have been able to conceive at least once but are now unable to (WHO, 1987).

### **1.2.2. Causes**

Psychologist and gynaecologists in the mid-20<sup>th</sup> century believed that women with specific personality characteristics such as anxiety, depression and neuroticism, were affected by infertility (Wischmann, 2003, Carson and McKenzie, 2010). At this time, unexplained/idiopathic infertility (which constituted >40% of cases) were assumed to be caused by emotional factors (Wischmann, 2003). More recently, with the advances in technologies such as laparoscopy, clomiphene citrate for inducing ovulation, *In vitro* fertilisation (IVF, Steptoe and Edwards, 1978) as well as Intracytoplasmic sperm injection (ICSI, Palermo, Joris, Devroey and Van Steirteghem, 1992), we now know that only 5-10% of infertility cases are unexplained (Adamson and Baker, 2003). Additionally, it is also known that female causes of infertility accounts for less than half the cases in

couples, with male factor contributing to approximately 30-40% of the diagnosis (Adamson and Baker, 2003).

The aetiology of couple infertility can be divided into four main groups: male factors, female factors, a combination of both partners problems and idiopathic (unexplained) factors (De Berardis et al., 2014). It is important to note here that the causes of infertility vary across communities and countries.

In 2013, the NICE guidelines stipulate that the main causes of infertility in the UK are ovulatory disorders (25%), tubal damage (20%), male factor (30%), unexplained (25%) and uterine or peritoneal disorders (10%) (NICE, 2013). A demographic study by Ekwere et al (2007) reported the causes of infertility in Nigeria over a five-year period (2001-2005). Female causes were reported as: Tubal damage/ chronic pelvic inflammatory disease (45.1%), unexplained infertility (25.1%), ovulation failure (14.5%), uterine fibroids (7.4%), ovarian cysts (3.7%), endometriosis (5.3%). While male causes were reported as: Genital infections (34.7%), Testicular failure (32.4%), varicoceles (20.4%), coital failure (6.7%), congenital causes (3.6%), Testicular torsion (1.8%), Heat atrophy (0.4%) (Abarikwu, 2013, Ekwere et al., 2007).

In summary, as described, the causes of infertility are multifaceted, and therefore, treatment for infertility is not a one size fits all.

## **1.2. INFERTILITY INCIDENCE AND EPIDEMIOLOGY**

### **1.2.1. Global fertility patterns**

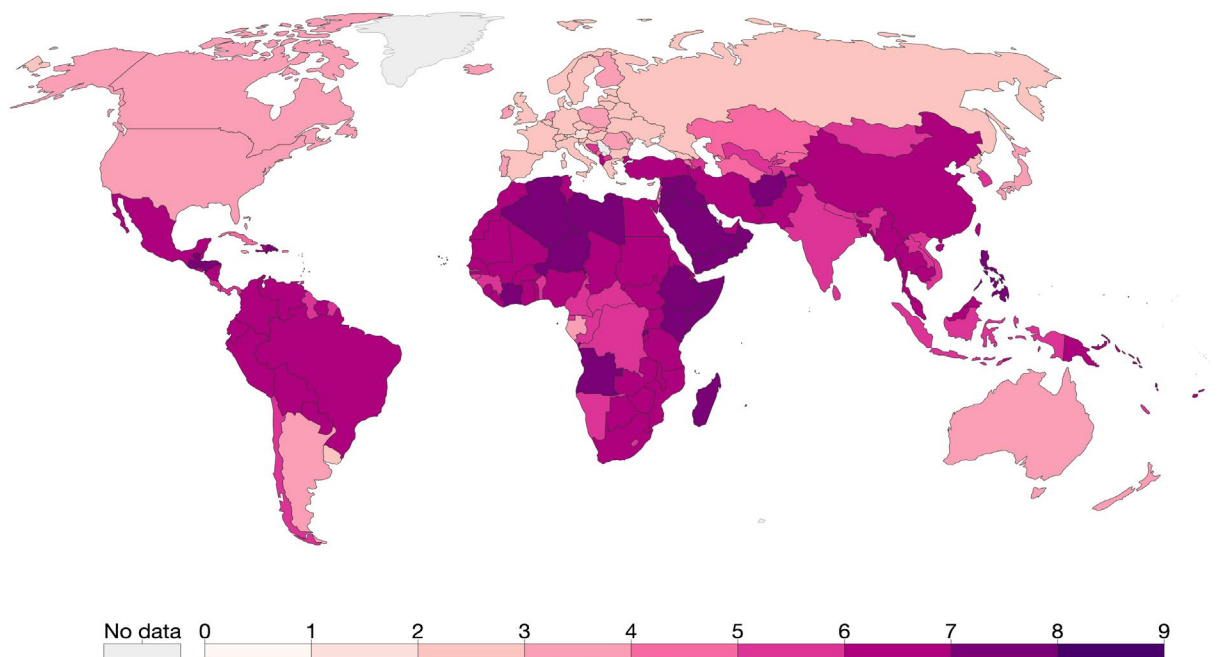
Several decades ago, up to the second half of the 20<sup>th</sup> century, global fertility rates<sup>1</sup> range between 4 and 7 children per woman were common (Figure 1.1). However, over the last 50 years, fertility rates have declined to below 2.5 children per woman (Affairs, 2015). Meaning that, today, averagely a woman has 2.5 fewer children than a woman living in a country at the same level of development in 1951.

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<sup>1</sup> The most commonly used metric to measure the average number of children per woman in a country is the total fertility rate (TFR).

## Children born per woman, 1951

Shown is the 'Total Fertility Rate' which measures the number of children that would be born to a woman if she were to live to the end of her childbearing years and bear children in accordance with the age-specific fertility rates of the specific year.



Source: Gapminder for estimates until 1949; UN Population Division for 1950 to 2015

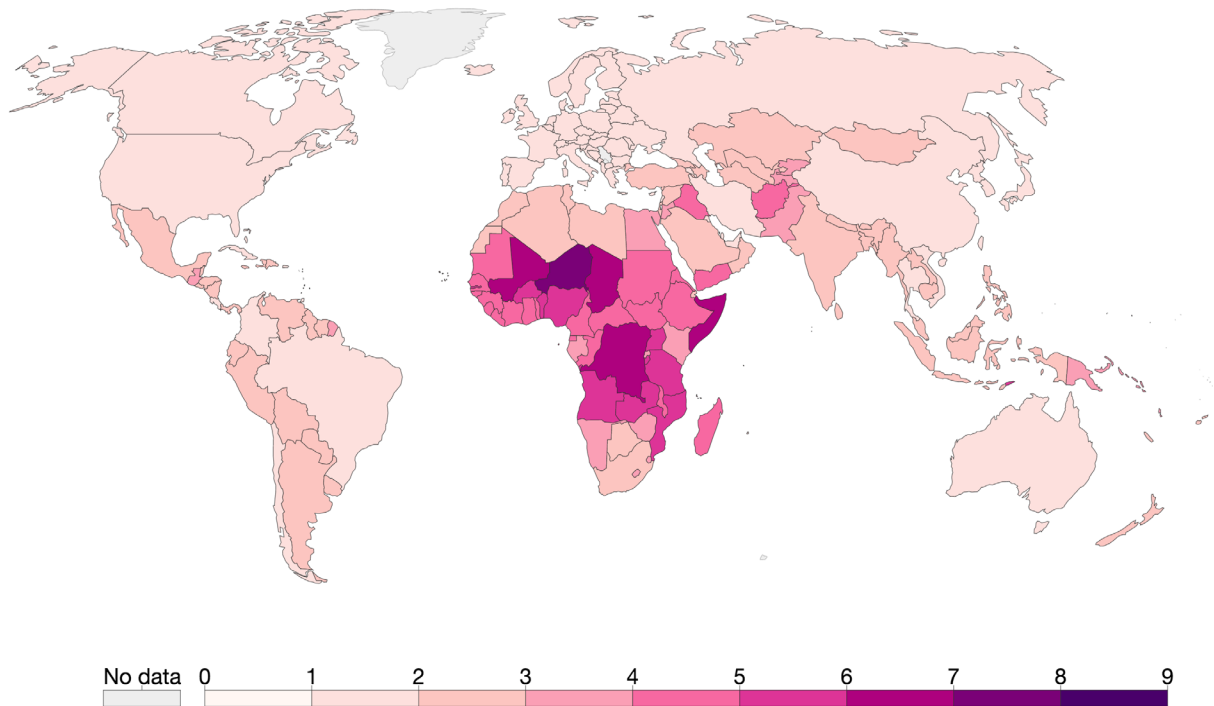
OurWorldInData.org/fertility-rate • CC BY

Figure 1.1: Total worldwide distribution of fertility rates around the world in 1951

Large fertility declines took place in most regions of the world as shown in Figure 1.2. Fertility rates fell from 5.4 to 1.8 between 1950 and 2015 in East Asia and the Pacific, from 6.8 to 2.8 in the Middle East and North Africa and from 6.0 to 2.5 in South Asia (De Silva and Tenreyro, 2017). While North America, Europe and Central Asia did not experience absolute declines in fertility, the percentage declines in these regions were equally significant, with nearly 50% in North America and almost 40% in Europe and Central Asia (De Silva and Tenreyro, 2017). These low fertility rates are quite common among developed nations of the world such as the UK (Figure 1.2). However, in developing countries, such as those in sub-Saharan Africa, although the fertility rates declined, it has been rather slow and women on average still have more than 5 children (Figure 1.2). Within this region, only South Africa and Mauritius have low fertility rates of 2.4 and 1.4 respectively (De Silva and Tenreyro, 2017).

## Children born per woman, 2015

Shown is the 'Total Fertility Rate' which measures the number of children that would be born to a woman if she were to live to the end of her childbearing years and bear children in accordance with the age-specific fertility rates of the specific year.



Source: Gapminder for estimates until 1949; UN Population Division for 1950 to 2015

OurWorldInData.org/fertility-rate • CC BY

Figure 1.2: Total worldwide distribution of fertility rates around the world in 2015

Governments of countries with higher fertility levels are more likely to have policies in place to reduce fertility rates, due to fears of population explosion (Affairs, 2015). These population control measures include “raising the minimum legal age at marriage, providing safe and effective contraception, integrating family planning and safe motherhood programmes into primary health care systems, as well as improving female education and employment opportunities” (De Silva and Tenreyro, 2017, Affairs, 2015).

While nationally, there are policies to restrict fertility, some couples/individuals cannot meet the minimum restrictive level of fertility for those populations, and these policies in some cases infringe on their reproductive rights. These individuals can be termed as ‘infertile’. Sexual and reproductive rights are fundamental human rights and include “*the right of everyone to make free and informed decisions and have full control over their body, sexuality, health, relationships, and if, when and with whom to partner, marry and have children - without any form of discrimination, stigma, coercion or violence*”

(Organization, 2015, Affairs, 2015). This also includes the “*right of everyone to be free from interference in making personal decisions about sexuality and reproductive matters, and to access sexual and reproductive health information, education, services and support*”(Affairs, 2015). These individuals have the right to desire children and should have access to the resources to regulate (increase or decrease) their fertility.

The determination of infertility rates across the world have been rather inconsistent, and proxy indicators are unable to adequately determine the situation at an individual level. This is in part due to the variety of definitions that generate infertility measurements. As shown in Table 1.1, the institutions that set guidelines for infertility definitions have not agreed on a standard definition, and the largest disparity is observed between the demographic and clinical definitions. Where demographic definitions measures infertility on a population level, relying on household surveys to understand the magnitude, distribution and underlying trends of infertility (Mascarenhas et al., 2012a), the clinical definition measures infertility on an individual level, oriented towards early detection with the aim of starting treatment as early as possible (Mascarenhas et al., 2012a). The estimates presented in both demographic and clinical surveys would be presented in this section.

In 2002, the World Health Organisation utilised data from 47 Demographic and Health Surveys (DHS), which focused on measuring primary and secondary infertility in women aged 15-49 years (Rutstein and Shah, 2004). They estimated that infertility affects approximately 186 million women from all parts of the world surveyed (except China)(Organization, 2002). In 2007, a second survey of infertility prevalence and treatment-seeking by Boivin et al (2007), utilising 25 population surveys from both developed and developing countries. The authors suggested that approximately 72.4 million women experienced infertility, with 56% actively seeking medical care (Boivin et al., 2007) and approximately 10-15% of couples would experience some form of fertility problem in their lifetime (Greil et al., 2010). The third survey by Mascarenhas et al, (2012), supported by the WHO and the Bill and Melinda Gates Foundation, as part of the 2010 Global Burden of Disease study, further provided a global examination of infertility trends based on an analysis of health surveys in 190 countries from 1990-2010. The authors reported an infertility prevalence of 15% worldwide by the end of 2012, with this figure expected to rise in a couple of years (Mascarenhas et al., 2012b).

Despite the variations in global infertility prevalence, and the absence of data on the population of infertile men in these surveys, infertility rates do not appear to have significantly increased in the last two decades (Mascarenhas et al., 2012b). This is probably because global fertility rates have significantly dropped, with fewer people willing to have children (Mascarenhas et al., 2012b, Inhorn and Patrizio, 2015).

### **1.2.2. Infertility prevalence and trends in Europe (UK)**

Between 1970 and 2000, the fertility rate in Europe dropped from 2.65 children per woman to 1.42 (United Nations, 2009), reaching historically low levels in 2010-2015 (Organization, 2015). More recently, with the implementation of various family planning and fertility policies, a number of the member nations have seen a slight increase in their fertility rates (Affairs, 2015). However, in many of these countries, fertility remains a significant public health concern, because a fertility rate of approximately 2.1 children per woman is needed to support a replacement of an ageing society and in some cases, population decline (Ledger, 2009, Organization, 2015). By 2013, the number of European countries with below replacement fertility levels had quadrupled (Affairs, 2015), with 66% of the European countries seeking to increase fertility rates.

In most developed countries, there is a trend for women to delay childbearing due to increased use of contraceptive methods, higher education and career prospects among others (Balasch and Gratacós, 2012, Bloom and Trussell, 1984, Matthews and Hamilton, 2009). However, while the prevention of conception is free and readily accessible, reproduction on demand is not, and becomes even more difficult with age (Veloso-Martins et al., 2010). Consequently, a growing number of couples in developed countries are confronted with the possibility of remaining childless, when over 95% of European young adults want to achieve parenthood (Fahey and Spéder, 2004).

Earlier estimates suggest that 10-15% of the UK population experience some form of subfertility (Evers, 2002); however, recent surveys depict the prevalence of primary infertility as 2.1% and 8.6% for secondary infertility as shown in Figure 1.3 (CIA, 2016). The UK office of National Statistics reported that in 2005, approximately 22,246 births were achieved by women over the age of 40 as opposed to the 11,319 recorded in 1995 (Office for National Statistics, 2005).

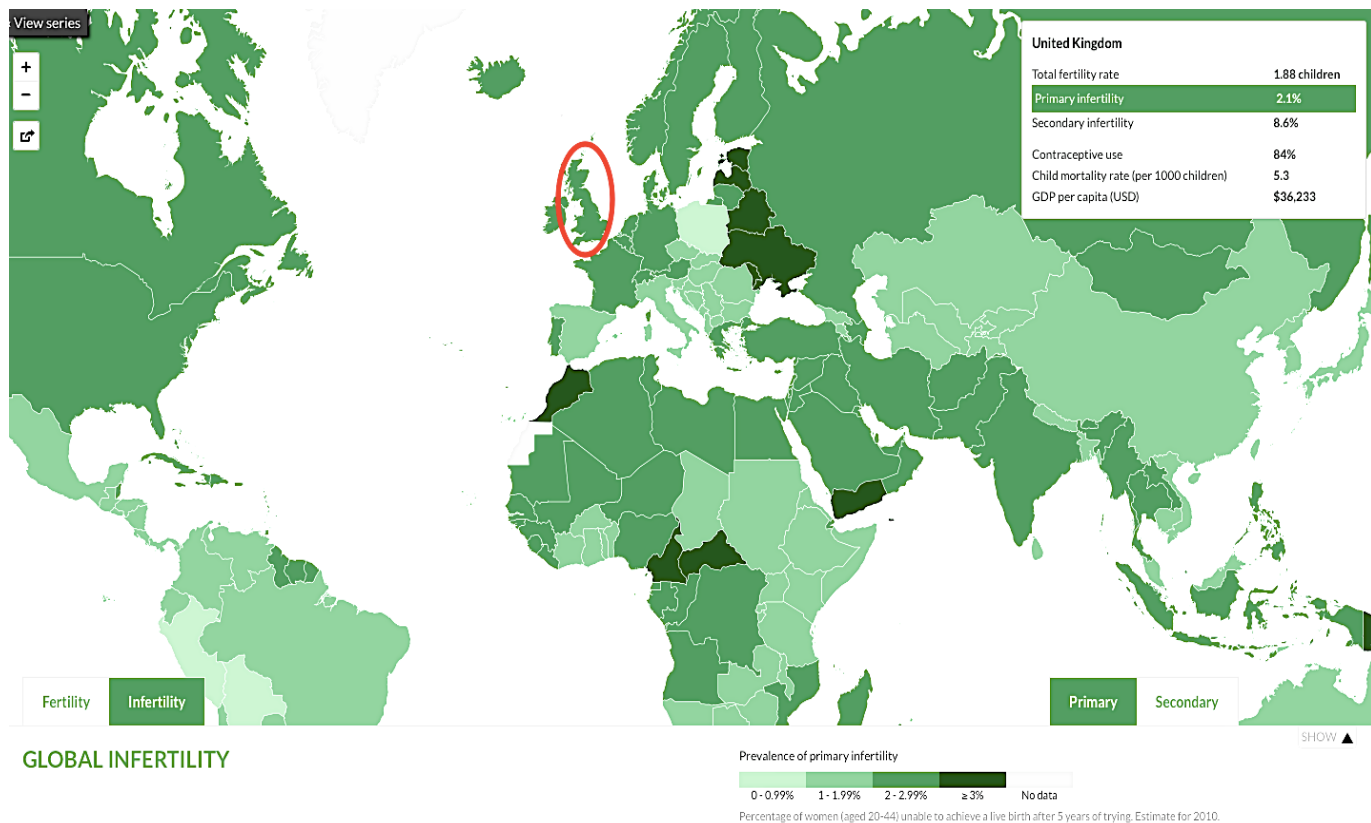


Figure 1.3: The global infertility rate (UK highlight) (<http://globalfertilitymap.com>) accessed on 25<sup>th</sup> February 2019

The increasing age at which women are opting to have children could have an impact on the prevalence of infertility in this country, as maternal ovarian reserve declines with age (Leridon, 2004, Jackson et al., 2015, Yogev et al., 2010).

### 1.2.3. Infertility prevalence and trends: Africa and South-Asia

Contrary to the fertility levels in Europe, total and adolescent fertility levels remain high in sub-Saharan Africa and in the group of the least Developed Countries (LDC)(Affairs, 2015). However, the issue of infertility appears to be more pronounced in the developing than the developed world. Studies from South-Asia and Latin-America report prevalence of 8-12%, which is quite similar to those reported by the European studies (Hiadzi, 2014). Surveys from East Africa report rates of 8-13%, which is lower than those reported in Southern African survey of 15-22% (Inhorn and Patrizio, 2015). Countries in sub-Saharan Africa report the highest prevalence of 15-30% (Okonofua, 2003). Two to three decades ago, there was very little information about the prevalence



of infertility in Sub-Saharan Africa, due to the lack of adequate population-based data (Templeton et al., 1991). The incidence was frequently said to be on the increase, with relatively limited and unsupported evidence (Young, 1979, Johnson et al., 1987). Studies conducted by the World Health Organisation (WHO) in recent years have helped to better understand the prevalence and aetiology of infertility globally (Larsen, 2000). However, literature on the prevalence is still limited in the developing world (Cates et al., 1985, Organization, 1987, Inhorn, 2003, Inhorn and Patrizio, 2015). The early WHO studies on infertility prevalence only covered four Sub-Saharan African countries; therefore, inferences could not accurately be made. For example, in determining the prevalence of infertility in the continent of Africa, only four city centres from four countries were used, namely; Ibadan (Nigeria), Lusaka (Zambia), Nairobi (Kenya) and Yaoundé (Cameroon) (Cates et al., 1985). Further weaknesses of these studies, were that participants with direct access to treatment were not necessarily sought, and the diagnosis for infertility was primarily based on a single partner's (usually the woman) diagnosis (Larsen, 2000).

Research suggests that the higher infertility rates observed in sub-Saharan Africa is largely due to untreated sexually transmitted and reproductive tract infections (Nachtigall, 2006, Bentley et al, 2000, Van Balen et al, 2002). A band of countries which includes Cameroon, Angola, Equatorial Guinea, Gabon, Congo and others in Central and Southern Africa termed "Africa's infertility belt", has been repeatedly established in a number of cross-national survey studies (Ericksen et al, 1996). Approximately, 49% of the men in these countries have (had) a sexually transmitted disease in their medical history. While two-thirds of the women were diagnosed with tubal blockages, sexually transmitted infections (STI) due to unsafe abortions, a rate 2 times higher than that of the rest of the world (Vayena et al, 2002, Nachtigall, 2006). Furthermore, over 30% of the women in some sub-Saharan such countries, experience secondary infertility due to post-partum, post abortive and iatrogenic infections (Nachtigall, 2006).

In Nigeria, the prevalence of infertility has been reported by epidemiologic and demographic surveys, as well as by clinical observations (Okonfuo, 1999), however, the numbers are quite few and contradicting. The prevalence of primary infertility in Nigeria by the demographic health survey (DHS) from 1994-2000 is reported to be 22.7% in 15-49year old women and 7.1% in 25-49year olds (Okonofua, 2003). However, more recent

survey depicts the prevalence of primary infertility in the country to be 2.2%, while secondary infertility was reported to be 13.8% as shown in Figure 1.4 (CIA, 2016).

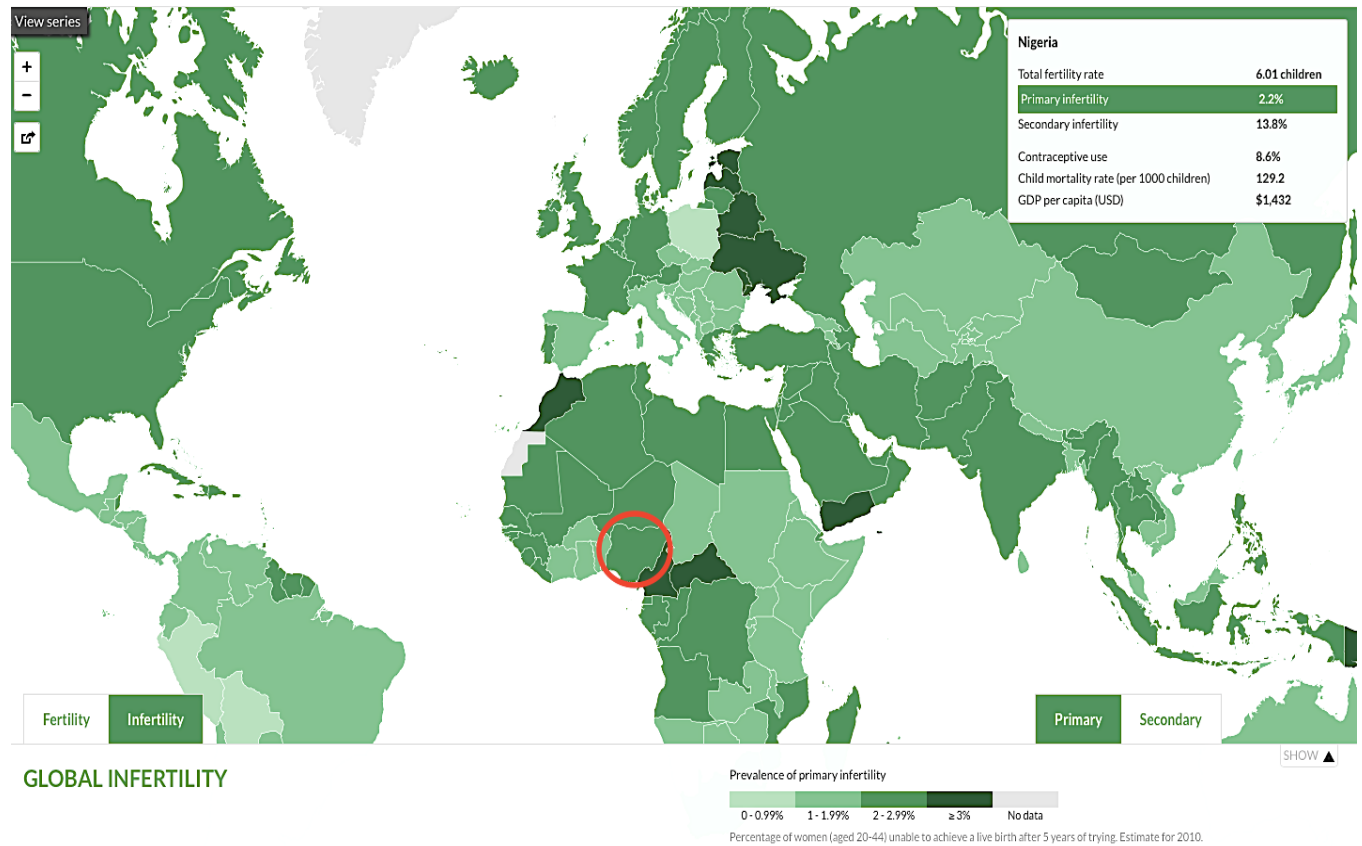


Figure 1.4: The global infertility rate (Nigeria highlight) (<http://globalfertilitymap.com>) accessed on 25<sup>th</sup> February 2019.

A survey of 1075 married women in Ile-Ife, Southwest Nigeria, using a WHO validated protocol reported an infertility prevalence rate of 20% (Adetoro and Ebomoyi, 1991a). As expected, the highest prevalence of infertility reported by the survey was located in the rural parts of the city. A similar but smaller sample sized survey among rural residents in Ilorin, North Central Nigeria reported a prevalence of approximately 35% (Adekunle, 2002). However, another survey in Ilora, South West, Nigeria, with a sample of 400 women, reported an infertility prevalence of 8.7% (Jimoh, 2004). Thus, epidemiological studies on infertility in Nigeria have been less than adequate in determining the true prevalence of infertility in Nigeria.

### 1.3. CONSEQUENCES OF INFERTILITY

In many cultures within Nigeria and most other developing countries in Africa, the sole purpose of life and marriage is exclusively to reproduce (Teoh *et al*, 2014). Children are considered a gift from the gods, and childlessness retribution for past sins (Okonofua *et al*, 1997). Infertile women are therefore often socially stigmatised, isolated from the community and may have certain rights and privileges stripped from them (Ombelet *et al*, 2008). There is often significant pressure on the male spouse of the childless infertile woman, from relatives, to take another wife/woman, given that polygamy is permitted in such societies. Family members often perceive infertility as being the woman's fault (Orji *et al*, 2002). Even when male factor infertility is suspected or confirmed, there often remains significant physical, psychological and financial impact on the female partner who may experience feelings of guilt and responsibility for the couple's predicament (Miranda *et al*, 1995).

According to studies from Africa, the Middle East and Asia, the consequences for infertility include but is not limited to: Loss of livelihood and income due to the lack of domestic labour and support children contribute (Dyer and Patel, 2012, Seybold, 2002, Nahar and Richters, 2011, Wiersema *et al*, 2006). Secondly, economic difficulties caused by cultural traditions and customary laws. For example, in most tribes of Nigeria and Cameroon, the negotiations of assets and land claims, are usually decided by the number of children (usually sons) present in the household (Hollos, 2003). Therefore, a childless widow would have little or no right to her late husband's assets (Okonfua *et al*, 1997). Thirdly, there is loss of economic security at one's old age due to lack of support from children (Hollos, 2003, Mogobe, 2005). Finally, a lack of financial security especially in the case of abandonment or divorce. In Cameroon, the husband of an infertile woman can withhold basic necessities including food, fuel and clothes (Dhont *et al*, 2011, Nahar and Richters, 2011).

In many cases, infertility has been associated with physical and emotional abuse, battery, social ostracism, stigmatisation, divorce (Dyer, 2007), ridicule and exile from the community, insecurity in future endeavours, ineffective and somewhat harmful therapies, and poverty (Inhorn, 2009). Additionally, there is a growing amount of evidence that suggests that sub-Sahara African infertile women are also more likely to be exposed to the Human Immuno-Deficiency Virus (HIV) due to their extramarital attempts

to conceive (Ikechebelu, 2002). Although little is known about the stress associated with male infertility, research from the Middle East and Africa suggests that infertile men like women, are subjected to ridicule from peers and other members of the community, particularly in high fertile communities (Bharadwaj, 2003).

#### **1.4. INFERTILITY TREATMENT**

Challenges to conception can occur due to a number of factors, clinical and otherwise (as stated in section 1.1), which may result in seeking reproductive treatment (Macaluso et al., 2010). Research in most developing countries have shown that infertile couples seek a resolution to their situation in two different ways: traditionally (cultural & herbal) or clinically.

##### **1.4.1. Traditionally (cultural)**

In many African countries where culture and tradition govern most actions, this equally holds true for infertility resolution. There are avenues in some cultures that allow infertile couples raise children that might not be biologically related to them as theirs. For example, in Swaziland, Asuti (1988) reports that a younger sexually immature girl (usually the infertile woman's sister, cousin or extended relation) is brought into the infertile couples' household for the purpose of bearing children for the infertile woman. Any child/children produced by the young lady is considered the child/children of the infertile woman. Similarly, the Akamba tribe of Central Kenya have a practice that allows an infertile couple to adopt a young girl and assume parenthood of any child/children she may bear through a third-party male. The children born out of these arrangements belong exclusively to the infertile couple and the third-party male assumes no responsibility to the adopted girl or as father to her children (Ueda, 1973). Additionally, in some parts of sub-Saharan Africa, an infertile woman may marry another woman into her household, and could lay claim to the children the woman bears (Caldwell and Caldwell, 1990). This practice is applied in various societies across African nations. The Lovedu of South Africa (Sacks and Brodtkin, 1979), as well as the Igbo's of Nigeria (Amadiume, 1987), both have a practice of female husbands, whereby an infertile wealthy woman can marry one or more women for the purpose of bearing children for her. There are a few other approaches to resolving infertility in the developing world. These include, re-marriage (Papreen et al., 2000), divorce (Okonofua et al., 1997, Papreen et al., 2000), engaging in extramarital relationships (Gerrits, 1997), all in an attempt to have children. Fostering

and adoption are equally viable methods of resolving infertility; however, research suggests that adoption is less accepted by infertile couples in developing countries (Mogobe, 2005, Inhorn, 1998, Oladokun et al., 2010).

#### **1.4.2. Traditional (Herbal)**

In addition to these cultural practices, some of which are no longer acceptable within their various societies today due to westernization and religion, there still exists a small group of local people specialised in the treatment of infertility traditionally. Inhorn (1994) refers to these local specialists as ethono-gynaecologists. These traditional healers include herbal and spiritual healers, native priests, as well as traditional reproductive health specialists among others. However, as some studies show, the desperation and treatment -seeking behaviour of infertile couples do not permit them to rely solely on any one practitioner at a time (Hiadzi, 2014). For example, the Macua women in Mozambique often visited *akulukanos* (*herbal healers*) and *majini* (*spiritual healers*) in search of treatment, and the prescribed remedies include herbal teas, balms, baths or exorcism rituals (Gerrits, 1997). In Bangladesh, infertile women rely heavily on traditional healers, who use amulets and herbs to treat infertility (Nahar and Richters, 2011, Papreen et al., 2000).

#### **1.4.3. Clinically**

Where traditional and cultural beliefs to resolving or treating infertility does not necessarily rely on systematic diagnosis and treatment of specific physiological disorders that impair reproductive function, modern approaches do (Hiadzi, 2014).

Assisted Reproductive Treatment (ART) refers to all treatment procedures that involve handling human or animal gametes (oocytes, sperm or embryo) *in vitro* to achieve a viable pregnancy, and in turn a live birth (Zegers-Hochschild et al., 2009). The development of ARTs was initially to overcome intractable subfertility, which includes intrauterine insemination (IUI), donor insemination (DI) and Intra-cytoplasmic sperm

injection<sup>2</sup> (ICSI) for cases related to male subfertility and *In vitro* fertilisation<sup>3</sup> (IVF) for women with blocked fallopian tubes (Inhorn and Birenbaum-Carmeli, 2008). Since the birth of the first ‘test-tube’ baby four decades ago via *in-vitro* fertilisation in England, the use of assisted reproductive technologies has greatly increased all across the world.

Table 1.2: Clinical indications for reproductive treatment such as *In-vitro* Fertilisation (IVF)

<b>Cause of Subfertility</b>	<b>Indications for Reproductive Treatment</b>
<b>Tubal Pathology</b>	After a subfertility duration of 2 years or more with a diagnosis of impaired tubal function.  If surgery cannot correct the tubal damage based on clinical assessment.
<b>Endometriosis</b>	If endometriosis is diagnosed as mild or moderate, it should be treated as unexplained infertility.  If endometriosis is diagnosed as severe, it should be treated as tubal pathology.
<b>Hormonal disturbances</b>	If ovulation induction is unsuccessful after 12 treatment cycles (anovulatory cycles)
<b>Unexplained Infertility</b>	If the woman is above the age of 36 years, and the subfertility duration exceeds three years, and no cause is readily found.
<b>Male Factor Infertility</b>	If the subfertility duration exceeds two years.  If motile sperm cells present are less than 1-2 million after sperm preparation (TMC <sup>4</sup> < 1million)

Source: Gardener et al., 2009

<sup>2</sup> ICSI: is the process of injecting a single sperm cell into the cytoplasm of the egg to be fertilized, then transferred as embryos to a woman’s uterus (Zegers-Hochschild et al, 2009)

<sup>3</sup> IVF: “a technique that involves the removal of an ovum from the woman or the use of a donor ovum, its fertilisation in the laboratory using either the male partners or donor sperm, then transferred as an embryo to a woman’s uterus” (Inhorn and Carmeli, 2008).

<sup>4</sup> TMC: Total motile count is the number of moving sperm in the entire ejaculate

## 1.5. CARE PATTERNS AND FUNDING

Studies have shown that of the estimated 10-15% of couples who are sub-fertile in high income countries<sup>5</sup> (HIC), 50-60% seek ART care (Boivin et al., 2007). One might conclude that it is a judicious market, devoid of constraints and limitations. However, this market is riddled with barriers that may affect the sub-fertile couple directly or indirectly. These barriers are present in either accessibility, affordability, or societal/cultural factors (Chambers et al., 2014b). The direct barriers to the accessibility of ART are those that either deliberately or unintentionally limit the number of people that can access the services (Daar, 2013). These are usually easy to detect. Some examples include restricting treatment to solely married couples for religious or cultural reasons (as in most countries in the Middle East such as Saudi Arabia and Egypt (Inhorn, 2013, Inhorn, 2014a, Inhorn, 2014b).

Another is restricting treatment to heterosexual couples only as is the case in the Netherlands and Sweden (Ethics Committee of American Society for Reproductive, 2013, White et al., 2006). Researchers over the last two decades have sought to understand the disparities in access to and use of ART services by various races and ethnicities (Robert, 1996). Recent studies on infertility incidence and utilisation suggest that Hispanic, Black and women of other races have a higher prevalence of infertility compared to white/Caucasian women (Inhorn and Fakih, 2006). However, despite the high incidence reported, these women are less likely to seek treatment (White et al., 2006).

In most low-middle income countries<sup>6</sup> (LMIC), these direct barriers mentioned earlier usually occur simultaneously; making reproductive care almost insurmountable. Consequently, ready and affordable access to fertility investigation and treatment remains scarce, very expensive and often not affordable in most LMIC (Inhorn and Patrizio, 2015). In a populous country like Nigeria, maternal and child health care indices are poor with unacceptably high mortality and morbidity rates as well as low life expectancy indices (Otubu, 1995). Given the governments preoccupation with attempting to improve these indices managing infertility and the provision of ART services is not a priority area of government funding and policy (Okonofua, 1996).

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<sup>5</sup> High-income countries (HIC) is defined by the World Bank as those countries with a gross national income (GNI) of \$12.236 or more (<http://worldbank.org>)

<sup>6</sup> Low-middle income countries (LMIC) is defined by the World Bank as those countries with a GNI per capita between \$1.026 and \$4.035 (<http://worldbank.org>)

Contrary to the situation in LMIC, like Nigeria, infertility treatment is more accessible to and affordable by women in most developed countries (Ledger, 2009). These countries often provide the required services through an appropriate health insurance scheme, e.g. the National Health Service in the UK (Haven et al., 2013), although with stringent eligibility criteria's (Ledger, 2009). The ready access to such services in high-income countries (HIC), the relatively high success rates of fertility treatments and their affordability (government-funded insurance schemes) should suggest that the degree of stress and anxiety associated with seeking and undergoing fertility treatment in such countries may be less than that experienced by women seeking such services in LMIC such as Nigeria. However, no studies have explored this avenue.

### **COST OF ART AND HEALTH ECONOMIC ISSUES**

Worldwide, the 'value for money' has become the major focus owing to the incessant technological advancements particularly in the health sector. This also holds true for an inexact science like ART. The utilisation of ART services is dependent on the demand, availability, cost and consumer price (Chambers et al., 2009). The cost of undergoing a single cycle of ART up until a clinical pregnancy is achieved includes: planning and managing the treatment cycles, ovarian stimulation and monitoring, ultrasound scanning, sperm preparation, follicular aspiration, embryo transfer, hospital theatre and accommodation, charges for the anaesthetists, embryology services (including blastocyst culture, assisted hatching, and Intra- Cytoplasmic Sperm Injection (ICSI), and cryopreservation of embryos inclusive of 1 year of storage fees (Chambers et al., 2006).

The variations in the funding structures for ART within and among countries are usually in line with the responsibility expressed by the government or private sector of that country to purchase healthcare (Chambers et al., 2013). Government funding of ART ranges from negligible subsidisation in the United States, virtually none in most Low-Income Countries (LIC), financing a restricted amount of cycles for eligible patients in most European countries, to the complete subsidisation with co-payments in Australia (Chambers et al., 2009, Hughes and Giacomini, 2001, Nachtigall, 2006). An estimated 85% of the world's populations live in countries that offer some form of assisted reproductive care (Collins, 2002). However, despite its increasing availability, even among developed countries, differences exist in its accessibility and utilisation, most notably due to its high costs (Chambers et al., 2014b).



### **1.7.1. Cost and affordability of ART in high income countries**

The cost of a single cycle of ART in the United States (U.S) was approximately \$12,400 as of 2003, \$12,513 in 2009 (Chambers et al., 2009), although in some clinics the cost can be as high as \$20,000 (Spar, 2005). With very few states mandating health insurance that covers the cost, the average American infertile couple is unable to afford the procedure and less than 1% would go for treatment (Nachtigall, 2006). In a study to determine ART availability and utilisation in the United States, Hammoud et al (2009) reported that ART coverage by health insurance would improve accessibility of the treatment (Hammoud et al., 2009). Unlike the U.S, in most European countries such as France, the costs of the treatment cycle (€ 2752) (de Mouzon et al., 2010) are fully reimbursed to the patients by the social security.

In other countries such as Denmark (€ 6607), Belgium (€ 2441) and Norway (\$4523), a bulk of the cost (not all) is borne by the state (Redmayne and Klein, 1993), other countries such as Germany (\$4148), and Brazil (\$3000) have relatively more flexible rates (Table 1.3). However, in the UK, there is a variation in the access to NHS-funded ART in England and Wales (Brown et al., 1999). The costs of a stimulated cycle of ART has increased in the UK from £1005 in 1997 to £1786 in 2001, €4375 (£3059) in 2003 (NICE, 2004), \$4016 (£2750) in 2006 and is most recently estimated at \$5244 (£3361) (Maheshwari et al., 2010) (Table 1.3). Approximately 1 in 4 IVF cycles are funded by the UK- NHS (Ledger and Skull, 2000), however, with the implementation of the NICE guidelines (which stipulates that couples which the women is within the age of 23-39 should be offered up to three stimulated ART cycles), this number is expected to increase (Ledger et al., 2006).

Table 1.3: Summary of the cost of a single cycle of ART in some HIC

<b>Authors, Year</b>	<b>Country</b>	<b>Cost of an IVF cycle (ICSI)</b>
Chambers et al, 2009	Australia	\$5,645 (+\$469 for ICSI)
	Canada	\$8,500 (+1,172 for ICSI)
	Japan	\$3,956 (+860 for ICSI)
	Scandinavian Countries	\$5,549 (+614 for ICSI)
	United States	\$12,513(+1,626 for ICSI)
Maheshwan et al, 2009	United Kingdom	\$5,244
Rauprich, 2010	Germany	\$4,148-\$4,977
Makuch et al, 2011	Brazil	\$3000
Huyser et al, 2013	South Africa	\$4,500-\$5296 for IVF
		\$4565-\$5429 for ICSI

Adopted from Chambers et al, 2009

A study by Chambers et al (2009) reviewed the economic aspects of ART in developed countries and found that without accounting for government subsidies, the cost of a single cycle of ART as a percentage of the patients annual disposable income varied from 50% in America, to approximately 20% in the UK and Scandinavian countries (Chambers et al., 2014a). With the exception of the United States, most high-income countries such as Australia, Denmark, UK and Sweden recognise the need for fertility treatment and have developed national health policies that caters to subfertility and cover the cost (either partially or fully) of subfertility treatment; though, the government might set restrictive regulations that could limit access to specific services (Spar, 2005). For instance in the UK, although the National Institute of Clinical Excellence (NICE) guidelines in 2004 stated that infertile couples and women under 40 years of age with unexplained infertility should be offered three free cycles of IVF on the NHS, the clinical commissioning groups (CCG's) are free to impose their own rules, and therefore IVF funding in the UK varies according to where a couple lives (Kennedy et al., 2006).

### **1.7.2. Costs and affordability of ART in low-middle income countries**

An international survey of the health economics of IVF and ICSI by Collins (2002) observed that in 25 countries, the average cost of an IVF cycle ranged from \$1300 in Iran to \$6400 in Hong Kong. The authors reported that the cost was more than half an average person's annual income in these countries. These prices were considered expensive for indigenes of these countries, much less infertile couples in low-middle income countries. Couples in LMIC in the bid to undergo ART may face crippling costs to their livelihood (Hovatta and Cooke, 2006). The only study to our knowledge that tried to evaluate this was a one by Dyer et al. (2013) that calculated the 'catastrophic' expenditure of Out of Pocket Payment (OPP) to the households of 135 infertile couples undergoing ART in South Africa. The participants in this study were categorised into three socio-economic tiers (lowest, intermediate and highest), and a prospective observational study was carried out over a two year period (Dyer et al., 2013). The study reported that not only were patients in all three income tiers affected by the 'catastrophic' expenditure of ART, but also about 66% of the couples had to cut down on necessary expenditures such as food and clothing. Furthermore, almost half of the participants reported that they had to work an extra job to generate additional income to cope with ART costs (Dyer et al., 2013), which was similar to participant reports in Wiersema et al. (2006). The authors (Dyer et al., 2013) were not surprised that households with a lower socioeconomic status were at the greatest risk of incurring 'catastrophic' payments on ART. Since this study (Dyer et al., 2013) is prone to possible erroneous information, due to the estimated annual household income by the participants, which could not be corroborated by the researchers, and because there are no other studies that have calculated the OPP of ART in LMIC, it would be premature to say that this study demonstrates an exorbitant cost of ART among patients in LMIC. However, the work of Dyer et al. (2013) does demonstrate that the OPP of ART within LMIC merits further investigation, to conclusively determine how stressful self-funding ART could be; which is what this study intends to accomplish.

In most developing countries, few studies provide quantitative insight on the out of pocket costs or cost burden of ART to the infertile couple or household. For instance, in Widge, (2005), this study did not provide any information on the impact of ART costs to the couples or household. The authors failed to effectively evaluate the impact of such costs on the overall income of the patients, but concluded that couples were being exploited and the costs posed some financial stress to them (Dyer and Patel, 2012, Widge,

2005). Additionally, in Nigeria, Giwa-Osagie (2002) reports that the average cost of an IVF cycle is between \$2000-\$2700; a figure that was well more than the national minimum wage of \$52-\$60 per month. Again, with no reference to the impact of the cost to the couples seeking treatment. Similarly, in 1997 when the annual per capita GNP in Egypt was approximately \$790, Inhorn (2001) reported that the cost of an average IVF cycle was approximately \$3000; which was more than twice the annual income of the average Egyptian. In Donkor and Sandall (2007), the authors estimated the cost of an IVF cycle to be \$3000, which with the annual income of an average Ghanaian less than \$400, would make the treatment prohibitive. Although all these studies mentioned the estimated costs of the treatment, they still did not capture the way funds were sought by these couples, as well as analyse the implications of such exorbitant costs to the couples.

Ongoing debates on the affordability of ART in LMIC are often informed by relatively scarce data on the subject. This is because most of the information on the financial impact of infertility is often usually obtained from qualitative research, which usually focuses on the stigmatization, financial and social consequences of infertility and rarely includes patients with direct access to ART (Hollos, 2003, Singh, 1996). In most LMIC, the increasing prevalence of poverty is a major factor that may hinder payment for health care services from people in desperate need of it (Inhorn, 2003). Good quality and affordable subfertility care was not reported in any of the studies and in most cases, is not provided in the public sector.

In the studies from countries like India (Widge, 2005) and Vietnam (Wiersema et al., 2006), in which the participants sought ART, the authors observed that it was available at high costs and therefore only accessible to a limited number of high income couples but data for this was not provided. It is possible that households incur impoverishing and 'catastrophic' health costs because they are willing to pay for an unaffordable treatment (Dyer et al., 2013).

In summary, there are few and limited economic studies accessing the financial implications of infertility treatment to the couples pocket (Singh, 1996, Dyer et al., 2013), its cost effectiveness and the impact of insurance coverage (Martin et al., 2011) on access and utilisation of the treatment (Macaluso et al., 2010) particularly in LMIC. Given the pressures to contain population growth rates and the tacit belief that attention needs to be focused on high fertility rates in the developing countries (with an emphasis on affordable family planning services, birth control and safe abortion practices), non-

western governments neither have the political will nor the resources to fund assisted reproductive services (Nachtigall, 2006). Despite this, there remains the demographic paradox referred to as 'barrenness amidst plenty' (Nachtigall, 2006, Inhorn and Patrizio, 2015).

## **1.8. STUDY SETTINGS**

### **1.8.1 Comparative Research: Developed versus developing countries**

Numerous studies have been conducted in developed countries on the stress associated with infertility, treatment and treatment outcomes (Abbey et al., 1992, Andrews et al., 1991a, Boivin and Takefman, 1995, Boivin and Schmidt, 2005, Campagne, 2006, Csemiczky et al., 2000, Edelman and Golombok, 1989, Glynn et al., 2008, Jane et al., 2010, Klonoff-Cohen et al., 2001, Matthiesen et al., 2011). Three additional studies examined the acceptable cost of the treatment (Chambers et al., 2013), international disparities in access to infertility services (Nachtigall, 2006) and the impact of consumer affordability on access to ART (Chambers et al., 2014b) in developed countries. However, such relevant studies have not been conducted in developing countries on such a scale and this has been noted. For example, Chambers et al (2013 p.4) emphasized that "*wide disparities exist in the availability, quality and delivery of infertility services between the developed and developing nations of the world*". They suggest that it is important to understand the experience and economic burden that ART represents to a consumer across different countries and regions. Hence, international comparative research should be conducted not only in developed countries, but also in developing countries, wherever possible. There are a number of important issues to consider when comparing developed and developing countries. These include social, economic, cultural, political and demographic variations. Developed countries by definition have a relatively better economy than developing countries, and equally tend to be more politically stable. Directly or indirectly, the economic and political environment of a nation influences the social welfare of infertile couples. Indeed, infertile couples in developed countries tend to have better access to infertility treatment without direct or indirect social barriers (see section 1.5) to treatment. Contrarily, in developing countries, given the pressures to reduce population growth rates, "most non-western governments have neither the political willingness to give attention to the infertility problem nor the resources to fund ART

programs (Nachtigall, 2006). Therefore, international comparisons between developed and developing countries must be concerned with economic conditions and the social environment of the people.

### **1.8.2. Comparison between UK and Nigeria**

This section presents the context of each country, health services and the clinics used for data collection.

#### **The UK**

The United Kingdom (UK) is located in western Europe, between the north Atlantic Ocean and the North Sea. It has a total area of 244,820sqkm, with a population of 65.64 million (2016 estimate). Majority of the population live in England, Scotland and Wales (The Central Intelligence Agency). As one of the world's leading trading powers and financial centres, in purchasing power parity, it has a Gross Domestic Product (GDP) of \$2.78 trillion (2016 estimates). According to the labour force statistics in 2016, 1.3 % of the population work in agriculture, 15.2% in industry and 83.5% in service (The Central Intelligence Agency). Sheffield is a city in the English county of South Yorkshire, England, with a metropolitan population of approximately 1.56 million and city population of 575,400 (mid-2016 estimate). Selection of Sheffield as the research location in the UK was based on the researchers' proximity to the Academic unit of Reproductive and Developmental Medicine in the University of Sheffield and the mixed population of the city in terms of socio-economic status and demographic characteristics.

#### ***Health care in the UK***

The UK health care system, National Health Service (NHS) was established on the 5<sup>th</sup> July, 1948 to create extensive health care for people living in the United Kingdom (Lassey and Lassey, 2001). It was founded by a former Minister for Health Aneurin Bevan, under the principles of universality and equity, which provides healthcare to people on the basis of need and not ability to pay (Grosios et al., 2010). In each of the UK countries, the NHS has its own distinct structure and organisation; in England the health policy is the responsibility of the central government, while in Scotland, Wales and Northern Ireland it is the responsibility of the respective governments. The NHS is the largest employer in the UK with over 1.3 million staff with a budget of over £90 billion (Committee, 1995,

Grosios et al., 2010, Ranade, 1997). A 2014 report by the commonwealth Fund ranking the healthcare systems in developed countries ranked the UK NHS as the overall best in the world in quality of care, access to care, equity and efficiency (Davis et al., 2016).

### ***Assisted Conception clinics in the UK***

The Human Fertilisation and Embryology Act of the United Kingdom was passed in 1990, leading to the formation of the Human Fertilisation and Embryology Authority (HFEA). It is the first statutory body to regulate and control assisted reproduction anywhere in the world. The principal function of the HFEA is to license and monitor clinics that carry out assisted reproductive treatments and embryo research in the country (Doyle, 1999). In March 2017, the Human Fertility and Embryology Authority (HFEA) state of the fertility sector (2016-17) report stated that there are 132 licensed fertility clinics and laboratories in the UK; with 96 of them being specialist treatment clinics (i.e. IVF and embryology services), 14 basic treatment clinics (such as insemination services), 13 research laboratories and 9 storage clinics (such as sperm banks). The majority of the clinics (34%) are privately owned, 22% are run solely by the NHS and 29% are run by the NHS/private partnership (HFEA, 2017). The report further states that there is a high proportion (60%) of self-funded treatment in the fertility services in both the private and NHS clinics (HFEA, 2017).

### **NIGERIA**

Nigeria is located in Western Africa, bordering the Gulf of Guinea, between Benin and Cameroon. It has a total area of 923,768sqkm, with significant populations scattered throughout the country. The highest population densities are located in Lagos (13.1 million), Kano (3.6 million), Ibadan (3.2 million), Abuja (2.4 million), Port Harcourt (2.3 million) and Benin (1.49 million) (2015 estimates) (The Central Intelligence Agency). As one of Sub-Saharan Africa's largest economies, in purchasing power parity, it has a GDP of \$1.09 trillion (2016 estimate). According to the labour force statistics of 1999, 70% of the population work in agriculture, 10 in industry and 20 % in service (The Central Intelligence Agency). The population of Nigeria is ethnically and religiously heterogeneous, with the Hausa-Fulani's of the North being the most populous group (28%), the Yoruba in the south-west (21%) and the Igbo's in the south -east (18%) (CIA, 2013). Religiously, the majority of the Hausa-Fulani practise Islam, the Yoruba's are

evenly distributed between Islam and Christianity, while the Igbo's mostly practise Christianity (National Geographic, 2013).

Benin city is the administrative capital of Edo state, Nigeria. It is located in the southern part of Nigeria, with a population of approximately 1.49 million. This is approximately 0.82% of the total Nigerian population (The Central Intelligence Agency). Benin city is home to one of Nigeria's reputable institutions of higher education namely the 'University of Benin', located at Ugbowo and Ekenwan. The mixed population of Benin city in terms of socioeconomic status and demographics also made it a good representative of the Nigerian population.

### ***Health Care in Nigeria***

The National Health Insurance Scheme (NHIS) was established under Decree number 35 of the 1999 constitution by the Federal Government of Nigeria (nhis.gov.ng). The NHIS is a social health insurance scheme aimed at providing universal health coverage was introduced to guarantee accessibility to healthcare for all Nigerians. The scheme introduced Health Maintenance Organisations (HMO's) as financial managers of the scheme, however, this did not come into place until 2005 (nhis.gov.ng). The healthcare system in Nigeria has been described by its managers as defective. Since its inception, present coverage of the NHIS is very low, it only covers 4-5% of Nigerians (Demsy et al., 2013); majorly federal government employees, children under five years of age, prison inmates, the armed forces and uniformed service personnel's (Uzochukwu et al., 2015). While the Nigerian government has put in place various policies and plans to address health care financing such as the national health bill, national strategic health development plan (2010-2015), and the health financing policy (Uzochukwu et al., 2015), the most common source of health care financing (69%) is out of pocket payments from the households (Demsy et al., 2013).

### ***Assisted conception clinics in Nigeria***

The provision of ART services in Nigeria is at present predominantly a private sector endeavour, with relatively few fertility clinics existing within the public sector (Bingel, 2012). Additionally, the NHIS does not offer financial assistance for fertility treatment in the country. According to Ajayi and Osadolor (2011), "This private sector dominance of the IVF field is informed by a population whose healthcare needs far outweigh its capacity



to meet them” (p.80). Furthermore, unlike the United Kingdom, there is no fertility regulatory authority in Nigeria, and so fertility clinics in the country are not accountable to anyone but themselves.

## **THESIS STRUCTURE**

The overall structure of this thesis is divided into seven chapters, including this introductory chapter.

**Chapter 1:** This chapter of this thesis is the introductory chapter which provides a background for this research and presents the study objectives and specific research questions.

**Chapter 2:** This chapter presents the relevant literature on topics such as stress and anxiety in subfertility, assisted reproduction and coping mechanisms such as social support and the quality of life of sub-fertile couples. This chapter also introduces the concept of affordability that can be used to further explain the cost of ART, the burden of affordability and its relationship to the perceived quality of life of the patients.

**Chapter 3:** This chapter is divided into three parts. Firstly, it presents the research methodology. It describes the research philosophical basis of the research, epistemological underpinnings and the rationale for using a mixed methods design. The next part (quantitative methods) presents the quantitative study elements, which includes the sampling frame, recruitment, methods of data collection, and data analysis. The final section presents the qualitative study elements, which involves the interviewing process, practicalities, analysis and a reflection of the qualitative process.

**Chapter 4:** It presents the quantitative and qualitative findings on the stress related anxiety patterns of women in both countries, the predicting socio-demographic factors and women’s experiences with their infertility.

**Chapter 5:** This chapter the quantitative and qualitative findings on the affordability of ART in both countries, using a series of methods to measure affordability. The ways in which funds were sought were equally identified from themes in the qualitative study.

**Chapter 6:** This chapter presents the qualitative and quantitative findings on the social support patterns and behaviours of women in both countries.

**Chapter 7:** This chapter presents the discussion of the key findings of the different research questions as well as describes the role of the researcher in the entire research process.

**Chapter 8:** This chapter presents integration of the qualitative and quantitative results.

**Chapter 9:** This chapter presents the strengths and limitations of the study, the methodological issues, key contributions to current work, recommendations for policy and practise and the conclusion section. Relevant documents are attached as appendices.

**CHAPTER 2:  
LITERATURE  
REVIEW**

## **CHAPTER TWO: STRESS, ANXIETY AND ASSISTED REPRODUCTIVE TREATMENT- A scoping review of the literature**

### **2.1. INTRODUCTION**

This chapter presents evidence from a systematic scoping literature review to understand the stress and anxiety associated with infertility treatment. The review also sought to identify the coping mechanisms adopted by infertile couples. This chapter draws together the evidence from high-income countries as well as any available research from low-middle income countries to develop an understanding of current evidence on this subject.

#### **2.1.1. Review Aim**

The aim of this review is to identify and systematically review both published and unpublished literature to explore the scope of the literature and evidence on the stress associated with infertility treatment and to identify any coping mechanisms patients adopt to manage stress.

The review addressed the following questions:

- What is the scope of literature available in HIC and LMIC that addressed stress and anxiety associated with infertility treatment?
- What evidence has been reported by the included studies that explored stress and anxiety association with infertility treatment?
- What are the coping strategies adopted by women to manage stress and anxiety associated with treatment of their infertility?
- Understand the quality/strength of evidence available in the literature to help make recommendation for further studies, policy and practice.

#### **2.1.2. Review Methodology**

A scoping approach to the published literature was adopted to capture the relevant articles addressing stress, anxiety and assisted reproductive treatment. This approach, as Anderson et al (2008) explains, can be conducted to examine broad areas and identify gaps in the evidence to inform further research. The authors state that it can equally be used to “*map evidence in relation to time (when it was published), location (country),*

*approach (how it was studied/researched) and origin (healthcare/academic)” (Anderson et al., 2008).*

### **2.1.2.1. Justification for using a scoping review**

The aim of a scoping review is to examine the magnitude and extent of the literature that have addressed a particular research topic; in this case the stress associated with treatment for infertility among couples. A scoping review was considered relevant to explore these issues because it allows the researcher to “map a specific field of research to determine its breadth and depth, summarise an area of research, identify gaps and analytically assess the state of the literature” (Bottorff et al., 2014, Levac et al., 2010, Pham et al., 2014). Findings of a scoping review could help researchers to understand and determine whether a systematic review is needed (Both et al, 2016). In this study our aim was to understand the scope of the literature that is available on the topic of stress, anxiety and infertility treatment, and to identify gaps in the literature to inform the design of the PhD primary research.

## **2.2. The Review Process**

### **2.2.1. Search Strategy**

A search strategy was developed in consultation with both supervisors and an information specialist at the university library. The strategy was tested and used to conduct an extensive literature search in key bibliographic databases: MEDLINE, Pubmed, EMBASE, PsycINFO and web of science. These databases were prioritised because they house the majority (~90%) of all health-related literature (Zhang et al, 2006). Grey literature sources were also searched: Hand searches including citations follow-up and reviewing the reference list of relevant studies were carried out to identify studies missed out following the database searches. Literature searches were carried out from June 2015 with update searches completed between December 2018 and January 2019. The searches were limited to literature published from 1990 till January, 2019.

### **2.2.2. Inclusion and Exclusion Criteria**

The Population, Intervention, Comparator and Outcome (PICO) protocol (Schardt et al, 2007) was used to select the studies for inclusion in the review. Using this framework, we included studies if they addressed the following:

1. **Population:** The target population were couples, or women aged 25-59, diagnosed with infertility. Studies needed to define infertility as the inability to conceive after >12 months of regular unprotected sex (Zegers-Hochschild et al., 2009). If studies reported that infertile couples/ women were targeted alongside fertile women as a comparator, they were included in the review. Studies not assessing infertility as the primary complaint were excluded.
2. **Intervention:** The interventions being evaluated in this review was the support for infertility treatment: social and psychological support received before and during the treatment. Studies not addressing infertility treatment, and/or the above supports were excluded.
3. **Outcomes:** The primary outcomes which must be measured were: Stress, Anxiety, Support and Coping strategies. Each outcome measured is defined below:  
Stress: refers to perceiving a situation as threatening and demanding and not having an immediate available or appropriate response to it (Cohen and Wills, 1985).  
Anxiety: “is an emotion described by a subjective feeling of tension, apprehension, nervousness and worry, and by activation or arousal by the autonomic nervous system” (Speilberger et al., 1977).  
Social Support: refers to “the content and availability of relationships with significant others, and social network. It equally refers to the quantitative and structural aspects of relationships (Saranson et al., 1990).  
Coping strategies: are “psychological patterns that individuals use to manage thoughts, feelings, and actions encountered during various stages of ill health and treatments” (Lazarus and Folkman 1984).
4. **Study Design:** The review included case, cohort and cross-sectional studies. Additionally, previous systematic reviews were not included but solely used for identification of additional studies. Abstracts from conferences in which the full content could not be obtained were excluded from this review.
5. **Language:** Only studies published in English Language were included due to the limited language competency of the researcher

### **2.2.3. Study selection**

The selection of studies process was carried out sequentially. The titles and abstracts from the retrieved studies were screened for relevance by Ada Achinanya (AA). Studies that potentially qualified for inclusion were printed and read repeatedly, and based on the inclusion criteria, they were screened at this stage for relevance. Studies that did not meet the full texts inclusion criteria were excluded. 10% of the rejected and included studies were cross-checked by another reviewer (Robert Akparibo (RA)). Any disagreement was resolved through discussion between the two reviewers.

### **2.2.4. Data Extraction**

Data extracted from the retrieved articles were inserted into a data extraction sheet, adopted from the Cochrane Consumers and Communication Review Groups data extraction template (2013). Only studies that met the inclusion criteria were printed, read and data extracted. The data extraction form included the following details: Author, Publication year, Country, Study design, Intervention (description of intervention), sample population and size, results and key limitations.

### **2.2.5. Data synthesis and Analysis**

Due to the nature of this research and the multiple outcomes measured, a meta-analysis could not be performed. Additionally, due to the heterogeneity of the included studies, a meta-analysis was not possible. Instead, the data were analysed and presented narratively. This implies a textual approach to describe, summarise and explain the synthesized evidence from the included studies. Where applicable, summary statistics such as means $\pm$  standard deviations, p-values and confidence intervals were presented. Due to the nature of this research and the multiple outcomes measured a meta-analysis could not be performed.

## **2.3. Theoretical framework adopted for scrutinizing the results**

Gerrity (2001) biopsychosocial theory of infertility was used as the framework to present the findings of this review. The biopsychosocial theory originates from the stress and coping model and has been modified to focus on inter-personal and couple-based stressors. It describes infertility as a non-event and life crisis which affects the individual, couple and families in a variety of stressful ways. The framework depicts individual

experiences as an interaction between biological, psychological and social. The biological discussion of this theory focuses on the physical impact infertility has on the individual, while the psychological aspect focuses on the mental or emotional impact infertility has on the individual or couple. The social aspect discusses the influence families, friends, and society has on the individual/couple, which can lead to interpersonal stressors and impact the relationship the infertile individual/couple has with their family or friends. Accordingly, the biopsychosocial theory can be classified into four stressors and two moderators. However, this review would focus on three stressors and one moderator, namely; physical stressors, emotional stressors and interpersonal stressors; and support as the moderator of stress (Gerrity, 2001). The stressors and moderators were used to scrutinize the couple's experiences with stress and affordability while undergoing ART.

## **2.4. RESULTS**

The result of the scoping review is presented narratively in detail below.

### **2.4.1. Scope of the literature**

In total, 103 published citations were retrieved from all five bibliographic databases. After duplicate entries were removed, 92 papers remained. The results of the literature selection process are summarised in the PRISMA flow chart in Figure 2.1.

### **2.4.2. Country and Settings**

The majority of the studies (29, Table 2.2) were conducted in high income countries, while few (4) were conducted in low-middle income countries. In terms of the specific countries where these studies were conducted, 5 were USA studies (Berg and Wilson, 1991, Downey and McKinney, 1992b, King, 2003, Turner et al., 2013) (Brucker and McKenry, 2004a), 9 were UK studies (Connolly et al., 1992, Edelmann et al., 1994, Harlow et al., 1996) (Anderson et al., 2003, Bayley et al., 2009, Cook et al., 1989, Edelmann and Connolly, 2000, Slade et al., 1997, Slade et al., 2007), three in Portugal (Galhardo et al., 2011, Galhardo et al., 2013, Martins et al., 2014), one each in Turkey (Karlidere et al., 2007), Sweden (Anderhaim et al., 1992), Italy (Ardenti et al., 1999), Finland (Vartiainen et al., 1994), Netherlands (Verhaak et al., 2001), Indonesia (Wiweko et al., 2017),



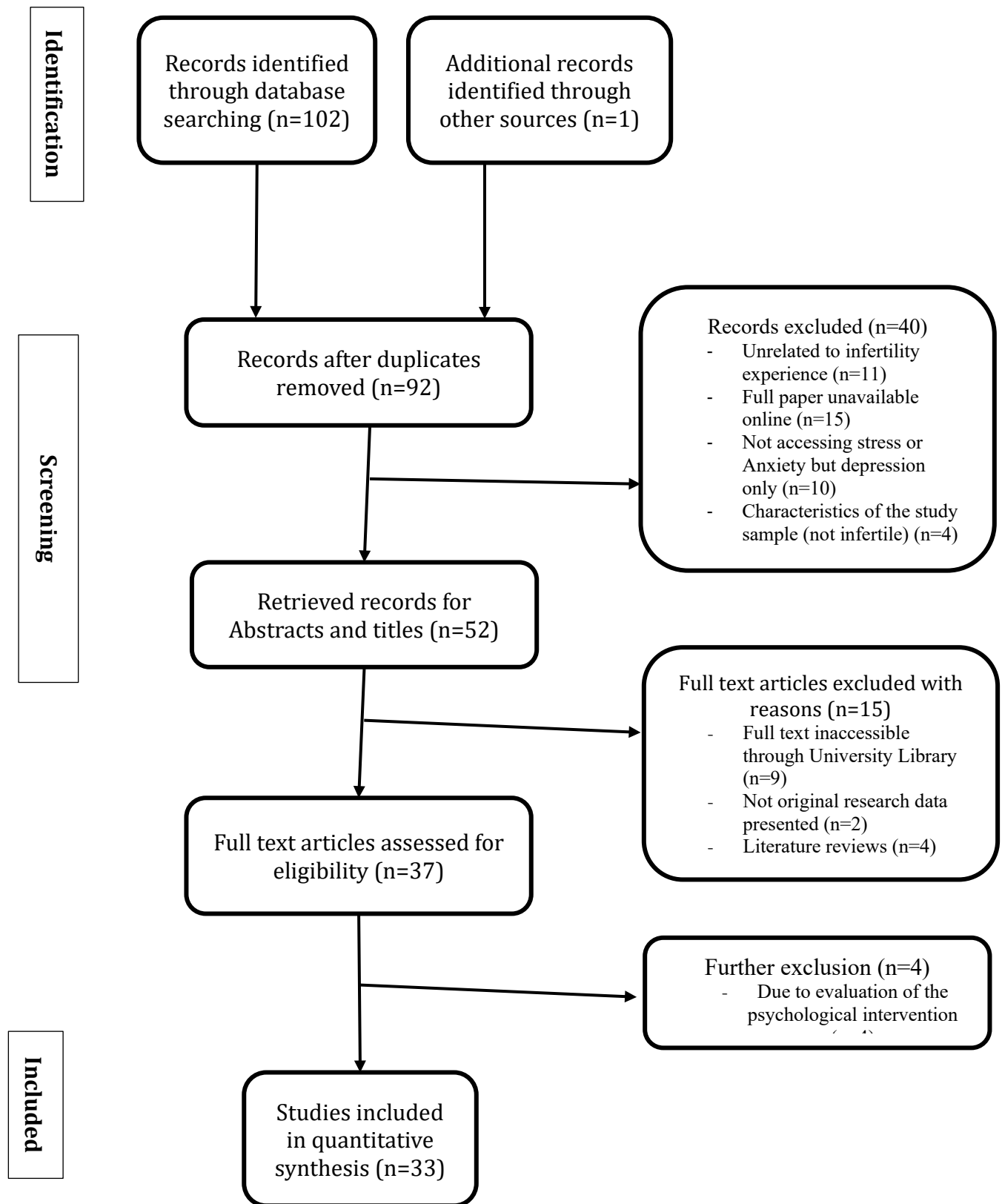


Figure 2.1: PRISMA diagram showing literature search and study selection.

Pakistan (Sultan and Tahir, 2011), China (Liu and Zhao, 2011), Canada (Newton and Houle, 1993), Malaysia (Musa et al., 2014), Germany (Wischmann et al., 2009), Thailand (Sreshthaputra et al., 2008a) and Nigeria (Fatoye et al., 2008). Majority of the studies were clinic-based samples, however, one study involved community-based samples (Brucker and McKenry, 2004a).

### **2.4.3. Participants, sample Size and study design**

All the studies reported that the target participants were women, men or couples diagnosed with infertility. Different definitions and classifications of infertility exist as shown in section 1.2 and stem either from the World Health Organisation (WHO) or organisations like the European Society of human Reproduction and Embryology (ESHRE) or from the authors of primary studies themselves. In addition to these classifications, there are also grading systems which range from fertile to infertile based on one's clinical characteristics as well as the durations of one's unfilled wish for a child.

The study participants were majorly recruited from clinic visits. Participants recruited in the clinics were infertile women/couples about to undergo assisted reproductive treatments like IUI, IVF and ICSI. The sample size recruited in all studies ranged from 25-10,847 women, 34-899 men and 53-200 couples. Of the 44 quantitative studies, there are 22 cross-sectional studies, six longitudinal studies (Anderheim et al., 2005, Connolly et al., 1992, Edelmann and Connolly, 2000, Slade et al., 1997, Newton and Houle, 1993, Verhaak et al., 2001), five case control studies (Hollos et al., 2009, Downey and McKinney, 1992b, Newton and Houle, 1993, Verhaak et al., 2001, Edelmann and Connolly, 2000, Slade et al., 1997), four exploratory studies (Ardenti et al., 1999, Edelmann et al., 1994), and two cohort studies (Turner et al., 2013, Anderson et al., 2003).

## **2.5. STUDY FOCUSED AND EVIDENCE**

### **2.5.1. Psychological stressor**

The results presented in Table 2.2 depict that a total of 15 studies reported on the stress patterns of infertile couples, using a myriad of instruments: Psychological General Well-being index (Anderhaim et al, 1992) , State-trait anxiety inventory (Ardenti et al., 1999, Connolly et al., 1992, Edelmann et al., 1994, Galhardo et al., 2011, Harlow et al., 1996, Turner et al., 2013, Vartiainen et al., 1994, Verhaak et al., 2001), Hospital Anxiety

and Depression scale (Chen et al., 2004), Beck Anxiety Inventory (Sultan and Tahir, 2011), Generalised Anxiety Disorder (King, 2003), Mood Disorder Questionnaire (Downey and McKinney, 1992b), SCL-90-R (Berg and Wilson, 1991), Self-Reporting Questionnaire (Wiweko et al., 2017).

Assisted reproductive treatments, ranging from pre-treatment tests to embryo transfer, carry physical, and emotional burdens on the couple. Two studies reported on the anxiety levels in women (Chen et al., 2004, Galhardo et al., 2011), while one reported on anxiety levels in infertile couples (Sultan and Tahir, 2011). In all three studies, the authors reported significantly high anxiety levels in infertile women and couples, compared to their fertile controls (Galhardo et al., 2011, Chen et al., 2004, Sultan and Tahir, 2011).

Conversely, results from three earlier studies suggest that couples entering an ART program are generally psychologically well adjusted. For instance, a study by Edelmann et al (1994) that recruited 152 couples without any previous IVF experience, completed a coping questionnaire, and several psychological instruments that measured general health, self-esteem, anxiety, personality and mood state. The authors observed that the couples showed little deviation on the standardized measures from the normative data. However, the state and trait anxiety scores for the women were elevated compared to the normative data on working adults, and the General Health Questionnaire scores were slightly lower (Edelmann et al., 1994). The authors concluded that couples presenting for IVF were generally psychologically well-adjusted, because as they explained, “only psychologically well-adjusted couples will seek medical help and confront the emotional demands of ART” (Edelmann et al., 1994). This was similar to results depicted in three studies that utilise the state-trait anxiety inventory. Two reported no difference in anxiety levels between infertile women and their fertile counterparts (Vartiainen et al., 1994, Verhaak et al., 2001), while the third reported that stress did not contribute greatly to infertility, as the trait anxiety scores were constant between the pregnant controls and the infertile sample (Harlow et al, 1996).

### **2.5.2. Stress and Anxiety: Gender differences**

A total of 19 studies measured the gender differences in stress and anxiety levels between infertile couples, using a variety of instruments. Of the 19 studies, 11 examined anxiety levels exclusively, three studies examined stress levels exclusively (Cserepes et al., 2013,

Galhardo et al., 2013, Sreshthaputra et al., 2008a), while four studies explored both stress and anxiety levels (Slade et al., 2007, Bayley et al., 2009, Musa et al., 2014, Brucker and McKenry, 2004b)(see Table 2.2).

### **2.5.2.1. Anxiety**

A total of 14 studies measured the anxiety levels of infertile couples of infertile couples, using different instruments: State-Trait Anxiety Inventory (Kazandi et al., 2011, Galhardo et al., 2011, Newton and Houle, 1993, Slade et al., 1997, Karlidere et al., 2007, Edelmann and Connolly, 2000, Cook et al., 1989), Fertility Problem Inventory (Bayley et al., 2009, Slade et al., 2007), Hospital Anxiety and Depression Scale (Anderson et al., 2003, Fatoye et al., 2008, Slade et al., 2007), Depression Anxiety and Stress Scale (Musa et al., 2014), Self-rating Anxiety scale (Liu and Zhao, 2011), the Brief Symptom Inventory (Brucker and McKenry, 2004a), the symptom checklist (Wischmann et al., 2009) (see Table 2.2).

Most of the studies that report on gender differences in psychological reactions to infertility suggest that infertile women exhibited higher anxiety levels than their male partners. For example, in a study that recruited 947 women and 899 of their male partners, to examine the emotional status of couples entering an IVF program, Newton et al (1990) observed that the women experienced significantly higher state and trait anxiety and depression compared to their partners. Two studies that also utilised the State-trait Anxiety Inventory, reported that females of infertile couples scored higher on the trait anxiety scale than their husbands (Edelmann and Connolly, 2000, Karlidere et al., 2007), however, only one study reported gender differences between infertile women and their husbands in the mean scores on the state anxiety subscale [STAI, M=36.72 vs 32.80] (Edelmann and Connolly, 2000).

Two studies that utilized the Hospital Anxiety and Depression Scale (HADS), observed mean scores of 3.93 versus 2.34 (Slade et al., 2007) and 6.05 versus 3.24 (Fatoye et al., 2008) for women and men respectively. Stating that women experienced more anxiety than their partners. Similarly, a study that used the Depression, Anxiety and Stress scale reported that more wives (56.1% vs. 30.1%,  $p < 0.05$ ) than husbands reported experiencing some form of anxiety (Musa et al., 2014). Additionally, in a longitudinal study that recruited 144 couples undergoing IVF, Slade et al (1997) observed that the state anxiety, trait anxiety and depression scores of the women were significantly higher than their partners. The authors equally reported lower scores on the self-esteem scale

for the women than their partners, however, the scores fell within the clinically acceptable range (Slade et al., 1997).

Two longitudinal studies examined the effect of time on anxiety levels between infertile men and women. In the first study of 113 couples which sought to examine emotional distress and infertility-related concerns in couples referred for infertility treatment and their changes over time, using the HADS, the authors reported that although there were gender differences within the anxiety subscale, the degree did not significantly change at the 6-month follow-up session [HADS, T1:T2, Women=25.7%: 21.8%, Men=8.9%: 10.9%](Anderson et al., 2003). In the second study that recruited 130 couples prior and 150 couples at follow-up, to explore if women experience greater distress than their partners with regard to infertility investigations and treatment, the authors reported gender differences on all measures (Edelmann and Connolly, 2000). However, overtime, there was no evidence of a differential increase in infertility attributable distress scores for women. This led the authors to posit that the claim that women are more adversely affected by infertility than men could just be attributed to gender stereotyping, as their study showed that women could adjust better to infertility. Of the seven studies that utilised the State-Trait Anxiety Inventory, four reported that among the infertile couples, women scored higher than their husbands/partners (Edelmann and Connolly, 2000, Newton and Houle, 1993, Slade et al., 1997, Karlidere et al., 2007). However, three studies reported no gender differences in the anxiety scores (Cook et al., 1989, Galhardo et al., 2011, Kazandi et al., 2011).

### ***2.5.2.2. Stress***

A total of seven studies explored the stress experienced by infertile couples using various survey instruments: Fertility Problem Inventory (Bayley et al., 2009, Cserepes et al., 2013, Galhardo et al., 2013, Slade et al., 2007, Sreshthaputra et al., 2008a), the Depression Anxiety and Stress Scale (Musa et al., 2014), and the Brief Symptom Inventory (Brucker and McKenry, 2004a) (See Table 2.2). A search of the literature found some studies that examined gender differences in infertility related stress using the Fertility Problem Inventory (FPI). All four of these studies reported that women experienced higher levels of infertility related stress than men (Cserepes et al., 2014, Bayley et al., 2009, Slade et al., 2007, Galhardo et al., 2013). Most studies reported higher stress levels in women than men. Using the FPI, four studies measured infertility related stress among

infertile couples and found that infertile women reported higher stress levels than men (Bayley et al., 2009, Slade et al., 2007, Galhardo et al., 2013, Cserepes et al., 2013). Similarly, a Malaysian study to evaluate characteristics and gender differences in perceived psychological difficulties reported by infertile couples, using the Depression Anxiety and Stress scale reported that stress was more prevalent among infertile women than men (25.2% vs 18.7%)(Musa et al., 2014). In Brucker and Mckenry, 2004, employing the Brief Symptom Inventory on 120 infertile couples, the authors concluded that females reported higher mean stress levels than males (M=0.75 vs 0.47) (Brucker and McKenry, 2004a). However, in a Thailand study by Sreshthaputra et al (2008), which sought to examine infertility related stress and social support among 238 infertile couples (124 women, 114 men), using the Fertility Problem Inventory, the authors reported that although infertile couples experienced a high level of stress, there was no gender difference in infertility-related stress [FPI: men vs women, 154.2 vs 154.7,  $p>0.05$ ] (Sreshthaputra et al., 2008a).

### **2.5.3. Relationship between Stress, Anxiety and ART outcomes**

Of the 15 studies, there are four studies reporting the effect of stress and anxiety on the ART outcomes. The first was a study by Berg and Wilson (1991), where the couples were separated into three different groups, based on the length of time they've spent pursuing fertility treatment. The authors reported that the stage of treatment may exert a major influence on the psychological function for infertile couples seeking treatment (Berg and Wilson, 1991). A year later, the longitudinal study by Connolly et al (1992) reported that scores on anxiety on the 252 individuals surveyed, declined between the first and second assessment which was over a period of about 7-9 months among couples seeking infertility treatment (Connolly et al., 1992). However, a study in the same year found no evidence that psychological stress had any influence on the outcome of IVF treatment (Anderhaim et al, 1992). A few more years ahead, a study by Ardenti et al (1999) reported that increased anxiety level was observed in participants with failed oocyte fertilisation, however, there were no significant differences in anxiety values with respect to the cycle number (Ardenti et al., 1999). A couple of years ahead, a longitudinal study by Turner et al (2013) estimated the stress and anxiety levels at different time points within the treatment cycle. The authors reported that stress and anxiety levels remained elevated across all cycles. Additionally, women with lower stress and anxiety

levels on the day prior to oocyte retrieval had a higher pregnancy rate (Turner et al., 2013).

It is noteworthy that age, educational level (Sultan and Tahir, 2011) and duration of infertility (Ardenti et al., 1999, Wiweko et al., 2017) play an important role in an infertile individuals state of stress or anxiety levels. For instance, in Wiweko et al (2017), the years of marriage, (also defined as the duration of infertility), the mean duration of infertility was a statistically significant risk factor for stress. However, one study by Chen et al (2004) that investigated the prevalence of depressive and anxiety disorders in 112 participants in a Taiwanese reproductive clinic, reported that demographic features and history of previous assisted reproductive treatment were not risk factors for anxiety disorders.

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients

<b>Author, year</b>	<b>Country</b>	<b>Participants</b>	<b>Study Design</b>	<b>Measures</b>	<b>Main findings</b>	<b>Limitations</b>
Anderhaim et al, 1992	Sweden	166 women	Prospective longitudinal study	Psychological General Well-being index (PGWB) and psychological effects of infertility by 14 items	There was no evidence that psychological stress had any influence on the outcome of IVF treatment.	Failure to find an association could be due to a lack of sensitivity of the instrument used
Anderson et al, 2003	UK	113 couples	Prospective cohort study	Hospital Anxiety and Depression Scale (HADS), Questionnaire for concerns in self-blame, self-esteem, avoidance and life satisfaction	Women scored higher in the anxiety scale, and avoided pregnant friends and those with children more than men	
Ardenti et al, 1999	Italy	200 women	Cross-sectional study	State-trait anxiety inventory (STAI-Y), Anxiety Scale Questionnaire (ASQ), Experiential World Inventory (EWI)	Women who experienced infertility for medium to long durations had lower state anxiety values. There were no significant differences in anxiety values with respect to the cycle number.	Poor response rate from participants probably due to failed fertilisation. Partners of the women were not included in the study.
Bayley et al, 2009	UK	98 women, 64 men	Cross-sectional study	Fertility Problem Inventory (FPI), Mental Health Inventory, Dyadic Adjustment Scale (DAS), Ways of Coping Scale	Attachment anxiety was associated with well-being via appraisal of infertility as a loss and use of self-blame in and avoidance coping in both men and women	Sampling bias towards white and higher education participants, and actively seeking treatment. The cross-sectional study design doesn't allow inferences to be made



Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

Author, year	Country	Participants	Study Design	Measures	Main findings	Limitations
Berg and Wilson, 1991	USA	104 couples	Cross-sectional study	General psychology was measured using SCL-90-R	The results suggest that the stage of treatment may exert a major influence on psychological functioning. An acute stress response reaction at initial diagnosis and treatment, overlaid with a chronic strain response to longer term treatment.	
Brucker and Mckenry, 2004	USA	73 women, 47 men	Cross-sectional study	Perceived support from health care providers, Global severity index (GSI), Brief symptom inventory (BSI)	Unlike men, for women, perceived support from health care providers did not predict levels of stress, depression or anxiety. For men it did but did not predict depression levels.	Cross sectional nature doesn't permit inferences to be drawn
Chen et al, 2004	Taiwan	112 women	Cross-sectional study	Hospital Anxiety and Depression scale	Majority of the women (40.2%) had a psychiatric disorder and most common diagnosis was anxiety disorder (23.2%)	
Connolly et al, 1992	UK	116 women and 107 men	Longitudinal study	General Health Questionnaire (GHQ), State-Trait Anxiety Inventory (STAI),	The results show little evidence of psychopathology in the sample, with low anxiety scores over the course of investigation. However, infertile participants were more anxious.	The two assessments were made in different settings; the first in the clinic, second in the patient's home, which could result in the decrease in anxiety assessment.

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

<b>Author, year</b>	<b>Country</b>	<b>Participants</b>	<b>Study Design</b>	<b>Measures</b>	<b>Main findings</b>	<b>Limitations</b>
Cook et al, 1989	UK	59 women and 34 of their partners	Cross-sectional study	State-Trait Anxiety Inventory (STAI); Beck Depression Inventory (BDI)	Both men and women experienced high levels of anxiety, but not depression.	The study has an insufficient sample size to generalise the main findings
Cserepes et al, 2013	Hungary	53 couples attending fertility unit	Cross-sectional study	Fertility Problem inventory (FPI), Beck Depression Inventory (BDI)	Infertility related stress have more intensive effects on women than men	Insufficient sample size, cross sectional nature doesn't permit inferences to be drawn
Downey and McKinney, 1992	USA	118 infertile women and 83 gynae-controls	Case controlled study	The Attitudes of Family scale; the Partner Relationship Satisfaction scale, the Brief Symptom Inventory (BSI), the Mood Disorder Questionnaire (MDQ).	Infertile women experienced more depressive episodes, however, this was not equivalent to psychological impairment. The infertile patients were as psychologically healthy as routine-care controls.	The study population consists of primarily white and middle-class patients, therefore does not depict the general population of sub-fertile women.
Edelmann et al, 1994	UK	152 couples referred to an IVF clinic	Exploratory study	General Health Questionnaire (GHQ), State-Trait Anxiety Inventory (STAI)	The results suggest that while infertility treatment could be emotionally demanding, couples presenting for IVF are generally well adjusted.	
Edelmann and Connelly, 2000	UK	130 couples prior, 150 couples at 7-months follow-up	Longitudinal study	General Health Questionnaire (GHQ), Beck Depression Inventory (BDI), State-Trait Anxiety Inventory (STAI)	Scores on the STAI and GHQ declined between assessments, with the scores for women showing greater decline over time than the scores for men	

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

<b>Author, year</b>	<b>Country</b>	<b>Participants</b>	<b>Study Design</b>	<b>Measures</b>	<b>Main findings</b>	<b>Limitations</b>
Fatoye et al, 2008	Nigeria	164 (82 women and their spouses)	Cross sectional study	Hospital Anxiety and Depression Scale (HADS)	The women had a significantly higher anxiety and depression scores than their husbands	The cross-sectional nature of the study prevents causal relationships to be examined
Galhardo et al, 2011	Portugal	100 infertile couples, 100 fertile couples, 40 adoption group	Cross-sectional study	Beck Depression Inventory (BDI), State Anxiety Inventory (STAI-Y)	Infertile women showed more depression, shame and self-judgement than men, but no differences in anxiety was observed	The authors caution a tentative approach to the findings, due to the cross-sectional study design
Galhardo et al, 2013	Portugal	162 women, 147 men	Cross-sectional study	Fertility problem inventory (FPI), Experience of Shame scale, Dyadic Adjustment scale	Women showed higher levels of infertility related stress than men	Methodological issues with sampling, design and analysis
Harlow et al, 1996	UK	Biochemical: 24 women in control, 25 IVF (unstimulated cycle), Survey: 95 for diagnostic laparoscopy following GnRH stimulation	Case-controlled study	State-Trait Anxiety Inventory (STAI), Serum hormone Assays: Cortisol from urine, Serum prolactin	Women who achieved a pregnancy had similar state anxiety scores to those who failed. Trait anxiety was constant within and between groups, suggesting that the degree of anxiety observed during IVF treatment is unlikely to influence the chance of pregnancy.	There was an insufficient sample size to compare the results according to diagnostic classification.

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

<b>Author, year</b>	<b>Country</b>	<b>Participants</b>	<b>Study Design</b>	<b>Measures</b>	<b>Main findings</b>	<b>Limitations</b>
Karlidere et al, 2007	Turkey	103 Infertile couples	Cross-sectional study	Spielberger state (STAI-S) and Trait Anxiety Inventory (STAI-T), Beck Depression Inventory (BDI), Perceived family support (PFS), Perceived peer support (PPS)	Women had more depressive symptoms than men when they were the cause of the couple's infertility, higher trait anxiety in all infertility groups, and perceived more family support.	Cross sectional nature doesn't permit inferences to be drawn
Kazandi et al, 2011	Turkey	248 infertile women, 96 infertile men, 51 fertile women, 40 fertile men	Cross-sectional study	The Beck Depression Inventory (BDI), State-Trait Anxiety Inventory (STAI)	Infertile couples experience more anxiety than their fertile counterparts, no gender differences were observed in anxiety and depression among the infertile group	Cross sectional nature doesn't permit inferences to be drawn
King et al, 2003	USA	Data of 10,847 women from the National Survey of Family Growth (NSFG)	Cross-sectional study	Generalised Anxiety Disorder (GAD)	Whether a sub-fecund respondent desires to have a child does not moderate the likelihood of being anxious, but does moderate the number of symptoms reported	The analysis was limited to the dichotomous category of the GAD and symptom severity among those that fit the diagnosis only.
Liu and Zhao, 2011	China	95 women, 69 men	Cross-sectional study	Self-rating anxiety scale (SAS), Self-rating depression scale (SDS), Coping style questionnaire (CSQ)	Depression and anxiety scores were higher for females than for males	Cross sectional nature doesn't permit inferences to be drawn

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

<b>Author, year</b>	<b>Country</b>	<b>Participants</b>	<b>Study Design</b>	<b>Measures</b>	<b>Main findings</b>	<b>Limitations</b>
Martins et al, 2014	Portugal	191 married infertile couples	Cross-sectional study	Multi-dimensional scale of perceived social support	Infertility stress was found to be associated with low family support for women, and low partner support for both	The study data are cross sectional and the generalizability of results are limited by self-selection
Musa et al, 2014	Malaysia	124 infertile couples	Cross-Sectional Study	The Depression, Anxiety and Stress Scale (DASS), Coping Inventory for Stressful situation (CISS)	Depression, anxiety and stress-related difficulties were reported at significantly higher frequency by wives than husbands	Small sample of participants with prior experience of the treatment as well as the cross-sectional study design made causal determinants of stress and anxiety limiting.
Newton et al, 1993	Canada	947 women and 899 men	Longitudinal study	State-Trait Anxiety Inventory (STAI); Beck Depression Inventory (BDI)	Women experienced higher transitory anxiety and depression levels than men before the treatment. After a failed first cycle, both males and females showed significant increases in anxiety and depressive symptoms.	Issues with self-report measures of stress
Slade et al, 2007	UK	151 (87 women and 64 men) 62 couples at their first fertility appointment	Cross-sectional study	Fertility Problem Inventory (FPI), Hospital Anxiety and Depression Scale (HADS)	Women reported significantly higher distress in terms of infertility related strain, anxiety and depression than men	Insufficient sample size due to low participation rate, which increases sampling bias.

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

Author, year	Country	Participants	Study Design	Measures	Main findings	Limitations
Slade et al, 1997	UK	144 couples embarking on their first cycle of IVF treatment.	Prospective longitudinal study	The State-Trait Anxiety Inventory (STAI), The Beck Depression Inventory (BDI), The Dyadic Adjustment Scale (DAS)	Women scored significantly higher on state anxiety, trait anxiety and depression than their partners. First and last treatment cycles were associated with greater anxiety.	
Sultan and Tahir, 2011	Pakistan	200 infertile couples and 200 fertile couples	Cross sectional study	Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), Marital satisfaction questionnaire	Infertile women demonstrated more anxiety compared to men, when they remain childless. Infertile couples demonstrated higher levels of anxiety and depression compared to fertile couples	Sample size, sampling method and income level are not representative of the infertile population in Pakistan
Sreshthaputra et al, 2008	Thailand	124 women, 114 men	Cross-sectional study	Fertility Problem Inventory (FPI), personal resource questionnaire (PRQ)	No gender differences were found in the FPI scores and perceived social support.	Cross sectional nature doesn't permit inferences to be drawn
Turner et al, 2013	USA	44 women undergoing IVF	Prospective cohort pilot study	The State-Trait Anxiety Inventory (STAI), Perceived stress scale (PSS), Infertility self-efficacy scale (ISES)	Women with lower stress and anxiety levels on the day prior to oocyte retrieval had a higher pregnancy rate. Stress and anxiety levels remained elevated across all cycles	Insufficient sample size, constraints of self-report measures of stress and anxiety, selection bias.

Table 2.2: Studies depicting variations in stress and anxiety patterns as well as gender differences in infertile patients (contd.)

Author, year	Country	Participants	Study Design	Measures	Main findings	Limitations
Vartiainen et al, 1994	Finland	191 women with no history of prior infertility; 180 at follow-up	Prospective study	Questionnaires adapted from the Finnish Institute of Occupational Health forms; The State-Trait Anxiety Inventory (STAI); A semi-structured psychiatric interview; and psychological testing	No differences in psychological tests, attitudes and life styles between the fertile and infertile samples were observed	The participants were mentally healthier than the average population. Additionally, the study methods were not exact enough to predict the participant's somatic reactions to a variety of life events, and therefore cannot be generalised.
Verhaak et al, 2001	Netherlands	207 women embarking on their first IVF & ICSI cycle	Longitudinal study	State-Trait Anxiety Inventory (STAI), Beck Depression Inventory (BDI)	Women in the sample did not differ from the normal group in terms of anxiety and depression levels	Selection bias; stress was given as a reason for non-participation
Wischmann et al, 2009	Germany	633 women, 535 men	Cross-sectional study	Questionnaire on stress-inducing events in the couple's lives	Women had higher anxiety levels than men in taking up counselling, while no significant difference was found in the no counselling group	Cross sectional nature doesn't permit inferences to be drawn
Wiweko et al, 2017	Indonesia	63 infertile patients	Cross-sectional study	Self-reporting questionnaire-(SRQ-20)	22% of the patients experienced stress mainly associated with the duration of their infertility	The study design did not allow for causation to be examined

## **2.6. MODERATORS OF STRESS IN INFERTILITY**

The effects of stress on infertility and ART has been documented in the previous sections, however, in the biopsychosocial theory, coping and support are regarded as two essential factors that mediate the impact of infertility and infertility related stress on the couples. A total of nine studies shown in Table 2.3, explored the coping strategies and the perception that infertile couples have of the support that they received from partners, family, friends and health care professionals.

### **2.6.1. Coping with stress and anxiety**

Four studies explored coping strategies, and used instruments, including the Ways of Coping Scale (Bayley et al., 2009), Coping style questionnaire (Liu and Zhao, 2011), Coping Inventory for Stressful situation (Musa et al., 2014) and Brief Stress and Coping Inventory (Cserepes et al., 2013).

In coping with infertility, Bayley et al, (2009) using the ways of coping-revised scale, reported that in coping with infertility, women reported greater use of self-blame and avoidance compared to men (mean=1.80 vs. 1.10), made more effort to seek emotional support (mean=1.86 vs. 1.20) while having higher levels of infertility related stress and lower total well-being (Bayley et al., 2009). Conversely, a Hungarian study using the Life Meaning Subscale from the Brief Stress and Coping Inventory, Cserepes et al, (2013) observed that men reported the use of a meaning-based coping strategy more than the women (M=12.62 vs. 11.11).

In contrast, a study by Musa et al (2014), using the coping inventory for stressful situations, reported that there was no significant gender difference among infertile couples in three coping styles: task-oriented coping, emotion-oriented coping and avoidance coping (Musa et al., 2014). Similarly, a Chinese study utilizing the coping styles questionnaire, reported no statistically significant gender differences in the coping styles of problem-solving, self-accusation, help-seeking, avoidance and rationalization among infertile men and women (Liu and Zhao, 2011). The authors further reported that infertile women more often than men use fantasy as a coping strategy (M=0.5 vs 0.4) (Liu and Zhao, 2011).



## **2.6.2. Social Support**

The results presented in Table 2.3 demonstrate that seven studies explored the social support perceptions infertile couples have from partners, family, friends and health care providers, using various instruments: Perceived support from health care providers (Brucker and McKenry, 2004a), Perceived family support (PFS) and Perceived peer support (PPS) (Karlidere et al., 2007), Multi-dimensional scale of perceived social support (Martins et al., 2014), Personal Resource questionnaire (Sreshthaputra et al., 2008a) and a self-developed scale (Slade et al., 2007, Wischmann et al., 2009, Anderson et al., 2003).

### ***2.6.2.1. Support from Family and Friends***

Of the seven studies, three reported no significant gender difference in perceived social support from family and friends (Slade et al., 2007, Sreshthaputra et al., 2008a, Wischmann et al., 2009). For instance, in Sreshthaputra et al (2008), the authors observed that social support was negatively correlated to stress in infertile women but not the men. They suggest that this could be because men and women use different mechanisms to cope with infertility (Sreshthaputra et al., 2008a). Similarly, one study used the marriage and partnership subscale of the Life satisfaction questionnaire to determine the psychosocial characteristics of men and women attending infertility counselling. The authors reported no gender differences in the satisfaction with friends, acquaintances and relatives in infertile couples attending counselling (Wischmann et al., 2009). Additionally, they reported no gender differences in satisfaction with marriage in both the group that took up counselling and those that did not. However, the results showed that higher distress for men in the counselling group was indicated by dissatisfaction with the relationship and because they seemed to worry about their partners depression (Wischmann et al., 2009).

In regard to support from family and friends, one study found a strong association between partner support and infertility related stress in both infertile men and women. Martins et al (2014), using both the multi-dimensional scale for perceived social support reported that low levels of family and partner support were associated with infertility related stress in women, while only partner support was correlated with infertility related stress for men. However, support from friends was not correlated with the infertility related stress experienced in either men or women (Martins et al., 2014).

It is important to note that in a few studies, the diagnosis/aetiology of infertility (male factor, female factor, unexplained) played a role in the perception of support received by the infertile couple. For instance, in a Turkish study by Karlidere et al (2007), although the scale used could not adequately define the mean perceived social support scores as either high or low, it was able to detect that in couples with female (M=26.5 vs. 22.3) and male (M=26.4 vs. 23.1) infertility, the perception of familial support was greater among women than men. However, no gender differences were observed for perception of peer support in both causes of infertility (Karlidere et al., 2007). The study equally examined the buffering hypotheses of social support on infertility related stress and reported that when the cause of infertility was unknown and when both partners were infertile, the perceived social support was unrelated to emotional symptoms of the individual. However, when one spouse was the direct cause of the infertility, emotional symptoms decreased as social support increased (Karlidere et al., 2007).

Based on the results of these studies, although majority of the studies found no gender differences in perceived social support, few showed that infertility related stress in women was negatively related to support from partners and family. However, for infertile men, perceived support from health care providers inversely predicted their stress.

#### ***2.6.2.2. Support from health care providers***

With regard to support from health care providers, due to the large numbers of infertility clinics and the amount of contact health care professionals have with sub-fertile couples seeking treatment, Brucker and McKenry (2004) established a study to examine the relationship between the support provided by health-care professionals and psychological adjustment for infertile couples (n=120). The authors observed that greater levels of perceived support from healthcare providers predicted lower levels of stress and anxiety in men but not for women. They concluded that support from nurses and other health service providers might buffer negative psychological adjustments in sub-fertile men (Brucker and McKenry, 2004b). The study however, did not address the reasons for this difference. The low-response rate and sampling bias are further limitations to the generalisability of this study.

Table 2.3: Studies showing the psychological adjustment and social support patterns among infertile couples

Author, year	Country	Participants characteristics	Study Design	Measures	Main findings	Limitations
Anderson et al, 2003	UK	113 couples	Prospective cohort study	Questionnaire for concerns in self-blame, self-esteem, avoidance and life satisfaction	Women avoided pregnant friends and those with children more than men	
Bayley et al, 2009	UK	98 women, 64 men	Cross-sectional study	Fertility Problem Inventory (FPI), Mental Health Inventory, Dyadic Adjustment Scale (DAS), Ways of Coping Scale	Attachment anxiety was associated with well-being in via appraisal of infertility as a loss and use of self-blame in and avoidance coping in both men and women	Sampling bias towards white and higher education participants, and actively seeking treatment. The cross-sectional study design doesn't allow inferences to be made
Brucker and Mckenry, 2004	USA	73 women, 47 men	Cross-sectional study	Perceived support from health care providers, Global severity index (GSI), Brief symptom inventory (BSI)	Support from nurses and other health care providers might provide greater understanding of ways to buffer negative psychological adjustment for men experiencing infertility in the couple relationship.	Low-response rate and sampling bias limit the generalisability of the study.
Cserepes et al, 2013	Hungary	53 people attending fertility unit	Cross-sectional study	Brief Stress and Coping Inventory	Men reported the use of a meaning-based coping strategy more than the women	

Karlidere et al, 2007	Turkey	103 Infertile couples	Cross-sectional study	Perceived family support (PFS), Perceived peer support (PPS)	Compared to men, women had more perceived social support of the family, whether they or their husbands were the cause of infertility.	Sample bias as the study excluded infertile couples with psychiatric diagnosis. Exclusion of individuals with less than 11yrs education
Liu and Zhao, 2011	China	95 women, 69 men	Cross-sectional study	Self-rating anxiety scale (SAS), Self-rating depression scale (SDS), Coping style questionnaire (CSQ)	Depression and anxiety scores were higher for females than for males	
Martins et al, 2014	Portugal	191 married infertile couples seeking treatment	Cross-sectional study	Multi-dimensional scale of perceived social support, Fertility Problem Inventory (FPI)	Infertility stress was found to be associated with low family support for women, and low partner support for both men and women ( $p < .001$ ). Men infertility stress was associated with their partners low levels of partner and family support ( $p < .001$ ). No significant partner effects were observed for women.	The study data are cross-sectional, and the generalizability of results is limited by self-selection. Self-selection bias limits the generalizability of the findings
Musa et al, 2014	Malaysia	124 infertile couples	Cross-Sectional Study	The Depression, Anxiety and Stress Scale (DASS), Coping Inventory for Stressful situation (CISS)	No significant gender differences in active or passive avoidance as a coping strategy for infertility related stress	Small sample of participants with prior experience of the treatment
Slade et al, 2007	UK	151 (87 women and 64 men) 62 couples at their first fertility appointment	Cross-sectional study	Fertility Problem Inventory (FPI), Hospital Anxiety and Depression Scale (HADS)	Social support was negatively related to anxiety, depression and overall infertility distress	Relatively small sample size

					and showed greater predictive capacity than satisfaction with partner relationship.	
Sreshthaputra et al, 2008	Thailand	124 women, 114 men	Cross-sectional study	Fertility Problem Inventory (FPI), Personal Resource questionnaire (PRQ)	There was a significant negative correlation between the global stress scores and the scores of perceived social support in infertile women ( $p < 0.001$ ), but not in men.	
Wischmann et al, 2009	Germany	633 women, 535 men	Cross-sectional study	Questionnaire on stress-inducing events in the couple's lives	No gender differences in the satisfaction with friends, acquaintances and relatives among infertile couples	A homogeneous sample was not examined, high proportion of academics prevents generalisability of results

## 2.7. DISCUSSION

This review explored evidence available from the research literature to understand the patterns of stress and anxiety in infertile couples, as well as examine the methods used to cope with them. The psychological experiences (stress and anxiety) of infertile couples were explored from the perspective of the biopsychosocial theory. The findings from the existing literature were organised into two domains: stressors and moderators

### *Stressors*

#### *Stress and Anxiety*

The results of this review showed that women generally had more negative experiences with infertility than men in the two major stressors examined, which are stress and anxiety. There were some inconsistencies in these study findings, however, these may be attributed to two reasons. Firstly, the variation in study samples (men, women or couples) and secondly, the variations in survey instruments used, such as the use of the State Trait Anxiety Inventory, the Beck Anxiety Inventory and the Hospital Anxiety Depression Scale to measure anxiety.

The majority of studies included in this review showed that infertile women reported higher levels of stress and anxiety than men when seeking treatment. However, it is possible that these gender differences might be influenced by gender stereotyping as women tend to report more distress than men (Edelmann and Connolly, 2000), as studies have shown that social norms emphasise a woman's role in childbearing. This might explain the gender differences in stress and anxiety patterns, as women feel more responsible for infertility than men (Greil et al., 2010). Majority of the research assessing the hypothesis of infertility being a source of psychological distress consists of studies that adopt predominantly quantitative research methods. Some researchers use standardised survey instruments that have been validated or normalised on a general population to compare with the sub-fertile population, to observed differences and similarities, while others compare the sub-fertile population with controls. When sub-fertile women are compared with controls; which sometimes includes either pregnant women or women with no history of subfertility, the evidence generated from this review has shown that they are more likely to experience higher levels of distress than comparison groups.

A few confounding factors such as age, educational level, duration of infertility and stage of treatment were identified in the review as socio-demographic factors that can predict infertility related stress. However, other factors such as economic status, marital status and cultural differences have not been taken into account and need to be investigated.

In conclusion, studies on gender differences and similarities in the psychological reactions to subfertility have made some interesting observations. However, most recent studies confirm earlier research that infertility is more distressing for women compared to men, because the effect of infertility is more 'direct' for women, while men experience the effect of infertility through their wives (Holter et al., 2006, Slade et al., 2007, Monga et al., 2004, Greil et al., 2010). This could be for a number of reasons, which include that women are more invested in having children (White et al., 2006), more treatment-oriented (Pasch and Christensen, 2000) and most importantly, women experience more stigma than men (Slade et al., 2007, Greil et al., 2010, McQuillan et al., 2003, Remennick, 2000).

## **Moderators**

### ***Coping***

The majority of papers identified in this review reported that infertile women had the tendency to perceive themselves as less capable of coping with infertility than their male partners. Regarding coping strategies, a number of instruments measuring various styles of coping strategies were employed by studies in this review. This equally made comparing findings rather difficult. Although these studies reported a variety of coping strategies, they can all be grouped under three major categories: emotion-focused coping, problem-focused coping and meaning-based coping (Peterson et al., 2006b). Emotion-focused coping refers to removing oneself from potentially painful situations (Schmidt et al., 2005b). These include: self-blame and avoidance (Bayley et al., 2009), self-accusation and rationalisation (Liu and Zhao, 2011). Under the category of problem-focused strategies, which refers to attempts at modifying stress by taking action towards a resolution, help seeking (Liu and Zhao, 2011), and seeking emotional support (Bayley et al., 2009), were identified, while strategies such as life-meaning coping which describes as seeing the positive side of a situation can be grouped under meaning-based coping.

It is therefore expected that majority of infertile couples would employ an emotion-focused strategy as opposed to a problem-focused strategy (Cserepes et al., 2013, Wischmann et al., 2009), as was evidenced in the studies included in this review. The finding that women more than men adopted an emotion-focused strategy has equally been supported by findings in an earlier study and review (Jordan and Revenson, 1999, Peterson et al., 2006a). Although the included studies have examined the coping strategies adopted by infertile couples there are significant gaps in the literature that have been identified through this review. Firstly, insufficient longitudinal studies exist to adequately examine the outcome (beneficial or otherwise) of these coping techniques before, during and after treatment.

### ***Social support***

Gender differences in the seeking and giving of social support has been addressed in research over the years (Abbey et al., 1991a, Abbey et al., 1995, Jordan and Revenson, 1999). In the vulnerable and high stressed time of infertility, some studies including a meta-analysis by Jordan and Revenson (1999) have shown that women in response to these stressors more readily seek social support than men. Inconsistent with the findings from previous reviews, most included studies found no gender differences in perceived social support among infertile couples. However, it was observed that infertile women reported more family support than men, while more men reported support from health care providers than women. In both men and women, partner support was inversely related to stress.

There is ample evidence of the buffering effects of social support on the negative effects of stress and psychological adjustment in a number of chronic stressors such as HIV-positive status, cancer, myocardial infarction (Kalichman et al., 2003, Schwarzer and Knoll, 2007, Moak and Agrawal, 2009), including infertility (Veloso-Martins et al., 2010, Abbey et al., 1991b, Abbey et al., 1995); which is so called because no immediate resolution can be offered and as Fleming and Burry (1988) state, 'it requires adaptation over time'. However, infertility differs from other stigmatized identities such as a HIV-positive status or homosexuality (Cousineau and Domar, 2007, Slade et al., 2007, McQuillan et al., 2003) because young married couples are often confronted by questions from family and friends about pregnancy and childbearing (Bute, 2009), therefore, they



have to deal with the anxiety that their infertility status would be revealed at some point (Ragins, 2008).

## **2.8. ADOPTION OF THE BIOPSYCHOSOCIAL THEORY**

The studies included in this review have revealed that infertility has impacts on the emotional and social domains, mediated by coping strategies and social support (Greil, 1999, Greil et al, 2010, Ying et al, 2015). Although some of the dynamics between stressors and moderators were identified in this review, further scrutiny is needed to strengthen the model by further examining the interactions between stressors and moderators (such as social support).

Furthermore, as previous research has suggested that the infertility experience is shaped by socio-cultural contexts such as race, ethnicity, religion and social class (Greil et al, 2010), it might be prudent to explore the cultural and social dimensions of the infertility experience and incorporate it into this model. For instance, a study by Bak et al (2010) conducted in Korea, reported that elevated depression levels were found in men when the cause of infertility was a low sperm count, which is a situation in which cultural and social expectations may be quite significant. However, in this review, all but one study reported that women regardless of country experienced more infertility related stress than men. Therefore, the influence of social and cultural settings should be considered in research and practise.

## **2.9. LIMITATIONS OF THE REVIEW**

This review has identified significant limitations and important gaps in the current knowledge base and has indicated some areas for further research. The studies discussed begin to give some indication of the types of instruments employed as well as the geographical disparity in researching this phenomenon. The studies reviewed demonstrated evidence only in terms of the effect of infertility related stress on women/couples in HIC. As few studies on stress and anxiety in infertility have been conducted in LMIC, it is important to recognise that generalisation from such limited data is problematic. More studies in LMIC are required before any clear conclusions can be made about the global picture regarding stress and anxiety patterns among infertile couples.

In addition to the limited empirical research in low-middle income countries, almost all the studies in this review used structured questionnaires. This makes achieving a holistic and nuanced understanding of the motivations, experiences and needs of the infertile couples difficult. The existing questionnaires have not effectively explored the patient's perspectives on factors that contribute to their stress and anxiety, and therefore these issues are under reported in the literature. Additionally, most studies that sought to examine gender differences in coping with infertility, use raw scores from the survey instruments in their analysis, which inherently over emphasizes women's coping behaviors and under-reports those of their partners.

Furthermore, a methodological limitation to the studies included in this review is that in all but one of the studies, the participants were clinic-based recruitments, and therefore infertile couples who had not sought treatment from health services were underrepresented. Additionally, a meta-analysis of the results could not be conducted. Although some of these studies measured similar concepts, the results were detailed in different ways with a number of variables and some only included a few studies, making it impossible for a meta-analysis to be carried out.

Additionally, there are insufficient longitudinal studies (Berghuis and Stanton, 2002, Martins, 2012) to effectively examine the outcome (beneficial or otherwise) of these coping techniques before, during and after treatment. As the efficacy of a coping strategy is determined by its effects in a given situation and long term (Sheu et al., 2002), longitudinal studies are of great importance especially because treatment failure is a frequent occurrence in this condition. As most studies employ a cross sectional design, it makes the determination of the directionality of findings between stress and coping strategies quite challenging.

Therefore, improved international data collection as well as a critical interdisciplinary cooperation rooted in empirical research and infused with social and economic variables will challenge theories and concepts and develop a more holistic understanding of this growing phenomenon. The considerable difficulties of collecting data on this topic are acknowledged in several contributions as patients particularly those in LMIC first seek alternative treatment sources before coming to orthodox clinic,

while a number do not seek treatment. This had led to suggestions that it would be more effective to collect data in the receiving clinics.

## **2.10. RECOMMENDATIONS FOR FUTURE RESEARCH**

Some directions for future studies was provided by this review. Firstly, while quantitative research techniques are advantageous, in assessing various responses, qualitative research provides a unique approach to achieve an in-depth understanding of the experiences of infertile couple. Greil et al (1997) in his critique on the literature on infertility and psychological distress states that the strength of much of these qualitative literature on infertility is that “it analyses the experience of infertility within its social context, paying special attention to gender roles, family structure, couple relationships and the importance of infertility treatment in shaping reactions to infertility”(Greil, 1997). Therefore, an integration of both research methods in the same study might be valuable in order to capture the whole spectrum of the experiences of infertile couples, including treatment seeking behaviour, economic consequences as well as pre and post treatment outcomes.

### ***Summary***

In this chapter, literature on the stress of infertility and the moderators of stress in infertility were reviewed. In summary, ART has been used to help infertile couples conceive, however, the treatment has been shown to contribute to the stress experienced by these couples, and the majority of the studies were performed in high income countries. It is therefore imperative to know the stress patterns of infertile couples in a LMIC compared to those in a HIC. The moderators of infertility related stress were discussed, highlighting coping strategies and social support as the major moderators in the literature. Overall, infertile women had a more negative experience than men, however, partner support was reported to be an important element of coping with infertility. While coping strategies can directly impact infertility related stress, a few studies have shown that they can equally act as mediators between stress and social support; where an increase in support facilitates effective coping strategies and in turn promotes better quality of life (Veloso-Martins et al., 2010). Therefore, it would be valuable to explore the psychological effects of infertility in different geographical

locations and interventions which aim to strengthen the coping mechanisms of infertile couples.

### **2.11: THE PHD PRIMARY RESEARCH PHASE: RATIONALE**

Firstly, there is scarce data regarding the differences in stress and anxiety levels associated with ART access and to our knowledge, no study has compared stress associated with ART in high-income countries<sup>7</sup> (HIC) to low-middle income countries<sup>8</sup> (LMIC). Because of the psychological effect stress (emotional and financial) can evoke in sub-fertile women, it is important to examine the behaviors these women use to minimise their experiences of it (Steuber and High, 2015). A growing body of research has documented the buffering effects of social support on stress (Aslund et al., 2014, Cohen and Wills, 1985, Dignam et al., 1986, Hyde et al., 2011, Lechner et al., 2006, Pidgeon et al., 2014), and it has been repeatedly linked to positive psychological wellbeing (Pidgeon et al., 2014, Uchino, 2009). The existing studies that examined the relationship between social support and infertility-related stress particularly in LMIC, have primarily used informants with no direct access to ART as a proxy for subfertility, and therefore presented results on informants descriptions of the psychosocial consequences of subfertility (Sreshthaputra et al., 2008b, Hollos, 2003, Hollos et al., 2009). Additionally, qualitative researchers in this niche have employed ethnographic study methods to examine this phenomenon. Although the ethnographic studies provide rich detail into the lived experiences of infertile couples, again predominantly social consequences are explored (Dyer and Patel, 2012, Dyer et al., 2013). There has been little evidence to date to support the hypothesis that social support buffers the overall life stress to ART relationship. This study would therefore investigate the moderating effect of social support on the stress related anxiety and quality of life in sub-fertile women funding ART in the UK and Nigeria.

Secondly, demographic studies on the economic implications of ART to the nation's health expenditure in HIC have often treated ART affordability as a "black box", without adequately exploring the intricacies through which ART costs influences the

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<sup>7</sup> High Income countries (HIC) is defined by the World Bank as those countries with a gross national income (GNI) of \$12.236 or more (<http://worldbank.org>)

<sup>8</sup> Low-middle income countries (LMIC) is defined by the World Bank as those countries with a GNI per capita between \$1.026 and \$4.035 (<http://worldbank.org>)

quality of life of the couple. Studies in LMIC that actually provide information on the cost of an IVF cycle are limited (Widge, 2005, Wiersema et al., 2006, Nahar and Richters, 2011), and those that qualitatively obtained information on the affordability of ART, provided no further information on either the household income before the treatment or the impact to the household. The authors simply concluded that couples were at an increased risk of exploitation and financial stress. Although the evidence was suggestive of the infertile couple's likelihood to engage in a form of financial sacrifice, and in turn induce financial stress, there was insufficient evidence to effectively determine the occurrence of ART 'unaffordability'. The present study tries to move past mere explanations of affordability based on population expenditure data (like most HIC studies) and subpar justifications of financial stress (like most LMIC studies) by exploring the underlying processes through which affordability of ART and the perceived quality of life of the sub-fertile couple are linked.

Furthermore, research suggests that psychological stress has a negative effect on reproductive function (Hjollund et al., 1999) and pre-treatment stress and anxiety is associated with increased discontinuation from treatment after one cycle of *In vitro* fertilisation (IVF) as well as reproductive failure (Smeenk et al., 2004). Financial stress ('persistent inability to afford the basic necessities of life') (Peirce et al., 1996) has also been implicated as a major cause of increased cycle discontinuation rates and in some cases failure rates (Smeenk et al., 2004). The psychological examination of women or couples undergoing fertility treatment often neglects the financial issues that couples face with regards to the cost of the treatment. Unlike most developed countries like the UK that provides some sort of funding assistance, sub-fertile Nigerian couples seeking reproductive treatment have no alternative than to fund the treatment themselves and few studies have explored the additional stress posed by the financial burden of privately funding ART. However, to my knowledge, no study has explored this aspect in Nigeria.

## **2.12. OBJECTIVES AND SPECIFIC RESEARCH QUESTIONS**

The specific research questions are listed below

**Objective 1:** To examine the extent to which affordability of ART contributes to the stress and anxiety of women in both countries

***Specific research questions:***

- 1.1. *What are the stress patterns of the women accessing ART in the UK compared to Nigeria?*
- 1.2. *What can be learned from a comparison of affordability of ART in the UK with Nigeria?*

The examination of stress during ART often neglects other concerns that women face which may have an impact on their quality of life. Therefore, a third research question was formulated, to assess the perceived quality of life of sub-fertile women self-funding ART.

- 1.3. *To what extent is the perceived quality of life experienced by women in both countries affected by funding the treatment?*

**Objective 2:** To explore the role and effect of social support in women accessing ART

**Specific research questions:**

- 2.1. *What is the impact of social support mechanisms on women accessing ART in UK compared to the Nigeria?*
- 2.2. *To what extent does social support contribute to the quality of life of sub-fertile women undergoing the treatment?*
- 2.3. *What role does social support play with how sub-fertile women cope with stress.*

**PART II:**  
**METHODOLOGY**  
**& METHODS**

## **CHAPTER 3: GENERAL METHODOLOGY**

### **3.0. INTRODUCTION**

The previous chapter presented evidence from a review of the literature to outline the important relationship between stress, social support and affordability of assisted reproductive treatment among infertile couples in HIC and LMIC. The literature review also highlighted the gaps and justification for further research to address the gaps. This chapter aims to describe the general mixed methods approach that was adopted in this study to address the gaps identified from the literature, as well as explain the research methodology and strategy. This chapter is divided into three parts. The first part is made up of sections 3.1-3.6 which presents an overview of the methodological approach, including a discussion of the epistemological underpinnings of mixed methods approach is presented. Followed by a description and justification of the study design employed in this mixed methods study. Section 3.6 describes the ethical considerations within the study in both countries. [for] and methods used in quantitative data collection and analysis. The second part made up of sections 3.7-3.12 presents the quantitative research methods, while the third part, 3.13- 3.17 describes the rationale [for] and methods used to collect and analyse the qualitative data.

### **3.1. PHILOSOPHY OF RESEARCH**

The 'worldview' of researchers is informed by the assumptions they make based on their knowledge, experience or preferences. These components either singly or in combination will influence the method/approach the researcher adopts and applies to a particular research topic (Saunders, 2011). It is vital to understand the relationship between philosophy and research methods because as stated by Easterby-Smith et al. (2002) it enables the researcher to make a more informed decision about the research design, particularly in knowing which design would work and which wouldn't. Creswell (2009) describes four different worldviews: positivism, constructivism, pragmatism and advocacy or participatory. A summary of the major components of each worldview is presented in Table 3.1 (Creswell (2009, p.6).



**Table 3.1:** The Four Worldviews

<b>Positivism/post-positivism</b>	<b>Constructivism</b>
Determination	Understanding
Reductionism	Multiple participant meanings
Empirical observation and measurement	Social and historical construction
Theory verification	Theory generation
<b>Pragmatism</b>	<b>Advocacy/Participatory</b>
Consequences of actions	Political
Problem-oriented	Empowerment issue-oriented
Pluralistic	Collaborative
Real-world practice oriented	Change-oriented

The positivist researcher holds the view that “*social research should adopt scientific methods, which consist of the rigorous testing of hypotheses by means of data that take the form of quantitative measurements*” (p.251)(Atkinson and Hammersley, 1994). These researchers are of the view that research should be conducted in an objective and value-free approach in which the researchers perspective or values do not affect the research and interpretation of the findings (Teddlie and Tashakkori, 2009). They posit that a single reality is expressed in terms of variables and measurements using standardised definitions. Positivist researchers mainly adopt a quantitative approach to explore knowledge (Onwuegbuzie and Leech, 2005).

Constructivist researchers, on the other hand, argue that “*there are multiple-constructed realities and multiple interpretations are available from different researchers that are all equally valid (ontology)*” (Teddlie and Tashakkori, 2009). The constructionist argues that research should be conducted in a subjective and value-bound approach (axiology), in which the researcher and the object of their study are dependent on each other (epistemology) (Onwuegbuzie and Leech, 2005). These researchers usually use a qualitative research approach to explore the world (Onwuegbuzie and Leech, 2005).

Consequently quantitative and qualitative research methods have been used in social research to understand the social world and generate knowledge (Teddlie and Tashakkori, 2009). While quantitative researchers are interested in numerical data and analyse the data using statistical methods, qualitative researchers are interested in understanding and analysing the social context and the views of their research participants (Bergman, 2008, Lewis and Ritchie, 2003, Teddlie and Tashakkori, 2009). Thus they mostly use textual data (Teddlie and Tashakkori, 2003). The characteristic

features of quantitative and qualitative research paradigms are summarised in Table 3.2 below.

**Table 3.2:** Characteristics of Quantitative & Qualitative research (Hammersley, 1992)

Quantitative	Qualitative
Idealism	Realism
The quest for objective knowledge	The quest for subjective knowledge
Single reality	One, many or no constructed realities
Underpinned by objectivist ontology	Underpinned by subjective ontology
Ability to generalise beyond contextual limits	The centrality of context, cannot generalise
Deductive research	Inductive or exploratory research
Utilises questionnaires and statistical tools	Utilises in-depth interviews and thematic analysis
Possibility and necessity of value-free research	Value-laden research process and output

Despite the benefits that come with using quantitative or qualitative research to address specific research questions, their single use to understand the social world has been strongly debated (Sechrest and Sidani, 1995). Some researchers notably the pragmatists believe that both methodologies have their strengths as well as their weaknesses when used alone in a single study. Therefore, combining qualitative with quantitative methods in one study will allow the strength of one method to compensate for the weakness of the other. This will also help the researchers to develop a holistic picture of what is being researched (Vidich and Shapiro, 1955).

Thus mixed methods researchers are often referred to as pragmatic researcher (Morgan, 2014, Joas, 1990). This stems from the paradigmatic claims of quantitative methods being synonymous with positivism and qualitative methods synonymous with constructivism.

### 3.2. MIXED METHODS APPROACH

Mixing methods in a single study offers an alternative to the traditional quantitative and qualitative research methods as described above. Teddlie and Tashakkori (2003) define mixed methods research as a *“type of research design in which qualitative and quantitative*

*approaches are used in the research methods, data collection, analysis procedures and inferences within a single study or programme of inquiry”* (p7). By definition, mixed-method research involves combining both qualitative and quantitative approaches in a single study to address a research question.

Mixed method designs are advantageous primarily for their triangularly, comprehensive, complementary and confirmatory approach to research. Social scientists, as well as health service researchers, often favour this method because it provides a more comprehensive understanding of the research topic (O’Cathain et al., 2007b). Moffatt et al. (2006) contend that using a mixed-method approach to study complex health issues *“increases the likelihood of arriving at a more thoroughly researched and better understood set of results”* (p.10) (Gell, 2013).

However, opponents of mixed methods research will argue that research methods are connected to the epistemological and ontological tenants underpinning the research (Shank, 2007, Howe, 2004, Holmes, 2006). Some researchers feel that quantitative and qualitative methods should not be combined since “the different methodologies subscribes to different versions of reality and how that reality can be interpreted (Giddings, 2006, Howe, 2004). It is further argued that qualitative and quantitative research methods are different paradigms and paradigms cannot be judged by a single standard of measurement, therefore, they cannot be integrated or mixed in a single study(Howe, 2004, Holmes, 2006). Those who favour mixed methods, however, have maintained that choosing a research method is not based solely on the researcher’s ideological views, rather the choice of a research method should be driven by the practicalities and appropriateness of the method to address the selected research question (Platt, 1998, Devine and Heath, 1999, Greene et al., 1989, Tashakkori and Teddlie, 1998).

### **3.2.1. The justification for using a mixed methods design for this study**

#### ***3.2.1.1. Why was a single design not used?***

Quantitative positivist research approaches have been widely used in the study of female psychology (Bowker, 2001) to examine, measure and understand mental health issues. Jomeen (2004) describes this as *“an objective reflection of a material reality”*. Over the years, the problem with psychology has always been the issue of quantifying the phenomenon under investigation, e.g. anxiety, depression or infertility-related stress. Measuring these phenomena requires that an identification of a set of behaviours which

display the phenomenon be obtained, while generating measurable indices for it (Jomeen and Martin, 2005), such as the Becks Anxiety Inventory (BAI) for anxiety. However, "*what is of concern is the status of the things they claim to measure*" (p.255) (Richards, 2002).

Within the topic of subfertility, this has been an important issue. The utilisation of these psychometric instruments is based on their claim to effectively identify patterns of association within and between the groups they measure. However, these identified associations can only occur within the measurable indices laid down by the scale (Jomeen, 2004). Furthermore, within self-assessment measures, such as the ones for infertility, the act of measuring specific indices such as 'stress' or 'anxiety' could potentially bring it into being for the infertile individual, who is then 'programmed' to accept it as part of their infertility experience (Jomeen, 2004).

These psychometric measures, cannot provide the researcher with the meaning or understanding that infertile couples themselves attribute to that concept (stress), or the way in which they culturally or socially understand it, with regards to their situation or experience. Using these measures alone denies exploration into the influences, experiences and psychological processes that underlie the condition (infertility) (Ussher, 1999). Hence such findings would lack contextual explanations. In the book 'cultural psychology', Jerome Bruner (1991) distinguishes paradigmatic or scientific knowing from narrative knowing by stating that although both are essential aspects of the human ability to make sense of the world, dismissing narrative knowing in psychology is "*irrational, vague, irrelevant and somehow not legitimate*" (p.28) (McLeod, 1997). It is essential that the research community can assess and identify infertile couples at risk of stress, anxiety or depression as it has been found to contribute to treatment outcomes (Campagne, 2006, Csemiczky et al., 2000). However, as earlier stated, these measures are constructed as scientific abstractions and cannot adequately inform the experiences of the couples. A broader approach is required to obtain a realistic understanding of the couple's experiences, how they make sense of the phenomenon (infertility), how they resist or incorporate it into their experiences (treatment-seeking behaviour) and how it informs their actions (funding the treatment). The challenge then to the psychological aspect of this study is to analyse and interpret the results from the perspective of the participants' interpretations of their everyday world. This would be better achieved by a combination of two methods; quantitative as well as qualitative.

### ***3.2.1.2. Why mixed methods design was used***

The research questions addressed in this study are the relationship between stress patterns of infertile women in LMIC (Nigeria) versus HIC (UK), the cost-burden of infertility treatment, their perceived quality of life and the impact social support has on them. The nature of the research question required the use of both quantitative and qualitative methods to address it adequately. The mixed methods approach adopted in this study allowed the researcher to explore the specific issues related to funding ART, stress patterns, social support behaviours and the perceived quality of life from the perspective of the infertile women, both qualitatively and quantitatively. The findings of the two strands can then be triangulated to give a holistic understanding of the stress and affordability of ART (Creswell et al., 2003). As findings of qualitative research cannot be generalised, the use of quantitative methods within the mixed method study, will compensate for this, so that the findings can be generalised. Additionally, the quantitative findings can be validated by the results obtained from the information extracted from participants in the qualitative phase (Creswell and Clark, 2007).

Furthermore, as pointed out in section 3.1, the use of a mixed methods design is considered appropriate within the pragmatism framework adopted, as both methods (quantitative & qualitative) are not considered 'incompatible'. Instead they can be used as tools to answer 'real world' questions (Teddlie and Tashakkori, 2009). By taking a mixed method approach to these 'real world' questions, it is hoped that the findings from this study can be translated into clinical practise and policy.

### **3.3. THE MIXED METHOD DESIGNS**

Two types of mixed method designs could be considered in this study. Concurrent design, where the researcher collects and analyses both quantitative and qualitative data at the same time, and a sequential design where either the researcher collects and analyses qualitative and quantitative data in different phases (Creswell and Clark, 2007). The concurrent design was used in this study because it was essential to obtain different but complementary findings to understand the research topic better. Additionally, there was a need for a comprehensive understanding of the research topics and a need to validate/corroborate the results from the quantitative scales. Furthermore, as the researcher had limited time to collect the data, this design was suitable for collecting both data types in one visit to the field as illustrated in Figure 3.1. Although this design has

been queried to be challenging due to the complexity of simultaneously running both strands and the need to employ different research teams, there are dissertations completed using this design by solo investigators (Sahu, 2010, Akparibo, 2014, Hargreaves, 2014).

### **3.4. SEQUENCE OF DATA COLLECTION AND ANALYSIS**

This section elaborates the sequence in which the primary data were collected and the rationale behind such a sequence. The field work was first commenced in the UK, followed by Nigeria. The data collection began in Sheffield because the researcher and both supervisors work and live in Sheffield and are quite knowledgeable about the socio-economic background of the city. Additionally, the research proposals had to be approved by the NHS Yorkshire & The Humber-South Yorkshire Research Ethics Committee (Sheffield) and the University of Benin Teaching Hospital Ethics Committee (Benin), before field work could begin. However, an estimable time frame for ethics approval was assured in the UK as opposed to Nigeria, and the ethics approval for the research arm in Sheffield came several months ahead of the ethical clearance documents in Nigeria. Hence, the data collection process was started in Sheffield, UK. This also gave the researcher more time to prepare all the necessary documentation and research materials needed for the study in Nigeria.

In both the UK and Nigeria, the data collection was done simultaneously. It usually began with the semi-structured interviews, which usually took place in an empty consulting room within the clinic and if there was more time available, the questionnaires were equally filled on the same day. However, if there wasn't as much time, then the participants were given the questionnaires and pre-paid envelopes to go home and post back at their convenience. However, sometimes, when the participants are in a rush to leave the clinic, they ask for and are given the questionnaires and a date and time in which a telephone interview could be scheduled.

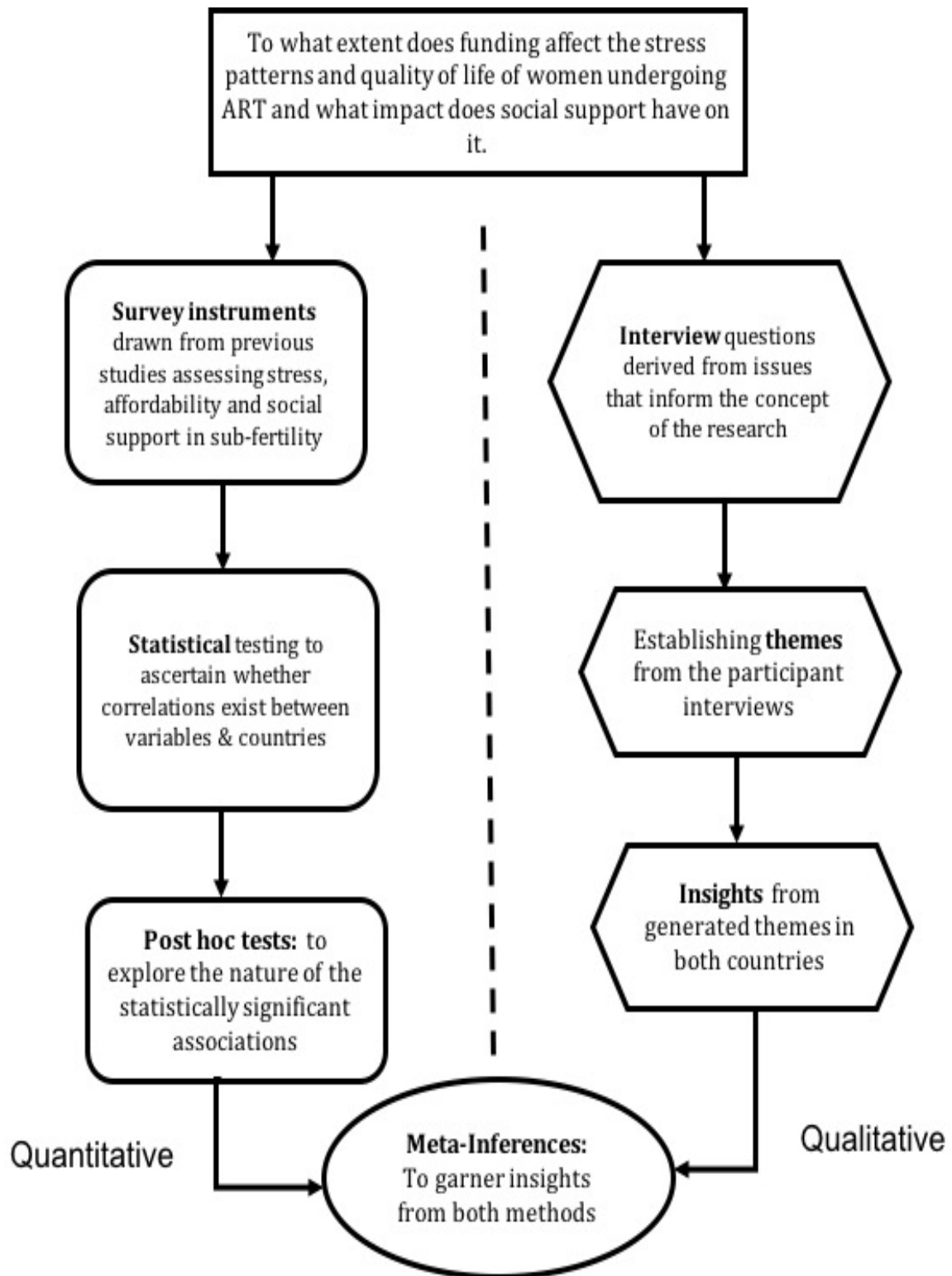


Figure 3.1: Graphic representation of the concurrent mixed methods design

By the time of the field work in Benin city, Nigeria, the study procedures had been confirmed and tested out in Sheffield. However, in Benin, although the data collection began quantitatively, the qualitative interviews were equally conducted at the same time. Details of the data collection and analysis process are clearly described in sections 3.8 and 3.11.

### 3.5. DATA INTEGRATION

The final step of the research process involves synthesising the results into a discussion form; and at this stage, results can be compared (Woolley, 2009). Previously, integration<sup>9</sup> of qualitative and quantitative findings were limited, which was caused by methodological preference, structure, skill scepticism as well as difficulty in writing for two different audiences (Bryman, 2007). However, as the literature on the topic (integration) grew, so did its implementation in various aspects of the mixed method research process (Bazeley, 2009).

Findings for convergent mixed method studies can be integrated in three ways; either by using a mixed method matrix, by following a thread (Moran-Ellis et al., 2006) or by triangulation (O’Cathain et al., 2010). This research uses triangulation.

As suggested by O’Cathain (2010), the term ‘triangulation’ is here understood as a specific approach to mixed methods research and is not limited to the interpretation described by Greene et al. (1989) alone (Viksveen, 2015). Greene et al. (1989) have been extensively quoted in much of the literature on mixed methods research. Here the authors describe triangulation as “*a ‘purpose’ of mixed methods research which seeks convergence, corroboration or correspondence of the results using different research methods*” (Greene et al., 1989). The authors failed to include the other purposes of performing mixed methods research, which include *complementarity* (enhancing the results from one method with another) *development* (involves sequentially using different methods), *expansion* (different methods present a broader range of findings) and *initiation* (discrepancies in the findings offer new perspectives).

Contrarily, O’Cathain (2010) describes triangulation not as a ‘purpose’, but as a specific approach, which provokes the simultaneous interrogation of both the qualitative and

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<sup>9</sup> Integration refers to “*the interaction or discussion between the qualitative and quantitative components of the study*” (p.1147) (O’Cathain, 2010)



quantitative data sets (Viksveen, 2015). This is done to identify areas of *convergence* (agreement in findings using both methods), complementarity (enhancing the results from one method with another) or divergence (findings in both methods contradict each other) of which further probing is employed to obtain a more in-depth understanding of the phenomenon under investigation.

This study integrated both methods at the interpretive/ reporting phase to gain useful insights and generate “*meaningful conclusions from consistent or inconsistent findings*” (p.305) (Teddlie and Tashakkori, 2009). Integrating both methods at this stage generated a better understanding particularly of the role of social support to sub-fertile women that would not have been identified using a mono-method approach. This, however, was equally a weakness of this approach because, only parts of the qualitative and quantitative findings can be integrated, as opposed to the researcher shifting back and forth between methods at the analysis stage, to present a more integrated method as employed when following a thread (O’Cathain, 2009). Integrating both methods at the interpretive phase was equally considered to be more feasible than making comparisons of interviews and questionnaires at the individual level as employed when using a mixed methods matrix (O’Cathain, 2009).

### **3.5.1. Managing data limitations**

It is acknowledged that findings within this study may complement or conflict, and one explanation proposed is that both methods are used to address different but related questions, therefore the different purposes and data sources would result in one method being better suited to answer specific questions as opposed to the other (Sale et al., 2002, Farmer et al., 2006). In addition, variations in outcome measures as described by Moffatt et al, 2006 or unevenly matched participant samples could account for the divergence between data sets (Moffatt et al., 2006).

Taking these potential limitations into account and honing on the stance by Moffatt et al. (2006) which states “... *we advocate treating qualitative and quantitative data sets as complementary rather than in competition, for identifying the true version of events*” (p.9)(Gell, 2013), a pragmatic approach to integration was taken. Therefore, where integration could occur, this was done, and where this was not possible, the various findings were used in a complementary manner to provide a richer understanding of the affordability of ART, the impact of social support and the perceived quality of life of the sub-fertile women in the UK and Nigeria.

### **3.5.2. Presentation of results**

The decision on how to report the findings from a mixed methods research can be quite challenging, especially when addressing issues of style, language, voice and order of results (O'Cathain, 2009).

A method recommended by O'Cathain (2009) during periods of reflexivity and positionality was for the researcher to refer to him/herself in the first person 'I', which is a method that has been used within this thesis (O'Cathain et al., 2007a). Reflexivity is about transparency and accountability of how the research was conducted (Narayan, 1993) while acknowledging the limits of the researcher's purview (Stanfield, 1993). Integration at the interpretive phase is often limited by the voice and language used within both methods (Sandelowski, 2003). For example, data is traditionally reported using numbers and figures quantitatively, while presented through writing in qualitative reporting, with the aim of avoiding quantifying language. Furthermore, quantitative findings are traditionally presented in a third person voice, while qualitative findings are usually presented in the first person (O'Cathain, 2009). This research shares the same dilemma but is reported in the third person, except where through reflexivity, a first-person voice would be used. A balance between charts, graphs, tables and quotations would be used in the results chapters to illustrate quantitative and qualitative findings. Due to the comparative nature of the study, the order in which the results are presented was situated in a comparative dimension (country: UK or Nigeria).

### **3.5.3. Quality in mixed methods research**

In a review by Sale and Brazil (2004) on the criteria for judging health-related mixed methods studies, the authors reported no explicit criteria for assessing quality in mixed methods studies. Furthermore, a general lack of transparency and justification in mixing methods in health research studies was reported in a review on mixed methods studies in UK health research (O'Cathain et al., 2008). However, O'Cathain et al. (2008) developed some criteria's for assessing quality in mixed methods research, which has been adopted by this study. The 'Good Reporting of A Mixed Methods Study' (GRAMMS) was used, and the different elements on the guidelines and the locations at which each criterion was implemented in this study are presented in Table 3.3. Using this criteria is in agreement with Teddlie and Tashakkoris' (2009) statement that quality mixed methods research is achieved by applying standards to not only individual elements

(qualitative or quantitative) but also to the meta-inferences drawn from mixing the methods (Teddlie and Tashakkori, 2009).

**Table 3.3:** GRAMMS criteria for quality mixed method studies (O’Cathain et al. 2008)

Quality Measure		Location
1	Justification for using a mixed method approach	Section 3.2.1
2	Description of the research design (sequence, purpose, priority)	Section 3.4
3	Description of each method	Chapter 3
4	Description of how and where data integration occurred	Section 3.5
5	Description of the limitations of the methods	Chapter 9
6	Description of the insight gained from combining both methods	Chapter 8

### 3.6. ETHICAL CONSIDERATIONS

#### 3.6.1. Ethical approval

Ethical review on this study was performed and was approved by the NHS Health Research Authority-South Yorkshire research ethics committee in April 2016 (See Appendix I) and from the University of Benin Teaching Hospital ethical committee in September 2016 (See Appendix II).

#### 3.6.2. Informed consent

Participants read the patient information leaflet (PIL), and informed consent was obtained from participants before conducting their interview (See Appendix III for consent sheet and IV for PIL). Informed consent “*requires that participants be aware of the purpose of the research, what is required of them, the topics that will be covered, how the data will be used and who will see the data*” (Lewis and Ritchie, 2003, Gell, 2013). This information was provided verbally and in writing during the recruitment process. Both (verbal and written consent) were obtained succinctly, to avoid overwhelming the patients with too many details about the research.

The eligible participants were assured that their participation was voluntary, and they were free to withdraw from the study at any time without giving a reason (Gell, 2013). They were equally informed that the process was confidential and solely members of the research team would hold all data. After reading the patient information sheet, the potential participants had the opportunity to ask questions about the study or interview

process. Once consented, an interview date and time was scheduled based on the convenience (face to face or telephone) of the participant. Contact details were exchanged at that time so that the researcher could text or call each participant 24 hours before the interview to ensure the time and date was still convenient for them.

### **3.6.3. Data confidentiality and protection**

Details of how the recorded material would be used and stored were outlined in the information sheet and were further explained to the participants if there were still some doubts or insecurities. Permission/consent to be recorded was also sought from the participants in the consent forms, which was signed and dated, providing an agreement regarding the recorded information. The audio-files were transferred to a password protected computer and the original media file deleted from the audio recorder history following each interview. Similarly, the transcripts were stored in password protected files.

### **3.6.4. Study site: Justification**

#### **UK**

The selection of the Assisted Conception Unit (ACU) of the Jessops Fertility clinic, Sheffield as the primary sampling unit is based on the reputation of the clinic/unit as one of the most “successful fully NHS managed centres” in the country. Over 150 couples present for treatment yearly, and the unit has a pregnancy rate per embryo transfer of approximately 48.8% ([jessopfertility.org.uk](http://jessopfertility.org.uk)).

#### **Nigeria**

The selection of the University of Benin Teaching Hospital’s *In Vitro* Fertilisation (IVF) unit as the primary sampling centre was based on the reputation of the unit as one of only four public IVF centres in the country. Approximately 140 couples present for sub-fertility treatment yearly, and the unit has a pregnancy rate per embryo transfer of approximately 28% ([ubth.org](http://ubth.org)). It is a referral hospital which caters to patients from all parts of the country. It was important to use a public health facility to better reflect and capture the diverse socio-economic characteristics of the target population.

## **SUMMARY**

The first part of this chapter has described the mixed methods approach adopted in the current research. The justifications for conducting mixed methods research including triangulation, complementarity or divergence were explored. The justification for using a mixed method approach in the current research was to provide a holistic understanding of the cost-burden of infertility treatment in two countries, their stress patterns, perceived quality of life and the impact of social support.

The research design was a concurrent/parallel mixed method study. Following the discussion of the mixed methods design, the sequence of data collection and analysis was described. Subsequently a framework for ensuring and judging quality research was identified. Table 3.3 outlined the key features of a good mixed methods study and presented the references to each section or chapter within this thesis that supports the adherence to these criteria. Finally, the ethical considerations were presented in section 3.6.

## **QUANTITATIVE METHODS**

### **3.7. RATIONALE**

The objective of the research study is to assess the affordability (via personal income or source of funding) of ART by infertile women, and in turn their quality of life. Additionally, the impact social support has on the stress patterns of these women were examined. Four research questions were posed within the broad research questions:

1. What is the cost burden to households accessing ART in the UK and Nigeria?
2. What are the stress patterns of sub-fertile women accessing ART in both countries and what socio-demographic factors predict them?
3. What socio-demographic factors predict quality of life of sub-fertile women in both countries?
4. Does social support moderate the relationship between perceived stress and quality of life?

### **3.8. PARTICIPANTS AND RECRUITMENT**

#### **3.8.1. Participants and settings**

Women about to undergo an initial or repeat cycle of IVF/ICSI at the assisted conception unit of the Jessop Fertility clinic, Sheffield, from August 2016 to January 2017, and at the University of Benin Teaching hospital IVF clinic from April-June 2017 were approached to participate in the study. Women were eligible for the study if they met the following inclusion criteria:

- Met the medical definition of infertility (i.e. had been trying to get pregnant for >12 months) (Fertilisation and Authority, 2001)
- Diagnosed with primary or secondary infertility and are about to undergo treatment.
- Starting a first IVF/ICSI treatment cycle
- Have had previous IVF/ICSI treatment and are returning for another
- Are NHS-funded or Self-funded and have paid for their treatment
- Using donor gametes (sperm or oocyte)

Exclusion criteria were as follows:

- Insufficient knowledge of the English language to read and understand questionnaires and accompanying information.

- Participants undergoing inter-uterine insemination (IUI)
- Participants having repeat cycles using frozen/stored embryo's

### **3.8.2. Recruitment strategy**

#### ***3.8.2.1. Sample frame***

Every eligible participant was identified through the fertility clinics software IDEAS V.5™. The software provides information on patient's demographics (age, marital status, ethnicity, occupation), contact details (email and telephone), scheduling, treatment management (IVF or ICSI) and billing patterns. Access to this software allowed for patient contact details to be retrieved and the research introductory letter was sent via email in the UK cohorts prior to their scheduled appointment dates.

The advantages of using the IDEAS V.5 software to establish the UK cohorts were: (1) it enables easy access to and screening of both self-funded and NHS-funded participants through its billing and invoicing module (2) easy screening of eligible participants through the treatment management module (3) easy access to participant details which helped when contacting them to return the questionnaires (4) easy access to participants demographics with footnotes on language barriers or interpretive issues, which helped exclude some patients. The limitation to using the IDEAS V.5 was that complete participant information on the system was dependent on a complete patient identification sheet, therefore, where telephone numbers or email addresses have not been provided, contacting participants about the questionnaires was difficult.

In Nigeria, however, no such system was available, therefore access to patient files from the records room of the clinic enabled contact details to be retrieved and telephone calls were made to the participants prior to their appointment dates. At weekly clinic meetings, women were then approached and recruited. Using these methods, approximately 90% of new and returning IVF/ICSI patients in the UK-cohort and 93% in Nigerian cohorts were successfully contacted.

#### ***3.8.2.3. Sample Size***

The alpha error (level of significance) was set to 0.05 and the power to 80%, as considered reasonable in clinical research (Whitley and Ball, 2002, Viksveen, 2015). Due to the different aspects of the study, there was no specific research to base the population of the study on for an easy sample size calculation to be made. One study that examined the effects of out of pocket payments for ART among south African sub-fertile couples,

used a sample size of 135 couples (Dyer et al, 2013). Another study that examined the impact of social support on infertility related stress in sub-fertile women had a sample size of 112 childless women (Martin et al, 2011). To our knowledge, no study has previously been carried out to assess the affordability of ART in two different countries or the impact of social support on the quality of life of sub-fertile women in a multi-country dimension. Therefore, previous research to base the expected effect size on was non-existent. The interpretation of effects size varies from one researcher to the next; however, the effect size ( $d$ ) used for the calculation of the sample size in this study was set to 0.5, which by Cohen (1988) would be considered medium (Cohen, 1988). In addition, the number of participants in each cohort estimated to return the questionnaires was 75%. This gave a final sample size of 128; in other words, 64 participants would be required in each arm of the study. Although the sample size estimation was taken into consideration during recruitment, it was acknowledged that in practice the sample size might differ from the pre-calculated value.

The sample size calculation according to Whitley & Ball (2002) is detailed below:

$$[2/(d^2)] \times [\text{power}] = [2/ (0.5)^2] \times [7.9] = 64$$

$$n \text{ (two countries)} = 64 \times 2 = \mathbf{128 \text{ women}}$$

Where: *Effect size (d) = 0.5,*

*power value =7.9 (for alpha 0.05 and power 80%).*

#### ***3.8.2.4. Sampling process***

The sampling process is summarised in Figure 3.2. Potential participants were identified through the IDEAS V.5 database in the UK clinic and invitation letters to the study along with the patient information sheet (Appendix 2) were sent via email with the scheduled appointment details. Through clinic diaries of women attending the fertility clinic in Nigeria, phone calls were made 72hours before their scheduled appointments, and some information about the study was given to them, along with their appointment confirmation.



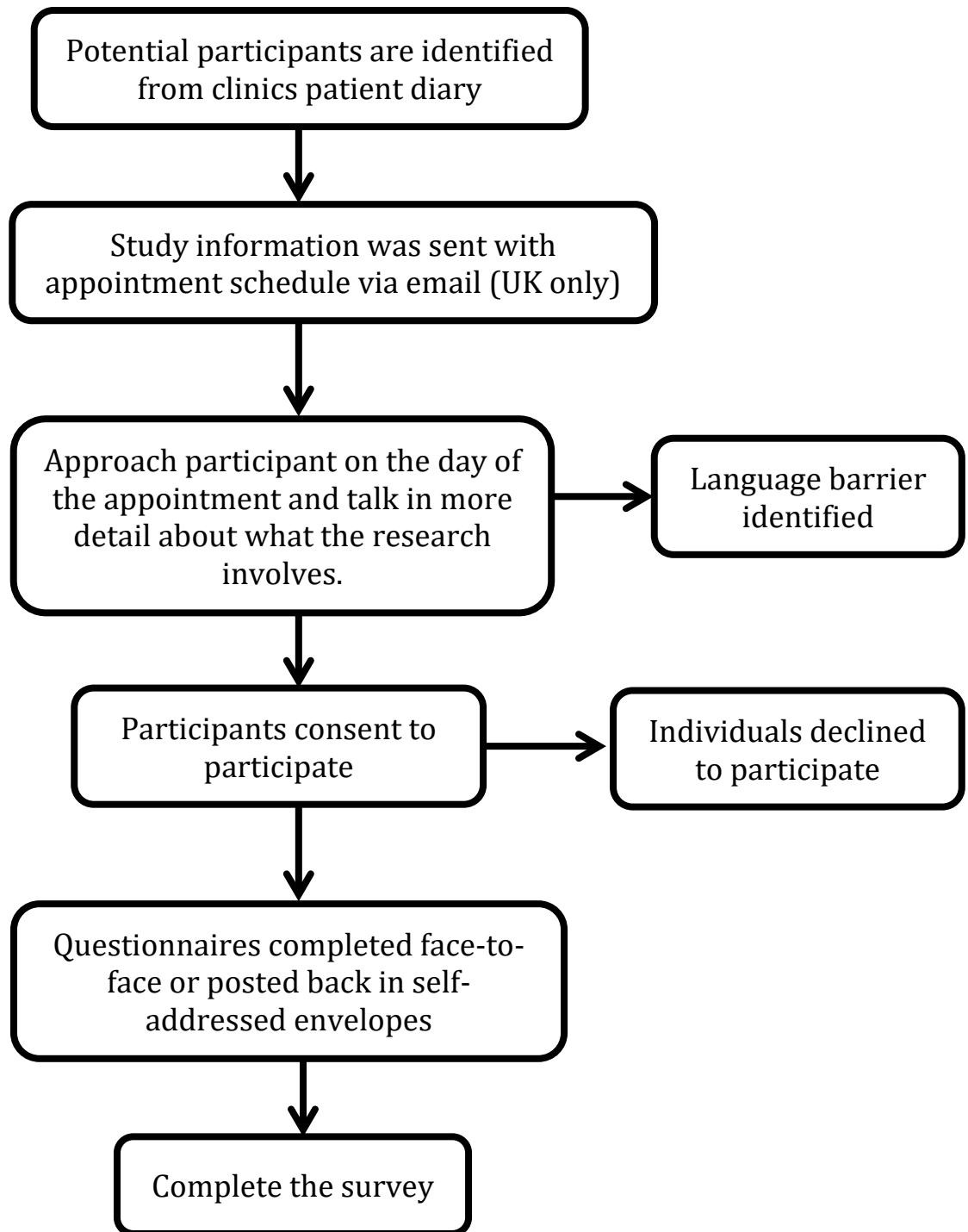


Figure 3.2: Flowchart of recruitment and consent process

On the scheduled appointment day, the clinic nurse/ matron at both clinics made the physical identification of the patients to the researcher, who then approaches the patients. The patients in the UK were asked if they received the letter and information about the study and if they had any questions. Those who did not remember the study or

hadn't looked at their emails, were given the information sheet again to read. In Nigeria, upon attendance, the patient was given the information sheet to read. Once they have read it, they would be given the opportunity to ask questions. If all questions are answered and the patient is content, they would then be de-briefed about the sensitive nature of some questions and asked if they would like to participate in the study. If they agree, they will be asked to sign a consent form (Appendix 3, 4), if not, no further contact is made. Those requiring more time to decide about taking part will be given participant information leaflets to take away after a detailed explanation. All documentation had been approved by the NHS Research Ethics review board and the University of Benin Teaching Hospital ethics review board.

After the consent forms were filled, the women were given the survey questionnaires, along with a prepaid addressed envelope for the UK participants. They had the option to return the survey questionnaires by post using the pre-paid envelope, or to hand it in to research staff on attendance for the commencement of their treatment protocol. Some participants were further contacted via text message or email after two weeks to remind them to return the questionnaires via post or during their next clinic visit.

In Nigeria, the survey instruments were given to women who were comfortable to complete the questionnaires themselves, to take home, fill it out and return it on their next appointment. Whereas women who did not feel confident or comfortable enough to complete the questionnaires on their own were asked if they would rather like the researcher to administer it to them via a face-to-face interview. Those who consented were assessed and the questionnaires were completed. Figure 3.3 and 3.4 show the flow from patient recruitment to questionnaire completion.

Out of the 78 UK women that consented to participate in the research, 66 questionnaires were returned, giving a response rate of 84.6% in the UK cohorts. Out of the 54 Nigerian women that consented to participate in the study, 52 questionnaires were completed and returned, giving a response rate of 96% in the Nigerian cohort. The high response rate among the Nigerian cohort could be attributed to the need for the researcher to administer the questionnaires to majority (80%) of the women.

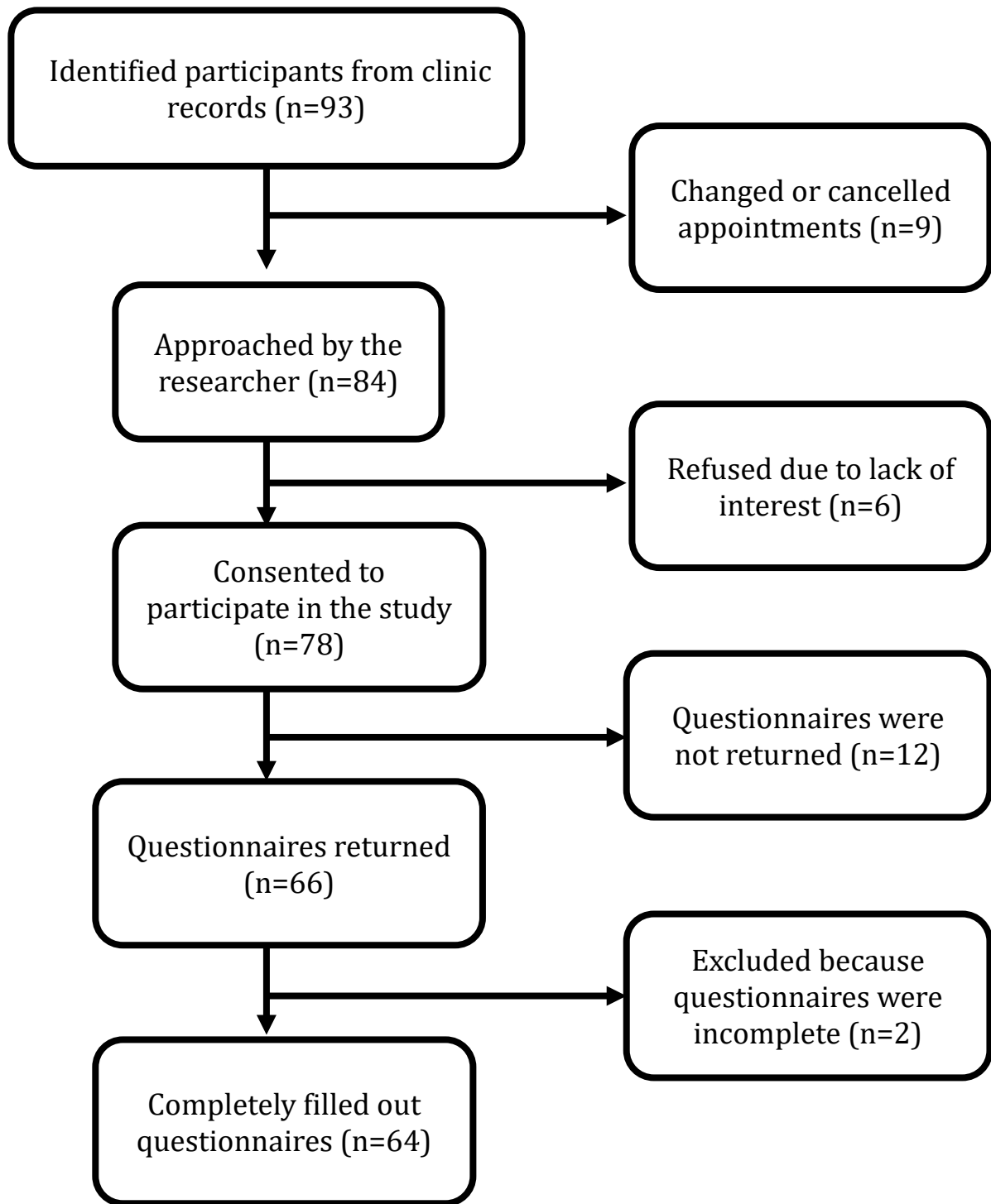


Figure 3.3: Flowchart of participant completion in the UK

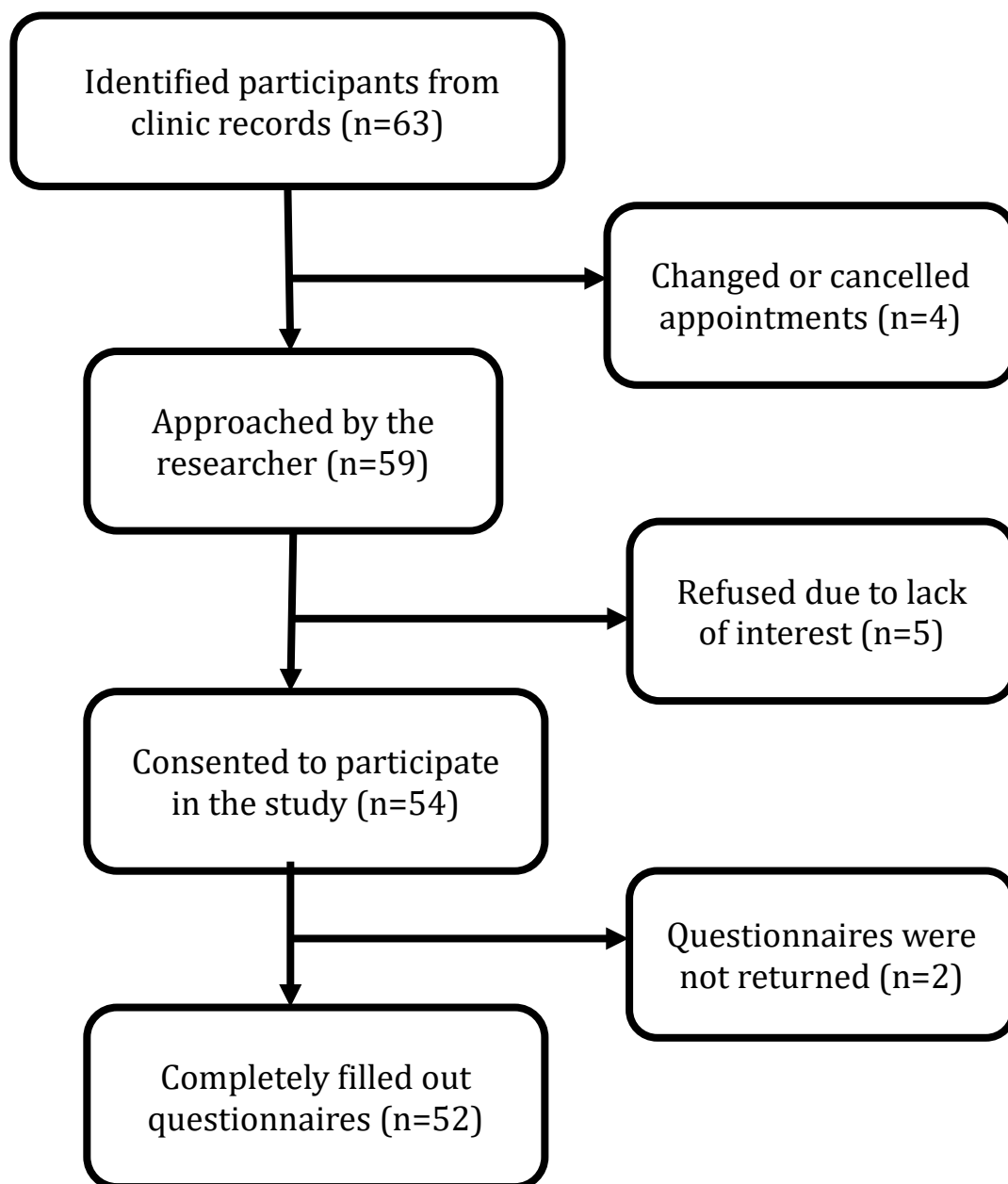


Figure 3.4. Flowchart of participant completion in Nigeria

### 3.9. DATA COLLECTION MEASURES

#### 3.9.1. Pro-forma

Patient information from both cohorts was captured using a pro-forma questionnaire (appendix 5) on which patients were asked to provide information on the following:

##### **Demographics questions**

- Age
- Educational level  
(Post-graduate/Bachelors/Diploma/secondary/primary/no school)
- Employment status (full-time/part-time/not working)
- Occupation

##### **Fertility questions**

- Duration of sub-fertility (>1years/1-2years/2-3 years/3-4years /4-5years/>5 years)
- Cost of current treatment

##### **Economic questions**

This portion of the pro-forma was modified to suite the characteristics of the population intended. In the UK, the British Pounds (£) was used and in Nigeria, the Naira (₦).

- Annual household income
- Monthly expenditure
- Monthly discretionary income

The lower and upper limits (of annual household income) for the UK cohorts was determined using the poverty threshold definition adopted by the UK government Department of works and pension as '*household income below 60 percent of the median income*'. Meaning, if all the households in the UK were listed from poorest to richest, the median would be the middle household. According to 2014/15 data, £473 per week (£24,596/year) was the median income in the UK. 60 percent of this figure is £284 a week (£14,758/ year), therefore, those households earning £14,758/year or below are considered to be in the low-income bracket. This represents the lower limit of the income distribution assessment for this study, which was set as <£15,000/ year. To estimate the upper limit (recorded as annual income >£40,000), data from the Institute for Fiscal Studies (IFS) and the Joseph Rowntree Foundation was sought. It reported that

households at the top of the income distribution in the UK (i.e. 90<sup>th</sup> percentile) have “*just over twice the income of those at the median*” (Gordon and Townsend, 2000, Pantazis et al., 2006). Income information was collected in intervals of £10,000, ranging from <£15,000 to >£40,000.

It was acknowledged that the ‘60% of median’ is just a proxy measure of poverty and can be considered by economists to be ‘arbitrary’ without proper corroboration from measurements of individual living standards. However, this threshold was used because it offers information on the low-income members of society and allows for comparison to be made within and between countries (Gordon and Townsend, 2000).

For the Nigerian cohorts, due to the complexity of data on the income distribution within the country, the world bank database for world development indicators (WDI) was sought to provide a lower limit. Here, the poverty head count ratio, described as ‘*the share of the population living on less than US\$1.25 a day purchasing power parity*<sup>10</sup>(PPP) terms’ was used. Although, it was acknowledged that different income levels have been proposed (such as \$1- \$2 a day) (Van Doorslaer et al., 2006, Chen and Ravallion, 2008, Chen and Ravallion, 2010), and as of October 2015, the new global poverty line was set at USD\$1.90 a day in 2011 purchasing power parity terms. However, the disparities in the population of the country below the poverty line from various sources, ranging from 53.4-70% (Factbook, 2012) resulted in the use of the 2008 US\$1.25 a day value, which is more sensitive, to better capture the low-income population equally seeking ART. The global poverty line and exchange rate was used, and the calculation for the lower limit is shown below:

In April 2017, \$1 = ₦312.01

Therefore, \$1.25 = ₦390/day

390 x 30 days = ₦ 11,700/month

₦ 11,700 x 12 = ₦ 140,404.5/year (£1044.3)

Hence, the lower limit for household income assessment was set at <₦150,000/ year (£1115.7), while the upper limit was estimated to be >₦ 500,000/year (£3719).

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<sup>10</sup> Purchasing power parity (PPP) are “*price relatives that show the ratio of the prices in national currencies of the same good or service in different economies*” (Schreyer and Koechlin, 2002). It determines how much a good/service would cost if parity did exist.

For comparability within this study, the 2016 purchasing power parity equivalents (instead of exchange rates) for both countries was used.

### **Other demographic information**

Other patient information was obtained through the IDEAS V.5 software and through the clinic records. These include:

- Marital status (Married/cohabiting)
- Nationality (British/Nigerian)
- Subfertility Diagnosis (Endometriosis/ovarian/male factor/tubal/unexplained)
- Treatment type (IVF/ICSI)
- Funding source (Self-funded/NHS funded)
- Attempt at treatment (1<sup>st</sup>/2<sup>nd</sup>/3<sup>rd</sup>/4<sup>th</sup>)
- 

### **3.9.2. The Becks Anxiety Inventory (BAI-21)**

This was used to assess anxiety in study participants. The Beck Anxiety Inventory (BAI), a 21-item multiple-choice self-assessment report questionnaire, created by Aaron T. Beck and colleagues, measures the severity of anxiety. The instrument offers advantages in both the clinical and research settings, and has consistently been regarded as a good tool for assessing cognitive and somatic aspects of self-reported anxiety including in infertility research (Beck and Steer, 1993, Bak et al., 2012, Naab et al., 2013, Drosdzol and Skrzypulec, 2009, Sultan and Tahir, 2011). Some merits of the BAI as an anxiety scale includes its easy and fast administration, its ability to make the connection between mind and body, its repeatability, its discriminatory power between symptoms of anxiety and depression, and its proven validity across age ranges, languages and cultures (Osman et al., 2002, Naab et al., 2013, Sultan and Tahir, 2011, Drosdzol and Skrzypulec, 2009).

The BAI-21 contains 21 items representing the common symptoms of anxiety and asks the respondent to indicate how much they had been bothered by each symptom in the past month, including the day of assessment on a 4-point scale (where 0=not at all and 3= severely). In classifying levels of anxiety, a score of 0-7 indicates minimal anxiety; 8-15 indicates mild anxiety; 16-25 indicates moderate anxiety; scores 26 and greater indicate severe anxiety (Beck and Steer, 1990). However, some studies have shown that a cut-off score of about 16 can lead to an optimal correct identification of clinical relevance (Bardhoshi et al., 2016).

### **3.9.3. The Perceived Stress Scale (PSS-10)**

Perceived stress is measured by the Cohen's perceived stress scale (Cohen et al., 1983). The perceived stress scale is a 10-item measurement instrument of global stress designed to prompt the degree to which patients/ participants find their lives unpredictable, overloading and uncontrollable: the three central components of stress (Gennaro et al., 2008). The PSS-10 was used over other versions of PSS (PSS-14 & PSS-4) because of its improved internal reliability and factor structure (Cohen and Williamson, 1988). This scale was first used in a sub-fertile specific population in 2000 (Lovely et al., 2003) and has continuously been applied in a number of other studies (Li et al., 2012, Balk et al., 2010, Cousineau et al., 2006).

The PSS-10 contains 10-items on a 5-point scale (1= never and 5= very often) that asks the respondent about feelings and thoughts during the previous month (e.g. 'felt upset' or 'stressed out') (Giurgescu et al., 2015). Of the 10 items, 4 items are worded in a positive direction and so were reverse-scored. The sum of the scores create a psychological stress core and the higher the scores, the higher the levels of perceived stress (Giurgescu et al., 2015).

### **3.9.4. The Social Support Scale (SSQ-12)**

Research within the past two decades suggest that psychological distress is mainly prevented by perceived social support or a subjective evaluation of what adequate support is (Furukawa et al., 1999). The studies show that the size of an individual's social network or 'embeddedness' is weakly correlated to their health (Henderson, 1992, Cohen and Wills, 1985), whereas the received support has been shown to be inversely related to well-being (Wethington and Kessler, 1986, Dignam et al., 1986). Therefore, emphasis should be placed on the quality of the relationships and not the size. Two reviews (McDowell and Newell, 1987, Brugha, 1989) on the 'assessment of social support' recommended the Interview Schedule of Social Interaction (ISSI) by Henderson et al, (1980) and the Social Support Questionnaire (SSQ) by Sarason et al (1983) as the best measures for social support because they both quantify the availability of and satisfaction with social support.

This study would utilise the Brief social support questionnaire (SSQ). The regular SSQ is a 54-item self-report questionnaire, and while it is impressive in terms of both its



psychometrics properties and data regarding its validity, it is an overly long questionnaire in practice (Siegert et al, 1987).

The SSQ-12 is a six-item scale divided into two parts. The first part 'SSQ-N' refers to 'availability or number of people'. It assesses the 'available number of people the individual feels they can turn to in times of need at various situation' (Furukawa et al., 1999). When completing this part, the respondents were instructed to supply the initials of supporters and in bracket their relationship with that person (e.g. mother) for each of the six items (e.g. "who can you really rely on when you need help?"). On the scale, the SSQ-N score is the average number of persons listed for the items and varies from 0 to 54. The second part 'SSQ-S' refers to 'satisfaction'. It assesses the degree of satisfaction with the perceived available support in those situations, reported on a 6-point Linkert scale where 1='very dissatisfied' and 6= 'very satisfied' and varies from 6 to 36 (Sarason et al., 1987b).

### **3.9.5. The W.H.O Quality of Life Scale (WHOQOL-BREF)**

The concept of QOL means different things to different people, and these differences usually depend on the specific circumstances in which the term is applied or measured. For this study, QOL would go beyond an individual or patient's infertility status and be defined as all aspects of one's well-being, influenced by his/her perceived level of satisfaction with his/her physical, psychological, social and economic environment (i.e. perceived satisfaction to one's life in general).

The best quality of life instruments are designed to 'probe' participants in a structured way, to give meaningful and reproducible quantitative assessments of how people perceive satisfaction with their life (Research et al., 2006). A review of 16 quality of life instruments by Nilsson et al (2004) found that only the WHOQOL-100 instrument included domains on physical, psychological, social, economic, environmental and spiritual dimensions (Nilsson et al., 2004) making it a more generic QOL measure. The World Health Organisation has a shortened 26-item version of the World Health Organisation Quality of LIFE (WHOQOL-100) instrument known as the WHOQOL-BREF. The WHOQOL-BREF was chosen for this research for a couple of reasons. Firstly, the WHOQOL-BREF is the most common and generic QOL assessment instrument that has been validated across a variety of languages and cultures (Bolsoy et al., 2010, Onat and

Beji, 2012, Aduloju et al., 2018, Chachamovich et al., 2010). Secondly, the short length of the scale makes it the appropriate instrument for this study. Finally, the suitability of the WHOQOL-BREF to evaluate quality of life in various health conditions including infertility has previously been demonstrated (Chachamovich et al., 2007, Aliyeh and Laya, 2007, Aduloju et al., 2018).

The WHOQOL-BREF is a 26-item scale of which 24 of the items are divided into four domains. Physical health (7 items), psychological health (6 items), social relationships (3 items) and environmental health (8 items), which would be referred to as DOM1, DOM2, DOM3 and DOM4 respectively (Table 3.4). The scores on each part reflect the participant's perception of their quality of life in that particular area (Jatuff et al, 2007). The first two items (depicted as Q1 & Q2) in the questionnaire that are examined separately. The first question asks about a participant's perception of quality of life, while the second question asks about a participant's overall perception of his or her health (Zubaran et al, 2009).

Table 3.4: WHOQOL-BREF DOMAINS

<b>Domain</b>	<b>Facets incorporated within the domain</b>
Physical Domain	Physical pain, Dependence on medical aids, Energy and fatigue, Mobility, Sleep and rest, Activities of daily living, Working capacity
Psychological domain	Life enjoyment, Meaningfulness of life, Concentration and memory, Body appearance, Self-esteem, Negative feelings
Social Domain	Personal relationships, Sexual activity, Social support
Environmental Domain	Safety, Physical environment, Financial resources, Daily information, Leisure activities, Home environment, Access to health care, Transport

The items are scored on a 1 to 5 response scale and the scores for each domain are between 4 and 20, with higher scores, indicating higher quality of life. According to the WHO guidelines for this scale, the raw scores for each domain would be transformed to a score from 0-100, to be directly comparable with the scores from the WHOQOL-100. Please refer to the WHOQOL guidelines for details on this step (Group, 1998).

### 3.9.6. Affordability measures within the study

The methods for calculating affordability requires the knowledge of (i) the price of the item in that particular location, (ii) the total household income and (iii) an approximate of the monthly expenses made by the household within the study population (Linden and English, 1994, Mhlanga and Suleman, 2014). Therefore, in calculating affordability within this study, information was obtained from the women about:

- **Annual household income:** referred to as ‘annual combined couple income’ in the pro-forma for easy understanding. The household (couple) income was chosen as the unit of analysis instead of individual income because “*a household is defined as an entity that shares all resources*”(Dyer et al., 2013) therefore, “*the cost of ART must be compared with resources available within that unit*” (Dyer et al., 2013). However, in most LMIC, a household is quite difficult to establish, as other extended family members might be considered part of the household. For this reason, the term ‘household’ was specified to the women to mean just the couple. In both countries, the women were considered to be the household reference person (HRP<sup>11</sup>) in this study.
- **Monthly household expenditure:** referred to as ‘monthly outgoings’ on the pro-forma, again for a user-friendly experience. This was an estimated amount of the total amount of money paid by households for all non-food expenses including but not limited to rent/mortgage, gas, electricity, fuel, council tax etc. in a month.
- **Price/cost of the treatment:** patients were asked to provide the cost of their current treatment cycle. However, actual treatment costs were also obtained from clinic records in both countries. This was to ensure the accuracy of the prices provided by the patients, because, it was observed that some patients included ‘indirect costs’ such as transportation to and from the clinic, accommodation costs if sleeping over to meet appointments etc. to the overall cost of the treatment. In the UK clinic, at the time of this study, the cost of the treatment was dependent on the treatment type, with IVF at £3390 (\$4856) and ICSI at £4078 (\$5842) while in Nigeria, this was relatively fixed dependent on the age of the woman at 700-800 thousand Nigerian Naira (\$7459-\$8524) for women 25-39years, and 900-

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<sup>11</sup> A household reference person (HRP) is a household member that best defines that households position, financially and otherwise, and is usually the woman. It is the same unit of analysis for class composition used by the UK Office of National Statistics in socio-economic classification.

1,000,000plus (\$9590-\$10,656) for women above 40 years. In both countries, the costs were fixed and covered all aspects of the treatment from consultations, drugs, monitoring, oocyte retrieval, embryo transfer and early pregnancy monitoring. However, in the UK the payment for the treatment is a lump-sum payment, while in Nigeria, there is an initial deposit of ₦350,000 (\$3729.67), and subsequently, other costs are spread out through-out the treatment.

Participants responses were taken at 'face-value' because no attempt was made to further validate the answers (Dyer et al., 2013) through for example pay slips or bank statements. The question on participant occupation was collected as an open-ended variable. For the UK participants, the clinic database was checked to ensure accuracy of occupation reported. This was however, not possible among the Nigerian cohorts and so occupation was taken from participant reports.

### **3.9.7 Challenges with administering the survey instruments**

This study used a total of five instruments; four validated survey instruments and one basic questionnaire for sociodemographic and subfertility characteristics. The psychometric properties of the survey instruments were good (i.e. >0.7) as indicated in section 3.9.2-5, and some have been used in cross-cultural studies where cross-cultural validity was shown to be acceptable. However, some of these questionnaires were designed, developed and validated by researchers in populations that are ethnically, culturally and demographically different from one of the sample populations within this study (Nigeria).

Although the majority of the Nigerian population speak and understand the English language, certain terms used in the BAI-21 such as 'face-flushed', 'numbness/ tingling' and 'hot/cold sweats' required further explanations as some 'uneducated' women could not understand those phrases. No translation was needed as it was not a language issue, however, synonyms or explanations of those words had to be considered during the data collection process.

## **3.10. DATA ANALYSIS**

### **3.10.1. Data entry, cleaning & management**

Anonymised raw data were first entered into a Microsoft Excel Spreadsheet, cleaned and coded. All entries were checked for errors before the data file was imported into SPSS

analysis software version 21, where the entries were further checked and analysed. Variables were recorded to conform to the SPSS software. An exploratory analysis was performed to check for consistencies, normality and outliers.

Three separate SPSS spread sheets were created. One for the UK cohorts, one for the Nigerian cohorts, and one with a combination of both (UK & NIG). The UK only spread sheet included all the socio demographic variables, but also included an additional variable titled 'Funding source'. This was: NHS/Self-funded;' 0=NHS, 1=Self'. The Nigerian only spread sheet, included all the socio-demographic variables and the income distribution laid out in the Nigerian adapted basic questionnaire. The combination spread sheet had the socio-demographic information of both countries, with the exception of the income distribution column but with an additional variable for 'Nationality', entered as '0= UK, 1=Nigerian', for easy comparative analysis.

Some instruments such as the PSS-10 and the WHOQOL-BREF, had certain questions that required the Linkert scale to be reversed in scoring. This was done in SPSS using the 'Transform → Recode into different variable' command. Additionally, the total scores in the WHOQOL-BREF for each domain was transformed into a 0-100 scale and inputted into the spreadsheet. The two parts (availability and satisfaction) of the SSQ was entered and denoted as 'SSQ\_N and SSQ\_S' respectively.

### **3.10.2. Affordability Analysis**

According to Maclennan and Williams, 'affordability has to do with securing a standard of living (e.g. housing, education, and transportation) at a price that would not impose, in the eyes of a third party (usually the government), an unreasonable burden on household incomes (Hancock, 1993). Therefore, to better understand the concept of affordability; one needs (i) knowledge of the price of the product in question (ii) information on household incomes (iii) a definition of 'unreasonable burden' referred to as 'threshold' henceforth (Niens et al., 2012). In calculating affordability, several methodologies have been developed and applied to effectively describe 'unreasonable burden/threshold' by health economists.

In analysing affordability, this study would utilise three main strategies/methods. These include; catastrophic expenditure method, subjective financial well-being evaluation, and the World Health Organisation/ Health Action International (WHO/HAI) method. Participants were asked to select an income range that best approximated their annual

household income and monthly expenditure. For the analysis of this data, a continuous income and expenditure variable was created by assigning the midpoint value of the selected range to each participant. Meaning that participants that selected an income range of £20,000-£30,000, were assigned an income of £25,000, and an expenditure range of £2,000-£3000 was assigned £2500. Additionally, the households were classified into socioeconomic quintiles based on annual income and household expenditure. Subsequent sub-sections would provide a brief explanation of these methods and how they would be implemented in this study.

### ***3.10.2.1. Catastrophic expenditure method***

This method is based upon the ratio of the payment for a particular product to a household's total income. This method "calculates the proportion of the sample population willing to spend more than X percent of their income to pay for a good or service" (Niëns and Brouwer, 2013). Catastrophic expenditure is achieved if the out-of-pocket expenditure exceeds a certain threshold in a particular period (Wagstaff, 2008). This threshold is an arbitrary value which can range from 5-40% of total income, however, the threshold of 40% has received wide approval and has been applied severally in empirical research (Xu et al., 2003, Xu et al., 2007) and in this study. Further information for interested readers can refer to O'Donnell et al (2008).

To calculate catastrophic affordability effects of ART, the variable for non-food household expenditure (referred to as 'capacity to pay') in both countries was used along with data on the cost of the current treatment cycle. It is acknowledged that there may be other 'indirect costs' to the patients, however, as this was not captured on the questionnaire, it was not included in the calculation. Additionally, where costs were covered through health insurance (in the UK), these were excluded in the analysis. Based on the information provided, households were categorised into tertiles (Poorest-Richest) of economic status based on their household income and annual expenditure. The monthly expenditure was multiplied by 12 to obtain an estimated annual household expenditure. The total treatment costs were then compared with annual household non-food expenditure to evaluate the proportion of households the cost 'burden' of ART met the criteria for catastrophic expenditure (Dyer et al., 2013). As stated in section 4.4.6, catastrophic expenditure occurs when 'total out of pocket payment divided by total household expenditure is greater than or equal to 40% of household expenditure (O'donnell et al., 2008, Xu et al., 2003). For each economic quintile of the study, the impact

on household economic welfare of OPP for ART was reported. The 40% threshold (Xu et al., 2003, Xu et al., 2007) is used to indicate catastrophic expenditure.

Additionally, where the catastrophic payment could not provide additional information, the intensity of expenditure burden was assessed using the *catastrophic overshoot*. The catastrophic overshoot captures the average degree by which payments (as a proportion of non-food expenditure) surpass the catastrophic threshold (40%) across all households (O'donnell et al., 2008). It is expressed as the proportion of additional payments above 40 % of the total household expenditure, divided by the total number of households.

### ***3.10.2.2. Subjective financial well-being evaluation***

Subjective financial well-being (SFW) in this study is defined as the individual's self-rating/perception of their income adequacy to meet their needs for the treatment (Arber et al., 2014). Financial well-being has been studied in various fields including but not limited to economics, financial counselling and psychology (Shim et al., 2009, O'Neill et al., 2005, Guo et al., 2013). Although this variable has been used in a number of studies, its definition and measurement have varied. However, most studies using this variable have classified its definition into three, based on the approach used. This includes those that have used objective characteristics; which includes quantitative indicators such as income level, debt, etc. (Vosloo, 2014), those that have used subjective characteristics; which accesses perceived satisfaction of financial well-being (Porter and Garman, 1992) and those that have adopted a combination of both (Cox et al., 2009). This study used a subjective measure of financial well-being because, although an objective measure such as the annual income or monthly expenditure provides an assessment of facets of an individual's financial condition, a subjective measure can better obtain a comprehensive account of an individual's perception about their financial condition (Norvilitis et al., 2003).

Using this definition of financial well-being, a separate item on the questionnaire to determine subjective financial satisfaction, which was an adaptation from the 12<sup>th</sup> item on the WHOQOL-BREF scale was used with a few adjustments. The question was: "Do you have enough money to meet your needs for this treatment?" The answers could range from 1 (not at all) to 5 (completely). These answers were used as an indicator of subjective financial well-being. This variable has not appeared in previous studies on

financial well-being assessment, and therefore, provides information on aspects of women's financial well-being not previously examined in infertility research.

### ***3.10.2.3. The World Health Organisation (WHO) and the Health Action International (HAI) method***

The WHO/HAI recently developed an alternative methodology for measuring affordability. This method expresses affordability as “the number of days’ wages the lowest paid unskilled government worker (LPGW) needs to spend to procure a course of treatment of a particular medicine” (Niëns and Brouwer, 2013, Kotwani, 2013). The WHO/HAI LPGW method does not impose a threshold, rather it leaves the measure of affordability to the discretion of the policy makers who can effectively position the LPGW wage in relation to the average income of the local population (Niëns and Brouwer, 2013). For this assessment, the estimated minimum wage in both countries was used as the threshold for the salary of the lowest paid government worker in both countries. While this study would not be using the WHO/HAI medicine price protocol, the study has adapted some methodologies recommended in the protocol.

As this study involves the cost of ART in two different countries (UK & Nigeria), cost estimates would be expressed in two different currencies (Pounds & Naira). Therefore, in order to make a meaningful comparison between the two costs of ART in both countries, these values need to be expressed using a ‘common metric’, which would require adjusting these values into a common currency.

For comparability, the 2016 purchasing power parity (PPP) values obtained from the CCEMG-EPPI-Centre cost converter which obtains values from the international monetary fund (IMF) database for both countries would be used. The CCEMG-EPPI-Centre cost converter is a web based tool developed by the Campbell and Cochrane Economics Methods Group (CCEMG) in collaboration with the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre), for adjusting estimates of costs to a specific target currency and price year (Shemilt et al., 2010). For more information refer to <https://eppi.ioe.ac.uk/costconversion/default.aspx>

It is known that measuring the real affordability of the treatment using this method might be quite challenging, therefore this method does not pose a threshold. It just estimates the number of days wage (for the UK) or month's salary (as is the case of Nigeria) the



lowest paid unskilled government worker needs to spend to procure a course of treatment using the 2016 PPP values for comparison.

### 3.10.3. Variables

The variables included in this study were obtained from the records of the women who participated in the research as well as from what previous studies have used and shown. For example, the literature reviewed observed an association between stress and social support (Amir et al., 1999, Cohen and Wills, 1985, Dignam et al., 1986), as well as social support and quality of life (Abbey et al., 1995, Aslund et al., 2014, Bodhare et al., 2015) Socio-demographic variables such as age, educational status and income have been implicated in previous studies to have an effect on quality of life (Bolsoy et al., 2010, El Kissi et al., 2014, Gholami et al., 2013a), therefore, this study purposefully selected these variables and included them in the analysis (Table 3.5).

Table 3.5. Categorisation of variables used in this study

<b>Independent/Explanatory variables</b>	<b>Outcome variables</b>
<p style="text-align: center;"><b>Socio-demographic:</b> Age, Education, Employment, Marital status, Income, Expenditure</p> <p style="text-align: center;"><b>Sub-fertility:</b> Duration of subfertility, Type of subfertility, funding status, Type of treatment, number of attempts</p> <p style="text-align: center;"><b>Social support</b> Number of support, Satisfaction with support</p>	<p style="text-align: center;"><b>QOL:</b> Physical QOL, Psychological QOL, Social QOL, Environmental QOL</p> <p style="text-align: center;"><b>Stress:</b> BAI scores, PSS scores</p> <p style="text-align: center;"><b>Affordability:</b> Catastrophic expenditure, WHO/HAI measure, Subjective poverty</p>

### 3.10.4. Descriptive analysis

The number and percentage in each demographic category were calculated to determine the characteristics of the sample population. Variables presenting continuous data were presented as means and standard deviations, while data on categorical variables were presented as proportions of the sample within each group. The affordability calculations were also presented as descriptive statistics using frequency tables and bar charts.

#### 3.10.4.1. Analysis to determine instrument reliability

In order to determine the reliability of all the instruments including the WHOQOL-BREF domains (in both study populations) Cronbach's alpha was used. Based on previous

literature, alpha values of 0.7 and over were deemed acceptable. Table 3.6 a & b shows the reliability scores of the questionnaires used within this study. The reliability of the scales was assessed using the SPSS software, ensuring that all negatively worded items were reversed before calculation.

Table 3.6a: Reliability scores of the questionnaires used in this study

<b>Scales Used</b>	<b>Cronbach's alpha (<math>\alpha</math>)</b>	<b>No. of items on scale</b>	<b>No of cases valid</b>	<b>No. excluded</b>	<b>Established Cronbach's alpha (<math>\alpha</math>)</b>
Beck Anxiety Inventory (BAI)	<b>.816</b>	21	115	1	.92-.94 (Beck et al, 1988)
Perceived Stress Scale (PSS-10)	<b>.815</b>	10	116	0	.74-.91 (Cohen et al, 1988)
Social Support Questionnaire (SSQ6)	<b>.892</b>	12	115	1	.83-.97 (Saranson et al, 1987)
W.H.O. Quality of Life Scale (WHOQOL-BREF)	<b>.870</b>	26	116	0	.89-.95 (World Health Organisation, 1993)

Table 3.6b: Reliability scores of the questionnaires in both cohorts

<b>Scales Used</b>	<b>Nigeria, <math>\alpha</math></b>	<b>UK, <math>\alpha</math></b>
Beck Anxiety Inventory (BAI)	.807	.830
Perceived stress scale (PSS-10)	.807	.805
Social Support Questionnaire (SSQ6)	.870	.884
W.H.O. Quality of Life Scale (WHOQOL-BREF)	.783	.896

#### **3.10.4.2. Exploring relationships**

Further statistics were performed to explore relationships. A multiple regression analysis was done to determine the relationship between multiple independent variables and one dependent variable. For example, to determine the cumulative influence of socio-demographic and fertility variables on perceived stress or anxiety, a multiple regression analysis would be used. A backward elimination regression procedure is used in the analysis.

Additionally, a moderation analysis was done to determine if the magnitude of one variable(s) (Anxiety/Perceived stress) effect on an outcome variable (Quality of life Domains) of interest depends on a third variable or set of variables (social support number or satisfaction). In this study, the add-on software 'PROCESS', developed by Andrew Hayes was used. This is a computational tool for SPSS "*that implements moderation and mediation analysis as well as their combination in an integrated conditional process model*" (Hayes, 2012). This tool would be used to estimate the direct or indirect effects of social support in this study, along with providing simple slopes for the visualisation of the conditionality of the effect.

#### ***3.10.4.3. Exploring variations***

T-tests were performed to determine if there were any significant differences between means in continuous variables, whereas the Chi-squared test was used to determine if distributions in categorical variables differ from each other. When the T-tests identified the significant differences, post-hoc tests were done to describe the nature of these differences.

#### **SUMMARY**

This quantitative methods section has described the methods that were used to collect and analyse quantitative data within the mixed methods project. Participants were recruited using a convenience sampling design. Data on a range of variables including stress, anxiety, social support and quality of life as well as economic variables was collected using a pro-forma and self-completed questionnaires. Data analysis was conducted using SPSS 21. Socio-demographic variations in stress and anxiety among infertile women in the UK and Nigeria were measured using linear regression models. The moderation effect of social support on stress and quality of life were calculated using the 'PROCESS' add-on.

Having described the methods used within the quantitative phase of this study, the next section presents the data collection methods and analysis used in the qualitative phase.

## QUALITATIVE METHODS

### 3.11. RATIONALE

The overarching objective of this study is to assess how the cost-burden of ART contributes to the stress experiences and coping mechanisms of sub-fertile women. Within the current study, qualitative methods would be used to explore the ideas, beliefs, and cultural influences of the experiences (financial and otherwise) that contributes to the stress of the women before treatment. The qualitative approach would address four specific research questions:

1. What can be learnt from the experiences of infertile women in both countries?
2. What are the perceptions and funding patterns exhibited by women seeking ART in both countries?
3. What extent is the quality of life experienced by women in both countries affected by funding the treatment?
4. What are the social support behaviours exhibited by the women in both countries and how does social support contribute to how women cope with stress?

### 3.12. METHOD SELECTION

In designing this component of the study, two data collection approaches were considered. These were either focus group discussions or interviews. In focus group discussions, a small group of people are recruited, who share a particular characteristic, and the researcher encourages an informal group discussion on a specific set of topics (Bloor et al, 2000, Silverman, 2011, Wilkonson, 2011), while the interactions between members of the group during the discussion are examined (Uwe Flick, 2004). On the other hand, interviews “*provide an opportunity for additional exploration of an individual’s perspective on a particular topic*” (Lewis and Ritchie, 2003, Gell, 2013).

Although both methods generate data through verbal recounting (Lewis and Ritchie, 2003) my interest was in understanding the individual account of “lived experiences” of sub-fertile couples through their stories, and the meaning they make of that experience. Therefore, the interview seemed the more appropriate tool for qualitative data collection in this study. Furthermore, the potentially sensitive and intensely personal nature of the interview topics supported the decision to use individual interviews, instead of group discussions. The terms ‘interviewee’, ‘respondents’, ‘women’, ‘participants’, and ‘patient’,

are used intermittently in this chapter; however, they all refer to the participants interviewed in this study.

### **3.13. SAMPLING**

In this study, the specific research questions informed the use of a purposive sampling strategy. The next section would describe the rationale for choosing this sampling method.

#### **3.13.1. Purposive sampling**

Silverman (2009) states that it is important to critically evaluate the criteria for sampling, and samples should be chosen based on how they might explain a particular phenomenon. In view of this, I had to ensure a balance was maintained between selecting a sample that would capture the diversity of the population and equally provide a good representation (heterogeneity) of each characteristic. This was to ensure that relevant factors in a particular aspect of the study (i.e. stress or affordability) can be identified (Lewis and Ritchie, 2003). To improve understanding of the experiences infertile women have with funding their treatment, I had to recruit and interview a heterogeneous sample of infertile women about to undergo treatment. Therefore, a purposive sampling method was used. "*Purposive sampling is a criteria-based selection method where individuals are chosen because of their ability to contribute information needed to answer the research questions*" (Gell, 2013, Mason, 2002).

This study focuses exclusively on women because they have a heightened emotional reaction to the subfertility diagnosis and treatment compared to men (Abbey et al., 1991a, Slade et al., 1997, Holter et al., 2006). Furthermore, as Steuber and High (2015) stated, women act as gatekeepers to the couple's relationship and may better reveal information related to their marital, social and financial challenges related to their diagnosis. By capturing heterogeneity, I aimed to represent the entire range of the phenomenon, which in this case refers to the psychosocial experiences with funding/affording the treatment and social support (Lewis and Ritchie, 2003, Mason, 2002).

In view of this, a maximum variation purposive type of sampling method was used. A maximum variation sampling (MVS) (Etikan et al., 2016, Suri, 2011, Sandelowski, 1995) approach "*involves selecting participants across a broad spectrum*" (Etikan et al., 2016) to capture a variety of experiences within the group of interviewees. In MVS, although the participants share some common characteristics (e.g. being infertile), there should be as

much variation within them as possible (e.g. age, duration of subfertility, number of attempts at ART). This is in contrast to homogenous sampling, in which the participants share similar or specific characteristics, and the focus is on comparing the shared similarity with the phenomenon under investigation (Suri, 2011). The risk with using the MVS approach is that there is a possibility of not identifying participants with more 'severe' cases. This means that, because not all the participants were interviewed, it is possible that some experiences which may have significantly contributed to the results, were missed. However, due to the variation in the sample, a broader spectrum of experiences was identified and reported.

In this study, participants were sampled until data saturation was reached. In total, 20 women from both countries were recruited and interviewed. This number was considered appropriate as research examining the operationalisation of saturation report that 6 to 30 participants is a reasonable number for saturation to occur (Guest et al, 2006).

In total, 17 interviews were conducted in Nigeria, and 15 in the UK. At this point, the researcher determined that no significantly new themes were identified after two (in UK) or three (in Nigeria) consecutive interviews (Glaser and Strauss, 1967). However, it is possible that more issues might have been identified had more interviews been done.

### **3.14. RECRUITMENT**

A subset of participants who consented to participate in the quantitative study were recruited into the qualitative research. The patient information sheet was explained meticulously to the patients and it was made clear that no additional risk would be incurred from participating in the study. They were equally informed about the level of confidentiality involved with the use of their audio taped interviews, and that contents from the interviews would not be shared with anyone outside of the research team. It was also made clear that whether they consented or not to participate in the research would have no effect on their care within the clinic. Those requiring more time to decide about taking part were given participant information leaflets to take away after a detailed explanation.

Ensuring a heterogeneous sample among self-funded and NHS patients in the UK, was not too challenging. However, obtaining a heterogeneous sample among the various ethnic minority patients that came into the clinic was a bit problematic. Patients of Iranian,

Pakistani and Indian origin often frequent the Assisted Conception Unit located in Sheffield, a city with a moderately sized South Asian community. However, when approached, women of these ethnic groups declined to participate in the study. Observing this trend, I sought to find out why by asking them. Some of the reasons I noted were that, most women insisted on obtaining the permission from their spouses before they could consent. Others stated that the topics were a bit too sensitive to discuss with a stranger, particularly those involving their finances. Some participants refused to give any reason. A small number of studies although sometimes reporting conflicting data have indicated low participation of south Asian women in reproductive research. One of such is a prospective UK study of 300 couples by Choudhary et al. (2004). The authors observed that “couples of ethnic-minority origins were less willing to consent for research using their embryos compared to their Caucasian counterparts”. A study by Haddrill et al (2014) alluded to this, by reporting that more complex reasons such as prevalent concepts of denial, poor reproductive health knowledge, as well as socio-cultural factors could be implicated as barriers to participation. More research should be conducted to explore the low participation rates of south Asian women in reproductive research as these inequalities provide a substantial bias towards this research area.

### **3.14.1. Time and venue for planned interviews**

Interviews were conducted in the clinics where patients were receiving treatment. The reason for conducting the interviews in the clinics was simply because participants preferred to be interviewed there. Telephone interviews were conducted with a small group of participants who preferred that type of interview. This group of participants said they were comfortable responding to telephone conversation about the topic than being interviewed face-to-face. The rationale for using taped telephone interviews was based on two reasons. Firstly, patients often attended from all over the county (South Yorkshire) and in some cases out of the county to the clinic. Similarly, in Nigeria, patients travelled from all over the country to come to the teaching hospital for treatment. Therefore, it would not have been feasible for me to travel to individual patient’s homes or work places to conduct the interviews. By undertaking the telephone interviews, I did not have to visit unknown neighbourhoods where my safety and security could not be guaranteed.

Debates about the use of telephone interview versus face to face have been on-going for decades. One of the challenges for me with using the telephone interview method was the obvious absence of visual cues. Holbrook et al. (2003) suggests that not being able to see the interviewer, but only hearing the question may make the interviewee fatigued, resulting in satisfying (socially acceptable) responses. Additionally, the visual presence of the interviewer may have relevance for pace and engagement (Holbrook et al., 2003). Regarding engagement, Jackle et al., (2010) suggests that a person is more likely to be multitasking during a telephone interview and may not be fully engaged with the process due to the lack of visual stimulus to concentrate (Jackle et al., 2010). However, in this research, the use of telephone interviews was an advantage as it was a good opportunity for all participants to freely express any negative experiences, memories, thoughts and emotions within the confines of their homes.



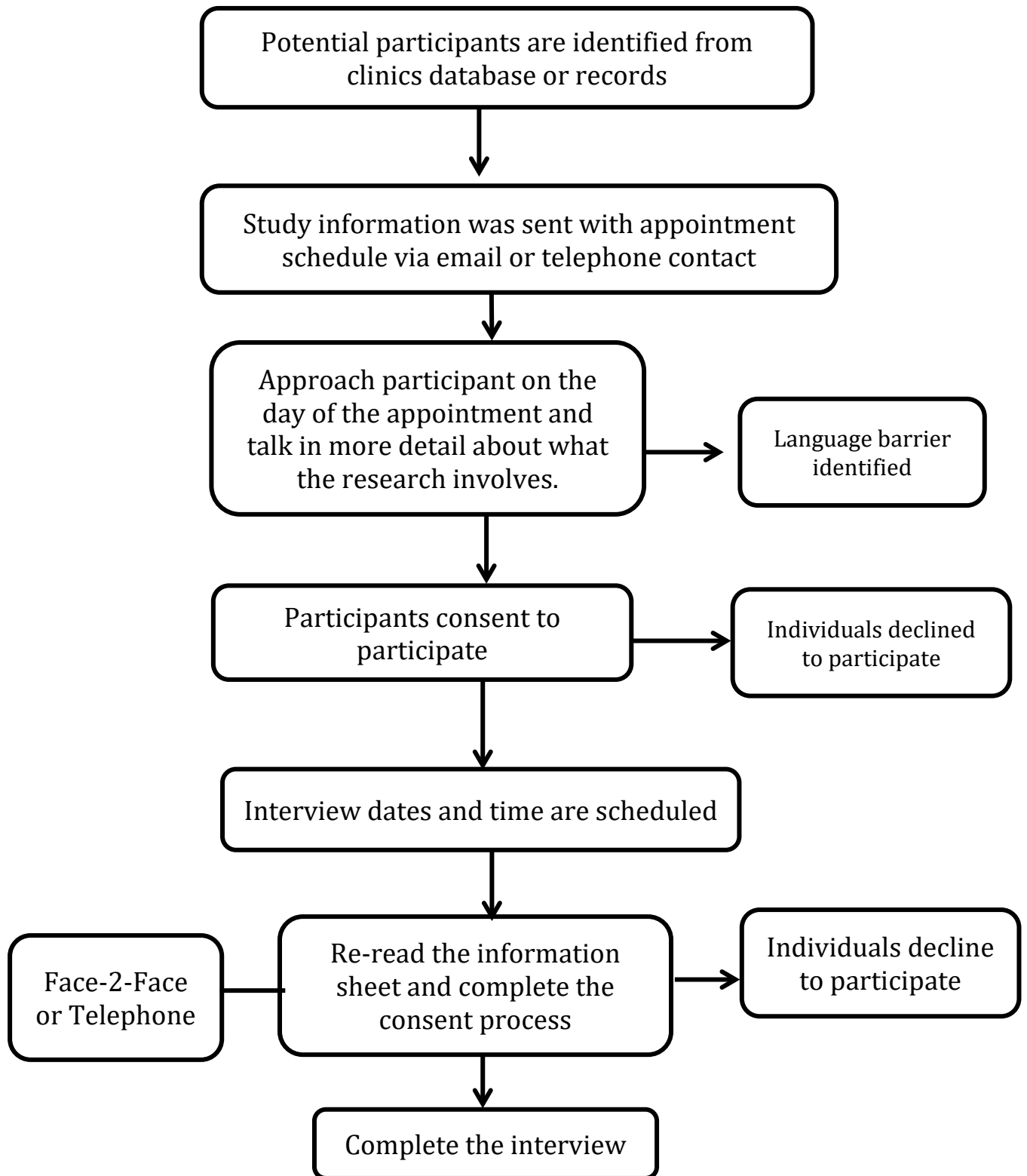


Figure 3.5: Flowchart of the qualitative recruitment and consent process

### **3.15. APPROACH TO INTERVIEWING**

Two types of qualitative interviews could have been used to collect information from participants: unstructured interviews, where the interview is not dictated by any pre-determined set of questions (Corbin & Morse, 2003), and semi-structured interviews, in which the researcher may ask pre-specific open-ended questions with accompanying probes for more detail (Kathleen Piercy, Unpublished). Of these two, the semi-structured type was considered appropriate. It is a more flexible method of interviewing was sought, without compromising on the overall generalizability of the topics to a broader population, as can happen unstructured interviews.

During the interviews, closed ended questions were first asked to build a good rapport between the researcher and the participants, followed by open-ended questions when participants were a bit more relaxed and readier for the interview. Four different topic areas were covered during the interviews, and each new topic was started with a broad question. For example, "*could you tell me a little bit about ...?*" was used to begin each topic area. The open-ended questioning allowed the interviewee to identify the territory to be explored, while giving them the freedom to take any direction in answering the question posed (Siedman, 2013), which facilitated probing for more detail as new topics revealed themselves.

Additionally, a topic guide (Appendix 5) was developed to be used as a '*memory aid*' during the interviews. This was done in each interview to ensure that there was consistency and flow in the range of topics to be explored (Gell, 2013). However, the order in which the questions were asked deviated slightly from the topic guide, depending on the interviewees' response or need for clarity.

### **3.16. INTERVIEW PRACTICALITIES**

The interviews were designed and scheduled to last a duration of 30-45 minutes. This was intended to be long enough to cover each topic (Lewis and Ritchie, 2003), but not so long that it interferes with the participants scheduled nurse appointment. Two interviews in the UK were under 15 minutes over the telephone. In the UK, most interviews were conducted face-to-face in the privacy of a consultation room, and about five were conducted over the telephone. In Nigeria however, the interviews were exclusively done face-to-face, and lasted for an average of 45 minutes. When selecting the

means of conducting the interview (either by face or telephone), the convenience of the participants was paramount, and the means was selected based on it.

When presenting myself to the participants during the face-to-face interview, it was important for me to balance professionalism with a certain level of approachability to enable me to build a relationship with each participant. In the UK, a few of the participants were within my age range, and so were relaxed enough to share their experiences with me, which made it easy to interview them. In Nigeria, however, most of my participants were older than me, which was one of my concerns. The Nigerian culture emphasises respecting those older than one's self, and so this made me quite nervous in the beginning. However, my nervousness was soon alleviated because most of the women were very happy to talk to me. One lady said, *"I've been looking for someone to vent on and I can't do it on my husband, because he is paying for this treatment you see, so it would make me look ungrateful"*.

Once that rapport was developed, I also had to balance my empathy for the participants/patients as a woman with my professionalism as a researcher to avoid changing the interviewing relationship into a therapeutic one (Seidman, 2013). The semi-structured nature of the interviews allowed for a 'two-lane' avenue of communication (Patton, 2001), which allowed the respondents feel comfortable enough to reveal personal stories about themselves and experiences. However, the researcher needs to stay in control of the interview, so it does not stray too far from the topic of discussion. For example, when I asked, *"Can you tell me about your experiences before deciding to undergo the treatment?"*, a few Nigerian respondents began to complain about their husbands. The question probably triggered some uncomfortable memories for them, which sometimes made it quite challenging for me to find out about their pre-ART experiences. However, those situations although challenging to sort through were equally informative for me.

It was quite important to learn how to pose certain questions to the women, and equally effectively deal with a lack of response. Sometimes, the respondent does not respond quickly enough, either because they are deep in thought, or do not want to respond to the question. It was important to know when to differentiate between the two; to either pursue the matter by probing the respondents' hesitation or respect their decision to be silent on the issue. For example, in Nigeria, when the spontaneous topic of 'abortions' came up, one lady went quiet. I was trying to avoid having an 'awkward silence' moment,

leading me to think she didn't want to tell me, and therefore wonder what to ask next. But after pausing to think, she began to narrate her experience with her former partner. It was an important and teachable experience for me to learn how important it is to be patient and allow my respondents time to think. If I had not waited, she might not have told me, and I would have lost some important information by her story. All the interviews were completed successfully.

### **3.16.1 Approaching sensitive topics**

Throughout the recruitment process, participants were made aware that potentially sensitive and intimate subjects about their subfertility, social support, income and affordability were to be discussed during the interviews; so, women who found these topics uncomfortable or too sensitive could choose not to participate. No problems were encountered by participants when probing the sub-fertility and social support topics. However, some participants found it quite uncomfortable talking about their inability to afford the treatment and their quality of life afterwards. The topic guide was designed for such scenarios; to introduce these topics after certain 'warm-up' questions were asked and answered. I also tried to create a comfortable atmosphere for the women to open up and talk about these sensitive issues and was careful not to pose the questions assertively.

Additionally, before certain sensitive subjects were approached, prior introduction was made. For example, sub-fertility is considered to be 'a woman's problem' in Nigeria and can be quite shameful. Therefore, before the topic was approached, it was introduced as "*Please madam, I need to ask some personal questions regarding your fertility issue. Can you tell me about your experiences before you were referred here?*" Introducing the topic 'gently' plays a vital role in establishing rapport with the participant and enables better quality data to be obtained.

Furthermore, the presence of the husbands during the interview was distracting for the female participants. Most women (particularly in Nigeria) kept quiet, while the husbands did all the talking. In a few instances, it was observed that the men either tried to prompt their wives to answer or answered on their behalf. Therefore, as much as possible, women were interviewed without their partners (particularly in Nigeria), because domestic abuse has been documented to be one of the burdens of sub-fertility in low-middle income countries. I felt that if such experiences existed, these women might feel

uncomfortable in the presence of their partners to discuss such sensitive topics and it would impair communication and rapport.

### **3.17 RECORDING AND TRANSCRIBING**

A digital voice recorder (Sony ICD-UX533 Digital Dictation Machine) was used during the interviews to capture a comprehensive account of the exchange. Recording the conversation allowed me pay attention to the interviewees own language and explore nuances. This in turn helped me formulate probing questions, rather than writing as they spoke. Transcription began as soon as possible following the file transfer, to enable a familiarisation of the information as an initial step towards the analysis process. This process took some time for me because there were a lot of good responses. During the transcription, all potentially identifying material such as respondent's names or home address were replaced with pseudonyms. I checked the transcription for accuracy by listening to the audio recording of the interview again while reading the transcript.

#### **3.17.1. Field notes**

During the interviews, I had to pay attention to changes in the respondent's speech patterns or tone, attitudes, behaviour and eyes in response to the questions asked. I noted the respondent's reactions to specific questions, so that emphasis on those aspects can be made during the analysis. I found it very useful to take notes at this point because the changes in behaviour would not be evident in the recordings.

After each session, I reported my notes on each person interviewed on a contact summary sheet adopted by Miles and Huberman (1994) (Appendix 6). Sometimes I wrote notes that exceeded the provided space on the form, and other times I dictated my impressions of the participant in to the audio recorder immediately after the interview, so that it was included in the transcript. It was a good way for me to record my concerns either about the limitations to the quality of data generated, some aspect of the interview questions that needed restructuring or rephrasing, my tone when asking specific questions or my impression of the participant and the dynamics of our encounter. It helped to identify emergent areas to explore that could be included to the topic guide (Gell, 2013). I was also alerted of my nuances as an interviewer and reporting this helped me change potentially problematic habits. For example, asking 'yes' or 'no' questions.

After most of the interviews, I was able to reflect on the interview process and the relationship formed within those few minutes. I also reflected on how I was perceived by

the interviewee. This could be either as a student, a researcher, a medic or a fellow woman asking them about their reproductive health, social life, and finances. Reflecting on how I was perceived considering my age, background and ethnicity contributed to my understanding of the variations in interviews. It equally helped me reflect on the different motivations people had for consenting to participate in the study, which included wanting to help a student, wanting to help out other women/couples in similar situations, or their need to talk about their views on the topic. Recognising the different reasons for participation helped me understand the differences in the interviewer-interviewee relationship, and to some extent determine the length of the interviews.

### **3.18. ANALYSIS**

While data collection was ongoing, data analysis had begun. It was essential to start the data analysis process as soon as possible because, it determined the initial stage of data managing which is, "*the process of sorting and reducing large amounts of data into more manageable formats*" (Gell, 2013, Lewis and Ritchie, 2003). This was done to effectively identify the point of saturation.

This concurrent approach of data collection, writing up field notes and transcribing, allowed for a more detailed recollection of each encounter, and facilitated a more accurate analysis (Maxwell, 1996). It also enabled the identification of emergent themes, which could then be used to enhance future interview questions (Pope & Mays, 2006; Patton, 2002).

#### **3.18.1. Approach to analysis**

I adopted an inductive iterative process to the data analysis, using a thematic approach. An inductive approach ensures that themes are more directly linked to the participants statements; which allows the findings to be driven by the data, and not a pre-existing framework as is in theoretical thematic analysis. Therefore, by using an inductive approach, I developed codes and themes based primarily on the participants statements during the interview process (Wengraf, 2001).

Braun and Clarke (2006) defined thematic analysis as "*a method used to identify, analyse and report patterns (themes) within data*" (p.79) (Viksveen, 2015). This probably prompted Bryman (2015) to refer to thematic analysis as a strategy without an

“identifiable heritage” or a distinctive/outlined cluster of techniques, unlike other strategies such as grounded theory or critical discourse analysis (Bryman, 2015). However, Boyatzis (1998) conceptualisation of thematic analysis was that “*thematic analysis assists the researcher in the search for insight as a process that can be used with most, if not all qualitative methods*” (Boyatzis, 1998). It was therefore a pragmatic decision to adopt a thematic approach to analysis in the current research, as it highlighted similarities or differences across the data, identified and generated unexpected insights. The method helped determine the appropriate framework for understanding the stress patterns to the women, the cost-burden of the treatment and the woman’s perceived quality of life, based on the generated data rather than a *priori* procedure based of previous research.

Although thematic analysis has been renowned for its flexibility and versatility (the fact that it can be used in various contexts and by different other methods), it has also been criticised for its absence/abandonment of several key conventional features of qualitative research. These include flexibility in sampling and design, an interactive data collection style and generation of themes (Bowling and Ebrahim, 2005). Caution should be implemented when conducting thematic analysis, and certain pitfalls should be avoided (Bowling and Ebrahim, 2005); such as using data collection questions as ‘themes’, frequent overlap between themes, failure to analyse the data and as Bazeley suggests, being vague about how themes are identified or emerge from the data when reporting the analysis (Bazeley, 2013). With these potential pitfalls identified, I could ensure that they were avoided. This was done by specifying the themes that were identified, the process of identification and justifying their importance or significance (Braun and Clarke, 2006, Bryman, 2015, Bazeley and Jackson, 2013). Hence, it can be inferred that the limitations of thematic analysis are not necessarily those of the technique, but of the researcher.

### **3.18.2. Data management tools**

Computer Aided Data Analysis (CADAS) make working with different complex data forms such as audio, video, pictorial and written more manageable (Pope et al., 2000). It provides a consistent approach to organising and retrieving data. This enables the researcher concentrate on the creative aspect necessary for ‘quality’ analysis. Additionally, these software packages allow for a more transparent analytical process, as

it provides a visual audit trail (Guba and Lincoln, 1994) for the researcher and others to identify logical flaws, conceptual density or inadequate conceptualisation and undeveloped categories (Corbin and Strauss, 2008, Seale, 1999). It is important to recognise here that certain limitations apply to the use of CADAS packages. Although some CADAS software's are more sophisticated than others, it does not replace the role of the researcher in generating quality qualitative analysis (Mason, 2002).

This research study used a CADAS software to help expedite the data management process. Following the second proof-reading of the transcripts to increase familiarisation with the data, the transcripts were imported into NVivo 11 qualitative data analysis software (QSR International Pty Ltd. 2014). Using the NVivo 11 software helped in identifying links between and within the data generated. Furthermore, it allowed for easy retrieval, manipulation and organisation of codes across the various transcripts. Initially, colour coding was done on pre-set<sup>12</sup> codes to enable easy identification of the codes used in the different contexts in the transcripts. However, this was short-lived because as the number of codes increased, I could not remember the colour-code combinations.

### **3.18.3. Stages of analysis**

The analysis process involved six phases, illustrated in Figure 3.6 which incorporates the generic steps involved in thematic analysis drawing from (Braun and Clarke, 2006, Clarke and Braun, 2014) and insights from (Ritchie et al., 2013, Thomas and Harden, 2008, Gioia et al., 2013, Attride-Stirling, 2001).

The first phase involved familiarisation with the transcripts and field notes. This was initially done during the transcription phase; however, each transcript was re-read to better acquaint myself with its content and to tease out the main issues. This allowed for a better focus on the most important concepts presented in the data and allowed me to understand the trend in the participants perspectives. By listing the recurrent ideas or pertinent issues in the text, key elements and dimensions were identified. This facilitated the identification of the pre-set codes in the second phase.

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<sup>12</sup> These are 'initial' codes derived from the research question, prior knowledge of the subject matter, or problem areas.



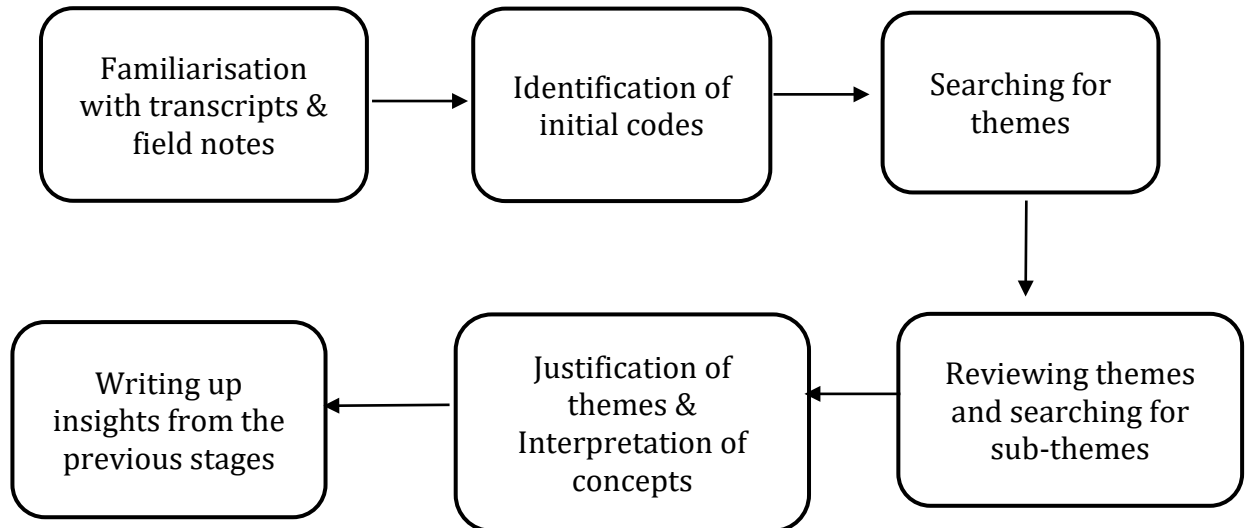


Figure 3.6: Phases of the thematic analysis process.

Codes were names given to a small portion of text used to identify similar constructs across the various transcripts (Gell, 2013). For example, ‘savings’ or ‘marital dispute’. While categories are higher-order codes (Bryman, 2015) that group codes of similar topics together (e.g. ‘funding source’ or ‘partner support’). Developing and identifying codes was based on Lofland and Lofland (1995) method of code development, which involves asking myself four fundamental questions about the text. These are:

(1) What does this item of data represent? (2) What is this item of data an example of (3) What is this item of data about? (4) What is this item of data trying to convey? (Lofland and Lofland, 1995).

As familiarisation with the text improved, codes were refined by adding, collapsing, expanding and revising the coding categories across the various transcripts. For example, after transcribing and coding seven interviews in Nigeria, 35 codes were identified. However, following the typification<sup>13</sup> across the interviews, a re-classification into 22 codes within seven broader categories resulted. As new interviews were transcribed, these codes and categories were applied and continuously reviewed throughout the process. Looking across the data, it became evident that the principles for coding according to Polit and Beck (2010) which include conceptual, relationship, participants

<sup>13</sup> This “is the process of grouping a range of codes under a ‘typical’ similarity that can be generalised despite the variety in details” (Ryan and Bernard, 2003)

perspective, participant characteristics and settings (Polit and Beck, 2010) could be adapted and used to organise the codes generated.

As the interviews continued and codes increased, the search for common elements 'themes' within the data began. Themes were identified using five observational techniques described by Ryan and Bernard (2003). These involve looking for repetitions in the text, metaphors, shifts in topics (transitions), similarities and differences across units in the texts, and linguistic connectors such as 'because' or 'instead of', which signify casual or conditional relations respectively (Ryan and Bernard, 2003). The data within and between categories were examined and compared to generate further plausible sub-themes that could aid in understanding the impact of funding the treatment, the role social support plays in this situation and its repercussions on the quality of life of the woman or household.

At this stage, an organisational framework that could be used to arrange data which involved the significant aspects of the study (financial stress, social support and quality of life) was used to classify the themes. However, as new themes developed (particularly in Nigeria), the classifications had to be adjusted to include texts that illustrated key arguments in the emergent themes, such as 'coping strategies' and 'stigmatisation'. Organising the data into this framework created a detailed index, which made for easy retrieval and exploration.

The penultimate phase of this analysis process was the justification and interpretation of the data. This process involved making sense of the data and triangulating it with the quantitative findings; given the mixed methods design of this study. The qualitative analysis adequately captured the intricacies of the psychological and social concepts under investigation and also introduced some unexplored aspects. It provided a descriptive account of women's experiences and concerns with funding ART, and the outcomes of social support. The final phase of the analysis process was the culmination of all the previous stages into writing this document. This phase ties the themes to the research question (using quotes from transcripts as illustrations) and compares them to established knowledge on the research phenomenon where possible in the discussion section.

### 3.18.4. Quality Criteria

Qualitative research has been criticised for being impressionistic and subjective, difficult to replicate, validate and to access credibility, unlike quantitative methods (Braun and Clarke, 2006). However, although the same standards cannot access quantitative research as quantitative research methods, Pope and May (2000) state that ‘it is possible to access both methods against a criterion common to both; which are validity and relevance, although the means of assessment might be modified’.

Various authors have established their methods of assessing quality in qualitative research (Seale, 1999, Corbin et al., 2014, Silverman, 2011). However, the 15-point checklist of criteria for good thematic analysis developed by Braun & Clarke (2006) (see Table 3.7) as well as “questions that might be asked of a qualitative study” by Pope and May (2000) were used as guides during the analysis process (Mays and Pope, 1995, Mays and Pope, 1996, Braun and Clarke, 2006, Pope et al., 2000). These checklists were cross-checked against the analysis process to ensure that it was conducted rigorously.

Table 3.7: Quality checklist for good thematic analysis (Braun and Clarke 2006)

Process	Criteria
Transcription	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for accuracy
Coding	Each data item has been given equal attention in the coding process. Themes have not been generated from a few vivid examples, but instead the coding process has been thorough, inclusive & comprehensive. All relevant extracts for each theme have been collated, and themes have been checked against each other and back to the original data set. Themes are internally coherent, consistent, and distinctive.
Analysis	Data have been analysed & interpreted rather than paraphrased or described. The analysis and data match each other – the extracts illustrate the analytic claims. Analysis tells a convincing and well-organised story about the data and topic. There is a good balance between analytic narrative and illustrative extracts
Overall	Enough time was allocated to complete all phases of the analysis adequately
Written report	The approach to thematic analysis are clear. The language & concepts used in writing are consistent with the epistemological position of the analysis. The researcher is positioned as active in the research process.

### 3.19. REFLECTION ON THE QUALITATIVE RESEARCH PROCESS

Kale (1996) likened interviewing to 'prospecting' for the facts and feelings residing within the interviewee, and the role of the interviewer as the 'excavator/miner' of the pre-existing data, which he refers to as 'nuggets' (Kale, 1996). Thereby assuming that there is knowledge within the interviewee waiting to be uncovered by the interviewer or researcher (Gell, 2013). However, another school of thought describes the role of the researcher as a 'data-generation collaborator', by presuming that the collaboration between the interviewer and interviewee results in the co-creation of knowledge (Mason, 2002). These two ideologies have been the subject of much debate among qualitative researchers (Lewis and Ritchie, 2003). Within the data generation process, many qualitative researchers believe they play an active role, which makes it necessary to reflect on their role in the interview process (Mason, 2002). My reflection on the interviewer-interviewee relationship, and how I obtained the research data is an essential aspect of the analysis process, which was expedited by the use of field notes.

There is a dearth of qualitative research methods on infertility in Nigeria (Hollos, 2003, Aghanwa et al., 1999, Fatoye et al., 2009, Omoaregba et al., 2011). A few researchers mentioned that it is difficult to properly conduct qualitative research in Nigeria because Nigerians normally do not discuss private matters such as their subfertility diagnosis with anyone except their health care providers (Hollos, 2003). Similarly, the English are considered private people preferring to discuss these matters only with close family members or their health care providers (Daniels, 1997). Knowing this, I was aware it was going to be difficult to get people to open up and discuss such private matters as subfertility and affordability, as some degree of reluctance can be expected.

So, I was initially worried, during the design stage, about the amount of information I was going to generate from my participants, but on the field, collecting the data, but it was not as difficult as I envisioned. In fact, I quite enjoyed listening to the experiences and stories that emerged from the interviews. However, the initial reluctance to discuss such private matters was still evident in both cohorts. Creating a good rapport and respecting the views of the participants, especially when they did not feel comfortable talking about an issue, encouraged them to share their experiences.

In social science research, when the data collection is characterised by face-to-face interactions, the identity of the researcher becomes important. Even as a Nigerian researcher, researching Nigerians, I had to accentuate facets of my personal identity

which were not only similar to the study participants, but also to the geographical location in which I was, and at the same time play down facets of my identity that differed. My linguistic identity was probably the most challenging. In an attempt to accentuate similarity between myself and the participants, I had to play down my grammatical competence of the English language. This was because there are over 250 different ethnic groups in the country, and the one lingua franca across all ethnic groups is an English-based creole language commonly referred to as 'pidgin or Broken'. Being able to converse in this language was key to establishing rapport between myself and my participants.

Secondly, dressing differently also helped make the visual differences between myself and my participants more apparent. I was advised to change my dressing, such as wearing a pair of lean trousers when dealing with Nigerian women as a researcher. In the UK, I was quite used to wearing my jeans, t-shirt and sneakers while recruiting and interviewing participants, as this did not cause any problem. But in Nigeria, I had to wear a blouse, skirt and flat work shoes while in the clinic and interviewing participants, to look professional, so that the participants can respect me and my work.

Furthermore, most women were quick to ask about my marital status, especially before they expressed their marital issues related to the subfertility diagnosis, and I was quite explicit about my unmarried status when asked. It had a dual effect. Sometimes it worked in my favour because then the women were quick to advise me about not making the mistakes they had made. Other times it did not, because they felt that due to my inexperience with marriage, I would not be able to adequately understand what they were going through.

To summarise, these strategies reflected my attempt to accentuate similarity between myself and the participants to build a good rapport. It also helped me understand the relevance of the researcher's personal identity in negotiating rapport with participants. This could probably be the reason for the dearth of good qualitative research in Nigeria. The process through which the data is generated is just as important as the data itself. Therefore, if the researcher is not sensitive to how his/her identity might influence the participants responses, it might compromise an essential aspect of qualitative interviewing i.e. rapport building.

### **Summary of the qualitative methods**

In this chapter, I have clearly described the qualitative data collection and analysis process within this mixed methods project, as well as reflected on how I have maintained professionalism while ensuring quality of the data collected. Semi-structured interviews were used to obtain the information on affordability, social support and quality of life from 15 UK and 17 Nigerian sub-fertile women reporting for ART. Participants were purposively sampled from reputable fertility clinics within both countries. Interviews were recorded and transcribed verbatim, before a thematic analysis was performed. NVivo 11 software was used to aid in data coding and management. A constant comparative method was used during the analysis to challenge my interpretations and conclusions drawn from the data. To ensure credibility and replicability of findings, a quality criteria checklist was used during the analysis phase. The next section presents the results from the qualitative study.

**PART III:**

**RESULTS &**

**DISCUSSION**

**CHAPTER 4:**  
**STRESS AND**  
**ANXIETY**  
**PATTERNS**



## **CHAPTER 4: STRESS AND ANXIETY PATTERNS**

### **4.1. INTRODUCTION**

This chapter presents findings on the level of stress and anxiety among UK and Nigerian women seeking ART. Section 4.2 describes the participants' characteristics and answers two of the research questions outlined in chapter 1: What are the stress patterns of sub-fertile women accessing ART in both countries and what socio-demographic factors predict them? Section 4.3 introduces the interview sample, describes the experiences with infertility that participants discussed during the interviews. This section answers one of the research questions identified in chapter 1: what can be learnt from the experiences of infertile women in both countries?

### **4.2. STRESS PATTERNS OF WOMEN ACCESSING ART IN THE UK AND NIGERIA**

#### **4.2.1. Characteristics of the study population**

Study population demographics and fertility characteristics are summarised in Table 4.1. Within the UK sample population, a total of 64 women were eligible for inclusion, completed all the questionnaires, and were included in the current analysis. The mean age among UK cohorts was 35.8 years (range 27-44), with the majority (54.7%) of the participants distributed across the 36-45 (years) age range. More than half the population had attained a university education, and the majority reported having full-time employment (78.1%). Participants were either married or cohabiting with their partners, and a large number had been trying to conceive for less than five years (75%). The majority of the participants had received a diagnosis regarding their subfertility with 36% reporting a female cause, only one participant had previously had a child through IVF, and was having a repeat of the treatment, 28.1% reported a male cause and 34.4% diagnosed as unexplained subfertility. More than half were undergoing IVF (64.1%) in their first attempt (68.8%) and were self-funded (54.7%). Significant differences were observed between NHS and self-funded participants only in the number of attempts at ART ( $X^2=4.55$ ,  $p<.05$ ) and the employment status ( $X^2= 7.16$ ,  $p<.05$ ).

Table 4.1: Characteristics of studied population in UK &amp; Nigeria

Variable	UK n=64 n (%)	Nigeria n=52 n (%)	$\chi^2$
<b>Age [mean±SD]</b>	35.8± 4.19	39.4± 6.91	
25-35	29 (45.3)	16 (30.8)	15.34**
36-45	35 (54.7)	25 (48.1)	
46-55	-	11 (21.2)	
<b>Educational level</b>			
University	45 (70.3)	31 (59.6)	6.25
High School	16 (25.0)	14 (26.9)	
Primary School	3 (4.7)	5 (9.6)	
No School	-	2 (3.8)	
<b>Employment status</b>			
Not working	3 (4.7)	2 (3.8)	3.66
Part-time	11 (17.2)	3 (5.8)	
Full time	50 (78.1)	47 (90.4)	
<b>Marital status</b>			
Married	41 (64.1)	47 (90.4)	10.85**
Unmarried/Cohabiting	23 (35.9)	5 (9.6)	
<b>Duration of Subfertility</b>			
<5 years	48 (75.0)	15 (28.8)	24.62**
>5 years	16 (25.0)	37 (71.2)	
<b>Cause of Sub-fertility</b>			
Female factor	23 (35.9)	17 (32.7)	23.02**
Male factor	18 (28.1)	7 (13.5)	
Unexplained	22 (34.4)	19 (36.5)	
2 <sup>0</sup> infertility	1 (1.6)	9 (17.3)	
<b>Type of ART</b>			
IVF	41 (64.1)	23 (44.2)	5.33*
ICSI	23 (35.9)	29 (55.8)	
<b>Number of Attempts</b>			
1 <sup>st</sup> Attempt	44(68.8)	43 (82.7)	6.57
Repeat	20 (31.3)	9 (17.3)	
<b>Source of Funding</b>			
Self-funded	35 (54.7)	52 (100.0)	31.42**
Government funded	29 (45.3)	-	

2<sup>0</sup>-Secondary, X<sup>2</sup> – Pearson chi-squared, \*p<.05, \*\*p<.001

Within the Nigerian sample, a total of 52 women were eligible for inclusion, completed all the questionnaires, and were included in the current analysis. The mean age was 39.4 (range 28-54), and a majority of the participants were equally within the 36-45 (years) age range; however, over 20% were distributed across the older age range. Half of these women had a university or higher education degree (50%) and majority were in full-time employment (90.4%).

Participants were mostly married or living together with their partners and had been trying to conceive for more than five years (71.2%). A majority had received a diagnosis regarding the cause of their subfertility, with 40.4% of them reporting a female cause, 17.3% had previously been pregnant and terminated it, or suffered a miscarriage or stillbirth (secondary sub-fertility). 13.5% had been diagnosed with male factor subfertility while 28.8% was unexplained. More than half were about to undergo IVF, the majority in their first attempt (82.7%), and all were self-funded.

### ***Comparison of both cohorts***

From the results presented in Table 4.1, the statistical analysis suggests that the UK and Nigerian study population varied in socio-demographic and fertility characteristics. Differences in both cohorts was observed in age, marital status, duration of subfertility, cause of subfertility, type of treatment and unsurprisingly the source of funding ( $p < .05$ ). No differences were observed in the educational levels of both cohorts, the employment status and the number of attempts at treatment ( $p > .05$ ).

## **BIVARATE ASSOCIATIONS BETWEEN THE STUDY VARIABLES**

### **4.2.2. Relationship between sociodemographic and fertility variables**

#### ***UK Cohort***

It was observed that the educational level of the participants was significantly correlated with the annual household income ( $r = .43$ ,  $p < 0.01$ ) and equally correlated with monthly expenditure ( $r = .41$ ,  $p < 0.01$ ), with higher educational levels associated with higher income and increased expenditure (Table 4.2). The cost of the procedure was unsurprisingly significantly correlated with the type of treatment procedure to undertake ( $r = .64$ ,  $p < 0.01$ ) and annual income showed a strong positive correlation with monthly expenditure ( $r = .68$ ,  $p < 0.01$ ). Surprisingly, annual income negatively correlated

with the duration of subfertility ( $r=-.41$ ,  $p<0.01$ ), with a decrease in annual income associated with an increase in the duration of subfertility. Annual household income was moderately correlated with employment status ( $r=.29$ ,  $p=0.01$ ) and so was household monthly expenditure ( $r=.28$ ,  $p=0.02$ ). Other moderate correlations were found between funding source and number of attempts ( $r=.25$ ,  $p=0.05$ ), household expenditure and duration of subfertility ( $r=.25$ ,  $p=0.05$ ) and annual household income and marital status ( $r=.25$ ,  $p=0.04$ ) (see Table 4.2).

### ***Nigerian Cohort***

Similar to the UK cohort, within the Nigerian cohort, it was equally observed that educational level of the participants was significantly correlated with annual household income ( $r=.45$ ,  $p<0.01$ ) and monthly expenditure ( $r=.47$ ,  $p<0.01$ ) (Table 4.2). With an increased educational level associated with an increased income and expenditure. Unsurprisingly, age was significantly correlated with the cost of the treatment ( $r=.65$ ,  $p<0.01$ ), duration of subfertility ( $r=.36$ ,  $p<0.01$ ) and cause of subfertility ( $r=-.54$ ,  $p<0.01$ ). This association between age and the cause of subfertility could possibly be due to the relatively high number of female factor subfertility (shown in Table 4.1) compared to the other causes. Moderate correlations were observed between cost of the procedure and number of attempts ( $r=.27$ ,  $p=0.05$ ) as well as duration of subfertility ( $r=.34$ ,  $p=0.01$ ). Equally significant was the correlation between the cause of subfertility and type of ART procedure ( $r=-.44$ ,  $p<0.01$ ) (see Table 4.2).

Table 4.2: Showing the correlations between each socio-economic and fertility index in both countries

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. Age	1	.02	.03	.12	-.07	.05	-.07	.08	-.16	-.22	-.17	-.01
p-value		.87	.81	.35	.59	.66	.56	.52	.19	.08	.17	.93
2. Education	<b>-.01</b>	1	-.15	-.12	-.08	<b>.43**</b>	<b>.41**</b>	.15	-.06	<b>-.28*</b>	-.14	-.09
p-value	<b>.93</b>		.21	.34	.52	<.01	<.01	.21	.60	.02	.24	.45
3. Employment	<b>-.08</b>	<b>-.17</b>	1	.25*	-.13	.29*	.28*	-.14	.02	-.17	.02	.19
p-value	<b>.55</b>	<b>.23</b>		.04	.29	.01	.02	.25	.85	.16	.89	.12
4. Marital status	<b>-.34*</b>	<b>-.01</b>	<b>-.10</b>	1	-.02	.25*	.12	-.18	.09	-.02	-.09	.09
p-value	<b>.01</b>	<b>.95</b>	<b>.48</b>		.90	.04	.36	.15	.48	.88	.46	.46
5. Cost of procedure	<b>.65**</b>	<b>-.08</b>	<b>-.05</b>	<b>-.31*</b>	1	-.22	-.10	-.10	-.02	<b>.64**</b>	.25*	.11
p-value	<b>&lt;.01</b>	<b>.57</b>	<b>.71</b>	<b>.02</b>		.07	.43	.43	.84	<.01	.04	.40
6. Annual income	<b>-.17</b>	<b>.45**</b>	<b>-.09</b>	<b>.08</b>	<b>.06</b>	1	<b>.68**</b>	<b>-.41**</b>	.02	.04	-.22	-.08
p-value	<b>.21</b>	<b>&lt;.01</b>	<b>.51</b>	<b>.56</b>	<b>.67</b>		<.01	<.01	.87	.75	.08	.52
7. Household expenditure	<b>-.16</b>	<b>.47**</b>	<b>.05</b>	<b>-.02</b>	<b>-.02</b>	<b>.53*</b>	1	<b>-.25*</b>	.00	.04	.05	.01
p-value	<b>.25</b>	<b>&lt;.01</b>	<b>.71</b>	<b>.84</b>	<b>.91</b>	<b>&lt;.01</b>		.05	.97	.72	.69	.95
8. Duration of subfertility	<b>.36**</b>	<b>-.12</b>	<b>-.09</b>	<b>-.22</b>	<b>.34*</b>	<b>.01</b>	<b>.18</b>	1	-.05	.01	.29*	.22
p-value	<b>&lt;.01</b>	<b>.36</b>	<b>.49</b>	<b>.11</b>	<b>.01</b>	<b>.92</b>	<b>.20</b>		.68	.96	.02	.08
9. Cause of subfertility	<b>-.54**</b>	<b>.02</b>	<b>.01</b>	<b>.09</b>	<b>-.23</b>	<b>.18</b>	<b>.04</b>	<b>-.24</b>	1	.06	.10	.06
p-value	<b>&lt;.01</b>	<b>.85</b>	<b>.94</b>	<b>.51</b>	<b>.09</b>	<b>.19</b>	<b>.77</b>	<b>.08</b>		.60	.42	.59
10. Type of ART	<b>.53**</b>	<b>-.10</b>	<b>-.10</b>	<b>-.23</b>	<b>.69**</b>	<b>-.02</b>	<b>.05</b>	<b>.46**</b>	<b>-.44**</b>	1	.17	.22
p-value	<b>&lt;.01</b>	<b>.46</b>	<b>.49</b>	<b>.09</b>	<b>&lt;.01</b>	<b>.89</b>	<b>.71</b>	<b>&lt;.01</b>	<b>&lt;.01</b>		.16	.07
11. Number of attempts	<b>.31*</b>	<b>-.11</b>	<b>.14</b>	<b>-.15</b>	<b>.27*</b>	<b>.18</b>	<b>.05</b>	<b>-.04</b>	<b>-.09</b>	<b>-.002</b>	1	<b>.25*</b>
p-value	<b>.03</b>	<b>.42</b>	<b>.32</b>	<b>.29</b>	<b>.05</b>	<b>.18</b>	<b>.71</b>	<b>.75</b>	<b>.49</b>	<b>.98</b>		<b>.05</b>
12. Funding source	a	a	a	a	a	a	a	a	a	a	a	1
p-value												

Correlations above the diagonal are for UK cohorts, correlations below the diagonal (in blue) are for Nigerian cohorts.

\*\* Correlation is significant at the 0.01 level (2-tailed), \* Correlation is significant at the 0.05 level (2-tailed), a- The funding source variable within the Nigerian cohort is a constant (self-funded) therefore correlations cannot be made.

## **4.2.2: STRESS AND ANXIETY PATTERNS AMONG THE UK AND NIGERIA**

### **4.2.2.1. ANXIETY (BAI-21)**

The item-by-item descriptive analysis of the BAI scale is shown in Table 4.9 and includes the percentage of respondents who endorsed each response option for each item in both countries. To better capture which items were reported to a greater extent by the population, the sample endorsing 'moderately' and 'severely' response options were collated, and the percentages are presented in this section.

#### ***UK Cohorts***

Within the UK population, the items "unable to relax" (42.2%), "fear of the worst happening" (40.7%) and "nervous" (45.3%) were endorsed by almost half the population. More than a quarter of the population endorsed the following items; "Heart-pounding" (23.4%) and "scared" (21.9%), while almost 20 percent of the population endorsed "terrified" (18.7%) and "feeling dizzy/lightheaded" (17.2%). The items that were reported by the least number of participants as affecting them moderately or severely were; "Difficulty breathing" (3.2%), "feelings of choking" (1.6%), "hands trembling" (0%) and "shaky" (4.7%) (Table 4.9).

An independent sample t-test was done to compare the BAI scores between NHS-funded and self-funded women. There was no significant difference in scores for NHS ( $M = 12.1$ ,  $SD = 7.3$ ) and self-funded ( $M = 11.1$ ,  $SD = 7.0$ ;  $t(61) = 0.6$ ,  $p = .58$ ). The magnitude of the difference in the means was very small ( $\eta^2 = .005$ ).

#### ***Nigerian cohorts***

Within the Nigerian population, more than half the sample population endorsed the item "fear of the worst happening" (51.9%), while a good majority endorsed "nervous" (48.1%), "terrified" (44.3%), and "heart-pounding" (42.3%). More than 20 percent endorsed "feeling hot" (30.7%), "fear of losing control" (28.9%), "unable to relax" (34.6%) and "feeling dizzy/ lightheaded" (25.9%). The items that were endorsed by the least number of participants as affecting them moderately or severely were "numbness" (1.9%), "feeling of choking" (0%), "fear of dying" (5.8%) and "hands trembling" (0%) (Table 4.9).

### ***Comparison of both cohorts***

The mean total score on the BAI-21 for UK women the mean score was 11.5 SD 7.1, ranging from 1-33, while in Nigerian women, the mean score was 12.7 SD 8.2, ranging from 0-29. Regarding severity of anxiety the suggested cut-off for significant clinical anxiety on the BAI is 16 (Beck and Steer, 1993). Therefore, 29.7% of UK cohorts experience high levels of anxiety while 30.8% of the Nigerian cohorts experience high levels of anxiety. Table 4.3 shows the distribution of both study cohorts by BAI classifications.

Table 4.3: Showing distribution of the samples regarding classification in the BAI scale

<b>BAI Scoring</b>	<b>UK =64 n (%)</b>	<b>NIGERIA=52 n (%)</b>
0-7 (minimal)	23 (35.9)	17 (32.7)
8-15 (mild)	22 (34.4)	19 (36.5)
16-25 (moderate)	16 (25.0)	12 (23.1)
26-63 (severe)	3 (4.7)	4 (7.7)

An independent t-test was conducted to compare the BAI scores between UK and Nigeria women. There was no significant difference in the anxiety scores for the UK (M=11.5, SD=7.13) and Nigerian [M=12.7, SD=8.23:  $t(114) = .82, p = .41$ ] cohorts. The magnitude of the differences in the means was very small (eta squared=.005).

Table 4.4: Item analysis of BAI overall scores

Item	Description	NOT AT ALL		MILDLY		MODERATELY		SEVERLY	
		n (%)		n (%)		n (%)		n (%)	
		UK	NIG	UK	NIG	UK	NIG	UK	NIG
1	Numbness	52 (81.3)	48 (92.3)	9 (14.1)	3 (5.8)	3 (4.7)	-		1 (1.9)
2	Feeling hot	32 (50.0)	27 (51.9)	23 (35.9)	9 (17.3)	7 (10.9)	6 (11.5)	2 (3.1)	10 (19.2)
3	Wobbliness in legs	48 (75.0)	41 (78.8)	12 (18.8)	5 (9.6)	4 (6.3)	3 (5.8)	-	3 (5.8)
4	Unable to relax	11 (17.2)	25 (48.1)	26 (40.6)	9 (17.3)	21 (32.8)	17 (32.7)	6 (9.4)	1 (1.9)
5	Fear of the worst happening	14 (21.9)	17 (32.7)	24 (37.5)	8 (15.4)	17 (26.6)	14 (26.9)	9 (14.1)	13 (25.0)
6	Dizzy or lightheaded	37 (57.8)	25(48.1)	16 (25.0)	13 (25.0)	9 (14.1)	12 (23.1)	2 (3.1)	2 (2.8)
7	Heart pounding or racing	32 (50.0)	27 (51.9)	17 (26.6)	3 (5.8)	13 (20.3)	16 (30.8)	2 (3.1)	6 (11.5)
8	Unsteady	46 (71.9)	31 (59.6)	14 (21.9)	16(30.8)	4 (6.3)	5 (9.6)	-	-
9	Terrified	30 (46.9)	17 (32.7)	22 (34.4)	12 (23.1)	10 (15.6)	16 (30.8)	2 (3.1)	7 (13.5)
10	Nervous	10 (15.6)	20 (38.5)	25 (39.1)	7 (13.5)	24 (37.5)	17 (32.7)	5 (7.8)	8 (15.4)
11	Feeling of choking	58 (90.6)	49 (94.2)	5 (7.8)	3 (5.8)	1 (1.6)	-	-	-



12	Hands trembling	51 (79.7)	49 (94.2)	13 (20.3)	3 (5.8)	-	-	-	-
13	Shaky	52 (81.3)	40 (76.9)	9 (14.1)	7 (13.5)	2 (3.1)	5 (9.6)	1 (1.6)	-
14	Fear of losing control	42 (65.6)	30 (57.7)	15 (23.4)	7 (13.5)	5 (7.8)	12(23.1)	2 (3.1)	3 (5.8)
15	Difficulty breathing	58 (90.6)	41 (78.8)	4 (6.3)	7 (13.5)	1 (1.6)	4 (7.7)	1 (1.6)	-
16	Fear of dying	53 (82.8)	45 (86.5)	8 (12.5)	4 (7.7)	3 (4.7)	3 (5.8)	-	-
17	Scared	32 (50.0)	34 (65.4)	18 (28.1)	5 (9.6)	11 (17.2)	8 (15.4)	3 (4.7)	5 (9.6)
18	Indigestion or discomfort in abdomen	50 (78.1)	49 (94.2)	8 (12.5)	3 (5.8)	5 (7.8)	-	-	-
19	Faint	49 (76.6)	39 (75.0)	10 (15.6)	3 (5.8)	5 (7.8)	9 (17.3)	-	1 (1.9)
20	Face flushed	38 (59.4)	39 (75.0)	20 (31.3)	8 (15.4)	5 (7.8)	3 (5.8)	1 (1.6)	2 (3.8)
21	Sweating (Not due to heat)	43 (67.2)	35 (67.3)	14 (21.9)	4 (7.7)	6 (9.4)	6 (11.5)	1 (1.6)	7 (13.5)

#### 4.2.2.2.1. Socio-demographic predictors of anxiety in both cohorts

##### *UK Cohort*

Similarly, multivariable linear regression models were analysed to assess the influence of the socio-demographic and fertility variables on the main outcome measure (Anxiety-BAI scores) in both countries. Correlation tests were equally done here to assess bivariate relationships between the stress levels and its potential correlates, and then a further analysis was done to estimate the correlation between the variables that would be entered into the regression model. Preliminary assumption testing was conducted to check for normality, linearity, outliers, and multicollinearity, with no serious violations noted. The five socio-demographic variables (age, education, employment, marital status and cost of the procedure) and the main outcome measure (BAI scores) were inputted into the regression analysis. The model outcome was not significant  $F(7,55) = .12, p=0.99$  (Table 4.5). This model explained 1.5% of the variance in anxiety  $R^2 = 0.015, p=0.99$ .

Table 4.5: Regression of socio-demographic variables predicting Anxiety levels in UK (n=64)

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>p</i>	<i>95%CI of B</i>
Age	-.04	0.23	-.023	.87	[-0.51, 0.39]
Educational level	.04	0.59	.008	.89	[-1.13, 1.21]
Employment status	-.48	1.83	-.037	.72	[-4.14, 3.17]
Marital status	.86	2.04	.058	.63	[-3.22, 4.95]
Annual income	-.65	1.66	-.08	.69	[-3.99, 2.68]
Monthly expenditure	1.05	1.42	.14	.46	[-1.81, 3.91]
Cost of procedure	.00	.002	.025	.88	[-.003, .004]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \* $p<0.05$  \*\* $p<0.01$

##### *Fertility variables*

A second regression analysis was done inputting the five fertility variables (shown in Table 4.6). The model outcome was not significant  $F(5,57) = 1.16, p=0.34$ . This model explained 9.2% of the variance in anxiety  $R^2 = 0.092$ . The model showed that none of the fertility variables were significant predictors ( $p>.05$ ) of anxiety among this cohort.

Table 4.6: Regression for fertility Variables Predicting Anxiety levels in UK (n=64)

Variable	<i>B</i>	<i>SE B</i>	$\beta$	95% CI of <i>B</i>
Duration of subfertility	1.16	0.67	.23	[-0.18, 2.52]
Cause of subfertility	.89	0.64	.17	[-0.39, 2.19]
Type of ART	-1.62	1.95	-.11	[-5.53, 2.28]
Number of attempts	-.29	1.38	-.03	[-3.07, 2.48]
Funding source	-1.46	1.91	-.10	[-5.30, 2.37]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p < 0.05$  \*\* $p < 0.01$

### ***Nigerian Cohort***

Similarly, the approach used involved the inclusion of the main outcome measure (BAI score) as the dependent variable and the five socio-demographic variables (as shown in Table 4.7) were entered into the regression analysis. The model outcome was not significant  $F(7,44) = .95, p = 0.47$ . This model explained 13.2% of the variance in anxiety  $R^2 = 0.132, p = 0.47$ . However, none of the socio-demographic variables were significant predictors ( $p > .05$ ) of anxiety among this cohort.

Table 4.7: Regression analysis for socio-demographic variables predicting Anxiety levels in Nigerian women (n=52)

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>P</i>	95%CI of <i>B</i>
Age	-.11	0.23	-.09	.62	[-0.58, 0.35]
Educational level	-.52	0.65	-.11	.50	[-2.06, 1.03]
Employment status	-3.62	2.67	-.19	.18	[-8.98, 1.73]
Marital status	-2.65	4.20	-.09	.53	[-11.14, 5.84]
Annual income	-1.68	1.47	-.20	.26	[-4.65, 1.29]
Monthly expenditure	2.07	1.43	.25	.15	[-0.80, 4.95]
Cost of procedure	.00	0.00	-.07	.70	[.00, .00]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p < 0.05$  \*\* $p < 0.01$

### ***Fertility Variables***

A second regression analysis was done by inputting the fertility variables (shown in Table 4.22), and the outcome variable (BAI scores) into the regression model. The overall model was not significant  $F(4, 47) = 1.7, p = 0.14$ . This model explained 13.3% of the variance in anxiety  $R^2 = 0.133$  (Adjusted  $R^2 = .059$ ),  $p = 0.14$ . However, the duration of subfertility was observed to be a significant predictor of Anxiety ( $\beta = .35, p = 0.02$ ).

Therefore, a backwards elimination approach was done, and non-significant variables were removed from the model, starting with the last one which gave a p-value above 0.05.

In **Model 2**, the cause of subfertility variable was removed, the overall model was not significant  $F(3, 48) = 2.3, p=0.08$ , and it explained 13% (Adjusted  $R^2=.076$ ) of the variance in anxiety  $R^2 = 0.130$ . Subsequently in **Model 3**, the number of attempts variable was removed, and at this point the model was significant  $F(2,49) = 3.45, p=0.04$ . The final model explained 12.3% of the variance in anxiety scores,  $R^2 = .123$ . Table 4.8 shows the summary of the regression analysis.

The analysis revealed that the beta of 0.35 for duration of subfertility is the largest, and the most highly statistically significant of the regression coefficients ( $p=0.02$ ). The sign of the beta coefficient is positive indicating that as the duration of subfertility increases, there is a subsequent increase in anxiety levels of these women.

The second significant co-efficient was the type of ART with  $\beta = -.32$ . Bearing in mind the way this variable is scored (0=IVF, 1= ICSI), the negative sign is interpreted to mean that women undergoing an IVF procedure have a higher anxiety score than those having ICSI.

Table 4.8: Regression Analyses for fertility Variables Predicting Anxiety levels in Nigeria (n=52)

Variables	B	SE B	$\beta$	95%CI of B
<b>Model 1</b>				
Duration of subfertility	6.322	2.75	.35*	[0.78, 11.86]
Cause of subfertility	.308	.86	.05	[-1.43, 2.04]
Type of ART	-4.81	2.72	-.29*	[-10.29, 0.65]
Number of attempts	-1.69	2.94	-.08	[-7.62, 4.23]
<b>Model 2</b>				
Duration of subfertility	6.27	2.72	.35*	[0.79, 11.75]
Type of ART	-5.19	2.48	-.32*	[-10.19, -0.20]
Number of attempts	-1.81	2.90	-.08	[-7.64, 4.02]
<b>Model 3</b>				
Duration of subfertility	6.35	2.70	.35*	[0.92, 11.79]
Type of ART	-5.23	2.46	-.32*	[-10.19, -0.27]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p < 0.05$

#### **4.2.2.2. PERCEIVED STRESS (PSS-10)**

Table 4.9 shows the item-by-item descriptive analysis of the PSS scale and includes the percentage of respondents who endorsed each response option for each item in both countries. To better capture which items were reported to a greater extent by both populations, items that were reported by more than half the populations are presented in this section.

##### ***UK Cohorts***

Within the UK population, more than half the population endorsed “sometimes” to the questions “how often have you been upset because of something that happened unexpectedly?” (51.6%) and “how often have you been angered because of things that were outside of your control?” (50%) (Table 4.10). An independent t-test showed a significant difference in perceived stress scores between married [M=15.39, SD=6.0, 13.47, 17.31 95%CI] and cohabiting women [M=19.13, SD=5.4, 16.79, 21.47 95%CI;  $t(62) = -2.45, p = .01$ ], with cohabiting women experiencing more perceived stress than their married counterparts. Additionally, an independent sample t-test was done to compare the PSS scores between NHS-funded and self-funded women. There was no significant difference in stress scores for NHS (M=17.24, SD=6.5) and self-funded (M=16.3, SD=5.7;  $t(62) = 0.61, p = 0.55$ ) women. The magnitude of the difference in the means was very small (eta squared = 0.006). Similarly, when an analysis of variance was done, no significant differences were observed in perceived stress scores for age, educational level, employment status, number of attempts, duration of subfertility and cause of subfertility between self-funded and NHS-funded women.

##### ***Nigerian cohorts***

Within the Nigerian population, more than half the population endorsed “sometimes” to the questions: “how often have you felt that things were going your way?” (67.3%), “how often have you been able to control irritations in your life?” (55.8%), “how often have you felt that you were on top of things?” (73.1%) and “how often have you felt difficulties piling up so high that you could not overcome them?” (50%) (Table 4.10). No significant differences were observed in both t-test and ANOVA analysis for the socio-demographic and fertility variables.

### **Comparison of both cohorts**

The mean total score on the PSS-10 for Nigerian women was [19.71 ± 5.8], ranging from 6-30, while for UK women, the mean score was [16.73 ±SD 6.1], also ranging from 6-30.

Table 4.9: Showing distribution of the samples regarding classification in the PSS scale

<b>PSS Scoring</b>	<b>UK =64 n (%)</b>	<b>NIGERIA=52 n (%)</b>
0-10 (low)	13 (20.3)	5 (9.6)
11-20 (moderate)	32 (50.0)	22 (42.3)
21-30 (high)	19 (29.7)	25 (48.1)
31-40 (severe)	-	-

Table 4.9 shows that half the population (50%) of the UK cohorts, reported moderate perceived stress levels, while almost half (48.1%) the Nigerian population reported high levels of perceived stress. However, none reported severe levels of perceived stress.

An independent sample t-test was used to understand whether there was a difference between UK & Nigerian women in the perception of stress. A significant difference was found between UK (M=16.73 SD=6.07) and Nigerian women [M=19.71 SD 5.80: t (114) =2.67, p= 0.008]. The magnitude of the difference in the means was moderate (eta squared=.059), expressed as a percentage, approximately 6% of the variance in perceived stress was explained by the country (UK or Nigerian).

Table 4.10: Perceived Stress scale items for UK and Nigeria

Item	Description	NEVER n (%)		ALMOST NEVER n (%)		SOMETIMES n (%)		FAIRLY OFTEN n (%)		VERY OFTEN n (%)	
		UK	NIG	UK	NIG	UK	NIG	UK	NIG	UK	NIG
1	You been upset because of something that happened unexpectedly?	5 (7.8)	5 (9.6)	15 (23.4)	10 (19.2)	33 (51.6)	20 (38.5)	4 (6.3)	8 (15.4)	7 (10.9)	9 (17.3)
2	You felt that you were unable to control the important things in your life	16 (25.0)	6 (11.5)	12 (18.8)	7 (13.5)	19 (29.7)	21 (40.4)	6 (9.4)	15 (28.8)	11 (17.2)	3 (5.8)
3	You felt nervous and "stressed"	5 (7.8)	3 (5.8)	3 (4.7)	8 (15.4)	26 (40.6)	12 (23.1)	22 (34.4)	18 (34.6)	8 (12.5)	11 (21.2)
4	You felt confident about your ability to handle your personal problems	2 (3.1)	-	4 (6.3)	9 (17.3)	18 (28.1)	25 (48.1)	25 (39.1)	14 (26.9)	15 (23.4)	4 (7.7)
5	You felt that things were going your way	1 (1.6)	1 (1.9)	6 (9.4)	9 (17.3)	27 (42.2)	35 (67.3)	21 (32.8)	3 (5.8)	9 (14.1)	4 (7.7)
6	You found that you could not cope with all the things that you had to do?	7 (10.9)	6 (11.5)	20 (31.3)	15 (28.8)	28 (43.8)	21 (40.4)	5 (7.8)	10 (19.2)	4 (6.3)	-

<b>7</b>	You been able to control irritations in your life	-	<b>2</b> <b>(3.8)</b>	<b>8</b> <b>(12.5)</b>	<b>3</b> <b>(5.8)</b>	<b>19</b> <b>(29.7)</b>	<b>29</b> <b>(55.8)</b>	<b>29</b> <b>(45.3)</b>	<b>13</b> <b>(25.0)</b>	<b>8</b> <b>(12.5)</b>	<b>5</b> <b>(9.6)</b>
<b>8</b>	You felt that you were on top of things?	<b>1</b> <b>(1.6)</b>	<b>2</b> <b>(3.8)</b>	<b>7</b> <b>(10.9)</b>	<b>5</b> <b>(9.6)</b>	<b>22</b> <b>(34.4)</b>	<b>38</b> <b>(73.1)</b>	<b>31</b> <b>(48.4)</b>	<b>5</b> <b>(9.6)</b>	<b>3</b> <b>(4.7)</b>	<b>2</b> <b>(3.8)</b>
<b>9</b>	You been angered because of things that were outside of your control	<b>3</b> <b>(4.7)</b>	<b>3</b> <b>(5.8)</b>	<b>20</b> <b>(31.3)</b>	<b>9</b> <b>(17.3)</b>	<b>32</b> <b>(50.0)</b>	<b>19</b> <b>(36.5)</b>	<b>6</b> <b>(9.4)</b>	<b>15</b> <b>(28.8)</b>	<b>3</b> <b>(4.7)</b>	<b>6</b> <b>(11.5)</b>
<b>10</b>	You felt difficulties were piling up so high that you could not overcome them?	<b>13</b> <b>(20.3)</b>	<b>5</b> <b>(9.6)</b>	<b>19</b> <b>(29.7)</b>	<b>13</b> <b>(25.0)</b>	<b>23</b> <b>(35.9)</b>	<b>26</b> <b>(50.0)</b>	<b>6</b> <b>(9.4)</b>	<b>8</b> <b>(15.4)</b>	<b>3</b> <b>(4.7)</b>	-



#### **4.2.2.2.1. Socio-demographic predictors of perceived stress in both cohorts**

Multivariable linear regression models were used to assess the influence of the socio-demographic and fertility variables on the main outcome measure (Perceived stress- PSS scores). Correlation tests were first done to assess bivariate relationships between the stress levels and its potential correlates, and then a further analysis was done to estimate the correlation between the variables that would be entered into the regression model. Preliminary assumption testing was conducted to check for normality, linearity, outliers, and multicollinearity, with no serious violations noted. The findings were corroborated by the analysis of the normal P-P and Q-Q plots. Then, taking into account the literature on stress, anxiety and subfertility, the socio-demographic and fertility variables were entered into the regression analysis.

#### ***UK Cohorts***

##### ***Demographic variables***

The first step was to enter the seven socio-economic variables (age, education, employment, marital status, annual income, monthly expenditure and cost of the procedure) and the main outcome measure (perceived stress- PSS score) into the regression analysis. The model outcome was not significant  $F(7,56) = 1.43, p=0.21$ . This first model explained 15.2% of the variance in perceived stress  $R^2 = 0.152, p=0.21$ . Then using a backward elimination method, non-significant covariates were excluded from the model. This was done one at a time, and each time a covariate was removed, a new test was run, with the final model including only covariates with p-values of 0.05 or less (shown in Table 4.11a).

The final model was significant  $F(2, 61) = 4.70, p=0.01$ , and accounted for 13.4% of the variance  $R^2 = .134$  in perceived stress scores. The exclusion of most of the other variables did not create any significant change to the final model  $\Delta F(1, 60) = 0.49, p=0.48$ , and  $\Delta R^2 = -.007$ . The results in Table 4.11a, show that for this regression model, the beta of 0.27 for marital status,  $t(61) = 2.27, p=0.03$  is the largest and the most highly statistically significant of the regression coefficients. Bearing in mind the way this variable was coded (0= Married, 1= cohabiting/ unmarried), the positive sign should be interpreted to mean that the unmarried /cohabiting participants experienced more anxiety than the married ones. Educational level,  $t(61) = -1.77$ , with  $\beta = -.21$  was equally implicated to be a negative predictor to perceived stress, however, this did not reach statistical significance ( $p=0.08$ ).

Table 4.11a: Regression summary of socio-demographic variables predicting Perceived stress among the UK cohort (n=64)

Variables	B	SE B	$\beta$	<i>p</i>	95%CI of B
<b>Model 1</b>					
Age	-.14	.18	-.09	.44	[-0.51, 0.22]
Education	-.75	.53	-.20	.16	[-1.82, 0.31]
Employment status	-.64	1.49	-.05	.67	[-3.63, 2.34]
Marital status	3.53	1.64	.28	.03*	[0.23, 6.83]
Annual income	.61	1.26	.09	.63	[-1.92, 3.15]
Monthly expenditure	-.42	1.12	-.06	.70	[-2.67, 1.82]
Cost of procedure	-.001	.001	-.06	.60	[-.003, .002]
<b>Model 2</b>					
Age	-.13	.18	-.09	.46	[-0.49, 0.22]
Education	-.73	.53	-.20	.16	[-1.79, 0.32]
Employment	-.72	1.46	-.06	.62	[-3.65, 2.21]
Marital status	3.59	1.62	.28	.03*	[0.34, 6.85]
Annual income	.33	1.02	.05	.74	[-1.71, 2.37]
Cost of procedure	-.001	.001	-.07	.59	[-.003, .002]
<b>Model 3</b>					
Age	-.13	.17	-.09	.46	[-0.48, 0.22]
Education	-.82	.45	-.22	.07	[-1.73, 0.08]
Employment	-.63	1.43	-.05	.66	[-3.49, 2.23]
Marital status	3.70	1.59	.29	.02*	[0.52, 6.87]
Cost of procedure	-.001	.001	-.08	.51	[-.003, .002]
<b>Model 4</b>					
Age	-.13	.17	-.09	.46	[-0.48, 0.22]
Education	-.79	.44	-.21	.08	[-1.68, 0.10]
Marital status	3.53	1.53	.28	.02*	[0.46, 6.60]
Cost of procedure	-.001	.001	-.07	.55	[-.003, .002]
<b>Model 5</b>					
Age	-.12	.17	-.08	.48	[-0.47, 0.22]
Education	-.77	.44	-.21	.08	[-1.65, 0.11]
Marital status	3.55	1.52	.28	.02*	[0.49, 6.59]
<b>Model 6</b>					
Education	-.78	.44	-.21	.08	[-1.66, 0.10]
Marital status	3.42	1.51	.27	.03*	[0.40, 6.43]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \* $p < 0.05$

#### 4.2.2.2.1. Bivariate analysis of NHS & Self-funded women

When the UK cohort was divided into self-funded and NHS-funded participants, a bivariate analysis of the sociodemographic variables of self-funded UK women with the perceived stress scores using a Pearson correlation coefficient, observed a moderate negative correlation between perceived stress scores and the age of the women ( $r = -.40$ ,  $p = .02$ ), with an increase in perceived stress associated with a decrease in the age of the

women. In NHS funded women a moderate positive correlation was observed between perceived stress scores and the cause of subfertility ( $r=.48, p=.01$ ).

### ***Fertility variables***

A second regression model was done, this time inputting the fertility variables. The overall model was significant  $F(5, 58) = 2.8, p=0.02$ . This model explained 19.5% of the variance in perceived stress  $R^2=0.195$  (Adjusted  $R^2=.126$ ),  $p=0.02$  (Table 4.11b).

Table 4.11b: Regression summary of fertility variables predicting perceived stress in UK cohort (n=64)

Variables	B	SE B	$\beta$	$p$	95%CI of B
<b>Model 1</b>					
Duration of subfertility	-.39	.52	-.09	.45	[-1.43, 0.65]
Cause of subfertility	1.55	.50	.36	.003**	[0.54, 2.55]
Type of ART	-.98	1.53	-.07	.52	[-4.05, 2.08]
Source of funding	-.05	1.56	-.004	.97	[-3.17, 3.07]
Number of attempts	2.90	1.60	.22	.07	[-0.30, 6.11]
<b>Model 2</b>					
Duration of subfertility	-.39	.51	-.09	.44	[-1.40, 0.61]
Cause of subfertility	1.54	.49	.36	.003**	[0.55, 2.54]
Type of ART	-.99	1.47	-.08	.50	[-3.94, 1.95]
Number of attempts	2.91	1.53	.22	.06	[-0.14, 5.98]
<b>Model 3</b>					
Duration of subfertility	-.40	.50	-.09	.43	[-1.40, 0.60]
Cause of subfertility	1.52	.49	.35	.003**	[0.53, 2.51]
Number of attempts	2.85	1.52	.22	.06	[-0.18, 5.89]
<b>Model 4</b>					
Cause of subfertility	1.54	.49	.36	.003**	[0.56, 2.53]
Number of attempts	2.98	1.50	.23	.05*	[-0.02, 5.99]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \* $p<0.05$  \*\* $p<0.01$

A backwards elimination regression analysis was done, and non-significant variables were removed from the model, starting with the last one which gave a p-value above 0.05. In **Model 2**, the source of funding variable was removed, and the overall model was significant  $F(4, 59) = 3.57, p=0.01$ . It explained 19.5% of the variance in perceived stress  $R^2 = 0.195$  (Adjusted  $R^2=.141$ ). Subsequently in **Model 3**, the type of ART variable was removed, the model was significant  $F(3,60) = 4.66, p=0.005$ . This model explained 18.9% of the variance in perceived stress scores,  $R^2 = .189$  (Adjusted  $R^2=.148$ ). In **Model 4**, duration of subfertility was removed, and the overall model was significant  $F(2, 61) = 6.71, p=0.002$ . This model explained 18% of the variance in perceived stress  $R^2=.180$

(Adjusted  $R^2 = .154$ ). The exclusion of most of the other variables did not create any significant change to the final model  $\Delta F (1, 60) = 0.63, p=0.43$ , and  $\Delta R^2 = -.009$ . From the results in Table 4.11b, cause of subfertility,  $t (61) = 3.13, p=0.003$  and number of attempts,  $t (61) = 1.98, p=0.05$  are significant predictors of perceived stress among the UK cohorts. However, from the magnitude of the t-statistics and the beta values, the cause of subfertility had significantly more impact than the number of attempts.

### ***Nigerian Cohorts***

#### ***Socio-demographic variables***

A similar regression model was applied to the Nigerian cohorts.

The first step was to enter the seven socio-demographic variables and the main outcome measure (PSS). The overall model was not significant  $F (7,43) = .60, p=0.75$ . The model explained 8.8% of the variance in perceived stress  $R^2 = 0.088, p=0.75$  (Table 4.12a). The analysis showed that none of the variables were significant predictors of perceived stress ( $p > .05$ ) among this cohort. This could be because the data was insufficient to provide enough information.

Table 4.12a Regression model of socio-demographic variables predicting Perceived stress (n=52)

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>p</i>	<i>95%CI of B</i>
Age	-.12	0.17	-.14	.48	[-0.46, 0.22]
Educational level	.05	0.55	.02	.92	[-1.06, 1.17]
Employment status	-2.51	1.92	-.19	.19	[-6.39, 1.36]
Marital status	-3.80	3.04	-.19	.22	[-9.94, 2.33]
Annual income	-.36	1.06	-.06	.73	[-2.51, 1.78]
Monthly expenditure	.39	1.03	.07	.70	[-1.68, 2.47]
Cost of procedure	.00	.00	.01	.95	[.00, .00]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval,  $p = *0.05$

#### ***Fertility variables***

A second regression model was done, this time inputting the fertility variables. The overall model was not significant  $F (4, 47) = 1.24, p=0.30$ . This model explained 9.6% of the variance in perceived stress  $R^2 = 0.095$  (Adjusted  $R^2 = .019$ ),  $p=0.30$ . A backwards elimination approach was done, and non-significant variables were removed from the model, starting with the last one which gave a p-value above 0.05.

Table 4.12b: Regression summary of fertility variables predicting perceived stress in Nigerian cohort (n=52)

Variables	B	SE B	$\beta$	<i>p</i>	95%CI of B
<b>Model 1</b>					
Duration of subfertility	1.80	1.98	.14	.36	[-2.19, 5.79]
Cause of subfertility	0.29	0.62	.07	.63	[-0.95, 1.55]
Type of ART	-3.15	1.96	-.27	.11	[-7.09, 0.79]
Number of attempts	-1.87	2.12	-.12	.38	[-6.14, 2.39]
<b>Model 2</b>					
Duration of subfertility	1.75	1.96	.13	.37	[-2.19, 5.71]
Type of ART	-3.51	1.79	-.30	.05*	[-7.11, 0.08]
Number of attempts	-1.98	2.09	-.13	.35	[-6.19, 2.22]
<b>Model 3</b>					
Type of ART	-2.78	1.58	-.24	.08	[-5.97, 0.41]
Number of attempts	-2.07	2.08	-.13	.32	[-6.26, 2.11]
<b>Model 4</b>					
Type of ART	-2.77	1.58	-.24	.08	[-5.96, 0.41]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p=0.05$

In **Model 2**, the cause of subfertility variable was removed, the overall model was not significant  $F(3, 48) = 1.61, p=0.19$ , and it explained 9.1% (Adjusted  $R^2=0.035$ ) of the variance in anxiety  $R^2 = 0.091$ . Subsequently in **Model 3**, the duration of subfertility variable was removed, and the model was not significant  $F(2,49) = 2.03, p=0.14$ . It explained 7.6% of the variance,  $R^2=0.076$  (Adjusted  $R^2=0.039$ ). The final model explained 5.8% of the variance in perceived stress scores,  $R^2 = 0.058$  (Adjusted  $R^2 = 0.039$ ). Table 4.12b shows the summary of the regression analysis.

The analysis revealed that the beta of -0.24 for the type of treatment is the largest, and from the codes of that variable (0=IVF, 1= ICSI) the negative sign can be interpreted to mean that IVF-women exhibit more perceived stress levels than those about to undergo ICSI in this cohort. However, this did not reach statistical significance ( $p=0.08$ ), but it does suggest that this might be a variable of interest.

#### 4.2.2.2.2. Relationship between Perceived stress and Anxiety

The relationship between anxiety (as measured by the BAI) and perceived stress (as measured by the PSS-10) was investigated using the Pearson product correlation coefficient ( $r$ ). There was a strong positive correlation between the two variables in both countries [Nigerian women ( $r=.68, n=52, p<0.01$ ) and UK women ( $r=.57, n=64, p<0.01$ )] with high levels of anxiety associated with higher levels of perceived stress. This indicates

a 46.2% and 32.5% shared variance respectively. Anxiety helps to explain 46 percent and nearly 33 percent of the variance in the Nigerian and UK respondents scores respectively on the perceived stress scale.

### **4.3. EXPERIENCES OF INFERTILE WOMEN**

This section presents information on the experiences of infertile women in the UK and Nigeria who were interviewed, as well as describes the participants characteristics for both cohorts, while the results exploring participants knowledge, beliefs and understanding of ART are presented in section. For clarity, main themes are in **bold small capital letters**, while sub-themes are in ***bold italics letters***. Quotes that further describe themes or sub-themes are presented in *italics*.

#### **4.3.1. Interview participant characteristics**

##### ***UK Cohorts***

The characteristics of the UK participants are described in Table 4.13a. There was one respondent who was already a mother (Katy) and others who had a series of miscarriages, but no live births (Karen, Lucy and Anna). The longest duration of sub-fertility was 6 years (Anna and Sarah) and the shortest was 2 years (Paulette and Katy). All the participants had full time jobs and considered themselves to be financially independent. Four women were having repeat cycles of ART, one in their second attempt (Fiona), while the other three (Lucy, Anna and Karen) were in their third attempt.

Table 4.13a: Interview participants characteristics in the UK

<i>Name*</i>	<i>Age</i>	<i>Marital status</i>	<i>Subfertility duration</i>	<i>Occupation</i>	<i>Funding source</i>	<i>Number of attempts</i>
<i>Anna</i>	37	Married	6 years	HR Officer	Self	3 <sup>rd</sup>
<i>Lisa</i>	35	Cohabit	5 years	Insurance advisor	Self	1 <sup>st</sup>
<i>Zoe</i>	32	Cohabit	3 years	Child social worker	Self	1 <sup>st</sup>
<i>Paulette</i>	44	Cohabit	2 years	Project manager	Self	1 <sup>st</sup>
<i>Karen</i>	36	Married	3 years	Nurse	Self	3 <sup>rd</sup>
<i>Lucy</i>	32	Cohabit	4 years	Factory manager	NHS	3 <sup>rd</sup>
<i>Sheree</i>	37	Married	3 years	Receptionist	Self	1 <sup>st</sup>
<i>Eleanor</i>	34	Married	4 years	Psychologist	NHS	1 <sup>st</sup>
<i>Fiona</i>	36	Cohabit	3 years	Doctor	Self	2 <sup>nd</sup>
<i>Katy</i>	31	Married	2 years	Cabin crew	Self	1 <sup>st</sup>
<i>Vanessa</i>	40	Married	3 years	Tree surgeon	NHS	1 <sup>st</sup>
<i>Sarah</i>	41	Married	6 years	Teacher	NHS	1 <sup>st</sup>
<i>Barbara</i>	41	Married	5 years	Speech therapist	NHS	1 <sup>st</sup>
<i>Sadia</i>	37	Married	3 years	Hotel manager	Self	1 <sup>st</sup>
<i>Rachael</i>	40	Married	3 years	Assistant manager	NHS	1 <sup>st</sup>

\* These are pseudonyms not real names

### ***Nigerian Cohorts***

Table 4.13b describes the interviewees' characteristics. Only one of the women was unmarried and cohabiting with her partner, while the other 16 were married. The longest duration of sub-fertility was 25 years (Chinwe) and the shortest was 4 years (Rosemary and Margaret). Chinwe had been pregnant 25 years ago, but the foetus was a still-birth and after the trauma, she couldn't get pregnant again. Rosemary had just come out of an abusive relationship, and had previously had several abortions, however, now she had a new partner has been unable to conceive for the 4 years they had been together, while Margaret's cause of subfertility was male-factor. Only three women were having repeat cycles of ART (Bose, Faith and Chioma), the others were just starting their first cycle. All the participants had full time jobs, but none considered themselves financially independent.

Table 4.13b: Interview participants characteristics in Nigeria

<i>Name*</i>	<i>Age</i>	<i>Marital status</i>	<i>Subfertility duration</i>	<i>Occupation</i>	<i>Funding source</i>	<i>Number of attempts</i>
<i>Helen</i>	38	Married	6 years	Cleaner	Self	1 <sup>st</sup>
<i>Rosemary</i>	28	Cohabit	4 years	Trader	Self	1 <sup>st</sup>
<i>Bose</i>	49	Married	12 years	Secretary	Self	2 <sup>nd</sup>
<i>Ijeoma</i>	38	Married	9 years	Trader	Self	1 <sup>st</sup>
<i>Happiness</i>	40	Married	10 years	House wife	Self	1 <sup>st</sup>
<i>Chinwe</i>	54	Married	25 years	Teacher	Self	1 <sup>st</sup>
<i>Ola</i>	32	Married	2 years	Trader	Self	1 <sup>st</sup>
<i>Faith</i>	34	Married	5 years	Secretary	Self	2 <sup>nd</sup>
<i>Chioma</i>	37	Married	8 years	Banker	Self	2 <sup>nd</sup>
<i>Onyiye</i>	39	Married	9 years	Civil servant	Self	1 <sup>st</sup>
<i>Alpha</i>	43	Married	12 years	Trader	Self	1 <sup>st</sup>
<i>Ohine</i>	40	Married	9 years	Teacher	Self	1 <sup>st</sup>
<i>Felicia</i>	41	Married	13 years	Academic staff	Self	1 <sup>st</sup>
<i>Ronke</i>	42	Married	15 years	Civil servant	Self	1 <sup>st</sup>
<i>Margaret</i>	36	Married	4 years	Lab Scientist	Self	1 <sup>st</sup>
<i>Kemi</i>	43	Married	6 years	Teacher	Self	1 <sup>st</sup>
<i>Joy</i>	30	Married	4 years	Tailor	Self	1 <sup>st</sup>

\*These are pseudonyms not real names

#### 4.3.2: SUB-FERTILITY EXPERIENCES

To recapitulate from the literature review, while most societies practise pro-natalism, some emphasize the centrality of ‘motherhood’ to a woman’s identity a lot more than others. A few studies have shown that ‘motherhood’, particularly in a LMIC like Nigeria, is tightly connected to marriage in many cultures, and just might be the key to unlocking a woman’s status and acceptability within her community (Hollos and Larsen, 2008, Hollos, 2003). Therefore, subfertility can have adverse social and psychological consequences on sub-fertile women from these countries. Although views on motherhood are less-striking in more developed countries like the UK, it is by no means less relevant to the experiences of the sub-fertile women in them (Cousineau and Domar,



2007). This section describes the participants experiences with subfertility. Women in this study describe their need for parenthood, their experiences with stigmatisation, the ways in which they cope with it and some guilt and regrets of past discretions. These are summarised in Table 4.14 and described in detail.

Table 4.14: Women’s experiences with subfertility

Theme	Sub-theme	Participant description
PSYCHOLOGICAL IMPACT	<i>Desperation, stress</i>	Participants describe their desperate need to have a child
STIGMATISATION	<i>Stigma, coping strategies (active and passive avoidance)</i>	Experiences with discrimination and psychological abuse, ways in which they cope with the stigmatisation
REGRETS	<i>Abortions, delayed-childbearing, unfairly punished by God</i>	Participants describe their regrets about abortions, regrets about delayed child-bearing

#### 4.3.2.1: Psychological Impact

Insights into the psychological impact of sub-fertility on the women was necessary as some women expressed intense emotions while talking about their childless marriage. The first sub-theme that emerged from their description of experiences is the **desperation to have a child**. Two UK women expressed this by saying:

*“...but you do, you kind of feel desperate, it gets to a point where you kind of feel very desperate and willing to try anything...” (Sadia, 37yrs, British, 1<sup>st</sup> attempt)*

*“It is really important! I mean, having a child is the really important part and the treatment is important too, because without it [...] well, I'm hoping that it works, but I mean, yeah, it's really important.” (Fiona, 35yrs, British, 2<sup>nd</sup> attempt)*

Among the Nigerian women, desperation for parenthood was a lot more evident:

*“I don't have a choice. You know, when a woman tells you she doesn't have a choice, you should know that the situation is serious. I don't have a choice, I have to save my marriage, I have to save my face in front of my in-laws...” (Onyiye, 39yrs, Nigerian, 1<sup>st</sup> attempt)*

*“...and the only problem I have is just this child issue. Once I have that child, everything would be okay [...] that's my only concern now, to conceive and have a child.” (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

A few studies including a WHO report, have shown that as many as 13% of sub-fertile women in LMIC contemplate suicide after an unsuccessful IVF cycle, as most of the women have been captured as saying they would rather die than to live with the mental torture caused by their subfertility (Baram et al., 1988, Kjaer et al., 2011). Most women did not hide their mental and emotional distress especially from their healthcare providers who they felt could help them with the IVF process.

*“Please, they should please just try their best for me with this IVF thing oh because the failure of it can mean suicide oh, I will just kill myself.” (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

**Stress** was another significant sub-theme that emerged in the interviews with the Nigerian cohort. Some women mentioned just how stressful they felt their situation was, with some calling themselves the embodiment of stress. It was evident that the duration of subfertility was a big predictor of heightened stress levels as evidenced by the following quotes:

*“Would I tell you that I'm not stressed, to be married for 10 years and no child to show for it, is that one not stress in human form?” (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

*“Sorry to say my dear, it is not easy, for you to think of any woman going through this type of stress I'm going through. I've been married for 12 years no issue, not even a miscarriage, ah stress is an understatement.” (Bose, 49yrs, Nigerian, 2<sup>nd</sup> attempt)*

#### **4.3.2.2: Stigmatisation**

In many LMIC, childless women experience marked discrimination and ostracism, in part due to perceived or real social isolation and lack of empathy from relatives, in-laws and other members of the community. It would be almost amiss to discuss experiences of sub-fertile women in a LMIC and not include this aspect of their lives. This experience was

exclusive to the Nigerian cohort as within the UK cohort, none of the informants felt isolated or stigmatised because of their subfertility. They also did not report any social pressures from family or friends. Some Nigerian women expressed intense emotions when talking about their experience of being **Stigmatised**<sup>14</sup> of their inability to have children. Examples of statements illustrating this theme include:

*“Some of the other tenants in our compound call me a witch, that I’m the one eating up all my children” (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

*“Last week, me and my husband went for a naming ceremony, and just after my husband had finished praying, somebody says, ‘I’m sure somebody here is feeling like, this child could have been my own oh’...I just started crying” (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

*“One woman said to me, “how are you?” and I said, “I’m fine” and she says “No! you are not fine, you don’t have a child”, and she now put her hand on my tummy and started speaking in tongues. I felt like slapping her, it’s just that she is old enough to be my mother.” (Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)*

A few women mentioned being called derogatory names, especially by their husband’s families:

*“My mother in-law tells my husband that he is married to a fellow man” (Ijeoma, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

*“My husband’s people call me ‘mnama’ (meaning, bull), that I’m not a woman” (Helen, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

In some cases, the stigma from in-laws became so unbearable that a few women become so driven to conceive as to have this as the only focus of their lives, and professional aspirations and life pursuits have to be placed on hold.

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<sup>14</sup> Stigma is defined as a “negative sense of social difference from others, that is, so outside the socially defined norm, it is both deeply discrediting and devalues the individual” (Slade et al, 2007)

*“Sometimes even when I talk about pursuing my masters, my mother in-law would start saying, ‘you don’t have children and yet you want to go and do masters, for what? Better sit down there and give me grandchildren!’ (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

Ironically, although subfertility has been treated as a genuine medical condition, the psychological aspects of the condition has been relegated into the background, in spite of the vast array of clinical literature on the psychosocial consequences of the condition.

#### **4.3.2.1.1: Coping strategies**

The first sub-theme ‘**stigma**’ identified on the basis of participants’ descriptions about the stigmatisation they had undergone as sub-fertile women, brought about the second sub-theme of how these women **cope** with the experience. Some women described the methods they had developed to **cope** with the stigmatisation and infertility related stress. One strategy adopted by most women was ‘**passive avoidance**’. They decided not to engage in behaviours that increase their infertility related stress as illustrated by the following:

*“Sometimes you can’t get rid of them; you just have to overlook it.” (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

*“...but there’s nothing you can do about it, you can’t be challenging everybody. So, you just have to leave them and feel your pain yourself.” (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

*“I’m depressed, but I’ve learnt to control it. Just maybe when we are at home, I would cry, but outside, no! if you do that it would kill everything about you....” (Ijeoma, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

The second method adopted was an ‘**active avoidance**’. Some women decided to actively engage in behaviours that decrease their infertility related stress. Some prefer to engage themselves with the word of God (Bible), others surround themselves with good people, and a few enjoy surfing the web and interacting on social media as illustrated by the following:

*"I like chatting and going on Facebook, it makes me happy, and I don't have to think too much about this issue" (Bose, 49yrs, Nigerian, 2<sup>nd</sup> attempt)*

*"I'm just living by using Gods words to console myself, it helps me block out everything people are saying." (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

*"Most times I'm depressed, but especially when you surround yourself with good people that have a better understanding about life, you won't really feel it that much." (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

#### **4.3.2.3. Guilt/Regret**

The third theme that emerged from the interviews with the Nigerian women was '**Guilt or Regret**' over past life experiences. It wasn't uncommon for sub-fertile women to feel that their subfertility was a punishment for their past sexual indiscretions. Some women spoke about their regrets over **abortions** they had earlier in life.

*"Well [...] I've actually taken-in before now, with some boyfriends then, but I never kept the pregnancies so (sniffs), that is just the thing. I've asked God to forgive me because I actually aborted them" (Ola, 32yrs, Nigerian, 1<sup>st</sup> attempt)*

*"If I had even known initially that doing all those D&C's (meaning; Dilation & Curettage) would lead to all these different complications now, I would never have done it" (Rosemary, 28yrs, Nigerian, 1<sup>st</sup> attempt)*

A few women took a more religious route and felt they were being **unfairly punished by God**:

*"I don't know why God has just decided to punish me like this, it's not as if I was wayward oh?" (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

*"It's not as if I'm suffering as a result of what I did in the days of my youth or something like that. In fact, I thank God I married my husband as a virgin before all these things started, if not..." (Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

*"I don't really know how it comes to this time, it's just God, let me just believe that God knows the best." (Ijeoma, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

Another aspect of **'guilt/regret'** women spoke about was in regard to the decision to **delay child bearing**. There is a perception that delayed childbearing is a notion that is primarily frequent among women in Western nations, as more of them are determined to pursue higher education and life goals before starting a family. The concept is not one that usually rings true in many Nigerian households, however, a few women mentioned doing it, although they now felt **regret** over the decision:

*"Me and my husband were so much interested in other things, and when anybody would talk to me about children, I'll just be saying 'what for?' at least let us gyrate a little first. And now see?" (Onyiye, 39yrs, Nigerian, 1<sup>st</sup> attempt)*

Only Zoe from the UK cohort described her frustrations with her decision to **delay child-bearing**. As with many women in Western countries, she believed she had practical reasons to delay childbearing, such as the need for relational and economic stability. She was asked if possibly her role as a child protection social worker was pertinent to her decision. Her response was:

*"I get a little bit frustrated that I'm in this position, where I've been really like, you know, like sensible and responsible and really thought about it and planned, in the sense that I've not been selfish and had a child because I wanted a child, I've waited and had a thought about what does this child need? So that's frustrating. [Ehrm], but I am really aware about it (stammers) in terms of like I don't really let it, you know, come between my professional role and my personal so [ehrm], but yeah. You know, certainly it does sometimes get upsetting [pursuing] children who aren't cared for, [in that] they are neglected and abused by parents who just really don't care, and yet those who really need children, don't have any, yeah, it does get quite frustrating" (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

After participants had spoken about their experiences before the treatment, they were then asked about the decision-making process to undergo treatment. It has been reported that the process of decision-making equally contributes to the stress experienced by

some women. The next section attempts to describe participants process of decision making to undergo ART.

#### 4.3.3. KNOWLEDGE, BELIEFS AND UNDERSTANDING OF ART

The knowledge, beliefs and understanding of the treatment was developed by some women through their experiences. Mainly those who had initially undergone IUI before being referred for IVF or ICSI and those who were having their 2<sup>nd</sup> and 3<sup>rd</sup> attempt at either procedure. Their knowledge and understanding provided important information on how the various aspects of the treatment; from funding up until an unsuccessful pregnancy confirmation, and how they ‘made sense’ of their experiences. For the women just starting their first cycle, they derived their knowledge and beliefs about the treatment from a variety of sources in their social environment. These include family or friends, the internet or other social media. Three themes were identified for this section based on patients’ responses to the question: “*can you tell me about your experiences before the decision to undergo ART?*” These are summarised in Table 4.15 and described in detail.

Table 4.15: Women’s knowledge, beliefs and understanding of ART

<b>Themes</b>	<b>Sub-themes</b>	<b>Patients descriptions</b>
TREATMENT-SEEKING BEHAVIOUR	<i>Alternative methods (religious groups, traditional, orthodox), Side effects, societal pressures, Complementary</i>	Initial remedies sought for subfertility; health consequences; alternatives to undergoing ART
KNOWLEDGE ABOUT ART	<i>No knowledge, Uncertainty, myths, knowledgeable</i>	Scepticisms about the treatment; uncertainty about treatment working mechanisms, information from various sources
REASONS FOR ART	<i>Doctors’ orders, personal decisions</i>	How decisions were made about having IVF or ICSI

##### 4.3.3.1: Treatment-seeking behaviour

The first theme, ‘**treatment-seeking behaviour**’, refers to the patients’ descriptions of the alternative and complementary treatment methods that were sought, preceding their decision to undergo ART. A consensus by many of the participants was that; because the women bear the brunt of the stigma associated with sub-fertility, treatment would

equally be directed to them. Several Nigerian women admitted trying **alternative methods** of treatments, which included **religious groups** (*churches*), **traditional**, and **orthodox** (*hospitals*). There was no agreement on which method was preferred, however, I had a sense that all three methods were either used simultaneously or sequentially. As most Nigerians are deeply convinced of the supernatural causes of sub-fertility, it was not surprising to learn that many of the women had often patronised religious and traditional healers first, before consulting orthodox medical practitioners. The words ‘*drug*’ and ‘*medicine*’ in the following quotes refers to traditional herbal mixtures not actual pharmaceuticals, and the traditional remedies were usually local concoctions prepared from herbs:

*“You know, one has to keep trying, I have gone to people that used herbs before....”*  
(Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)

*“I used to take all those concoctions from different herbal doctors, all those fertility people, many things, even this [DNFD] products, I was taking all those things...”*  
(Alpha, 43yrs, Nigerian, 1<sup>st</sup> attempt)

*“...a friend told me to go [...] if you go to these people, they would give you drugs, they would be massaging your tummy, if your womb is not fixed well, they would put it in the correct position.”* (Rosemary, 28yrs, Nigerian, 1<sup>st</sup> attempt)

*“...even this fibroid that they said I have, somebody took me to one place that they said that the woman there has fibroid medicine, that I should go there and take the drugs, I now went there and take the medicine...”* (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)

Some of these women presented a variety of experiences with these alternative remedies, with most feeling no benefits and instead experienced **side effects**. Examples of participants’ experiences include:

*“...in fact, when the woman gave me the fibroid medicine, my stomach was now scratching me, when I now went for another scan, the fibroid was now even bigger, the medicine did not work.”* (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)



A few women described feeling relief after they had stopped the drugs:

*"... since I stopped the drugs, in fact my body now came back to normal body"  
(Alpha, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

Some others had decided to stop the drugs completely, for fear of worse outcomes:

*"I now decide that I would not take any of those drugs or go there again, before I would now damage myself, it's just not an ordinary drug." (Rosemary, 28yrs, Nigerian, 1<sup>st</sup> attempt)*

When asked why they put themselves through such ordeals instead of going to the fertility specialist right away, most of the responses involved **societal pressures**. Most women felt they would be perceived as 'unserious' in their pursuit for a child if they did not try every possible solution:

*"...you know when one is looking for a baby, if they ask you to bring and you don't bring, people would feel as if you are not serious." (Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

*"...but you know that its people now, if you don't go, they would say 'you are not serious.'" (Rosemary, 28yrs, Nigerian, 1<sup>st</sup> attempt)*

Most of the spiritual beliefs about subfertility, infer that a woman's fertility is mediated by her spiritual actions. For example, most of the women who mentioned first tackling their subfertility spiritually, referred me to the Bible, (1<sup>st</sup> Samuel 1 verse 1-28), which depicts Hannah, the wife of Elkanah as downcast and emaciated, who only conceives after she prayed. So, some women described how their pastors had prescribed several days of fasting and prayers and making either personal or financial sacrifices to the church as curative measures for their subfertility:

*"...our pastor gave us anointing oil, that we should drink it before we make love"  
(Ijeoma)*

*"...we were put on 7 days fasting, 6 to 6, and the whole church had to pray for us before we can close the fasting, and if God says we cannot close the fast on the 7<sup>th</sup>*

*day, then we had to continue. On the final day of the fasting, we also had to do 'saraka' (meaning alms-giving) for children." (Onyiye)*

This method of spiritual healing was not mentioned by most women in the UK cohort, however, it was equally evident that some women were trying to exert some control over their fertility in an attempt to maximise their chances of conceiving. From acupuncture to yoga, herbal teas to positive thinking, these women were equally determined to **complement** their treatment with other remedies.

*"I'm having acupuncture and reflexology alongside the IVF, and that's £60 a week for acupuncture and herbs, but I think it helps [and] I've heard things about it helping with pregnancy" (Sadia, 37yrs, British, 1<sup>st</sup> attempt)*

*"I believe if you put a positive vibe into the atmosphere, you definitely get positive things happen to you" (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

It is no surprise then that when all these remedies and good intentions do not culminate in a live birth (baby), most women can feel like failures.

#### **4.3.3.2: Knowledge about ART**

The second theme '**knowledge about ART**' referred to women's overall knowledge about 'orthodox' subfertility treatment. Very commonly, some Nigerian women stated that they had **no knowledge** about the treatment, prior to having their first consultation. For example, when asked directly about prior knowledge about ART (or more commonly IVF), one woman responded:

*"I didn't know anything about it, they just said that if I come here, I will get a baby, so I said let me come." (Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)*

Another said:

*"My auntie said I should come here if I want to save my marriage, I didn't know what they do here, whether they manufacture babies here or what?" (Ola, 32yrs, Nigerian, 1<sup>st</sup> attempt)*

However, a few others had heard about the treatment and had formed their own opinions about it, which included **scepticisms and uncertainties**.

*“I heard that some women used to do it, but, me I was sceptical about it, how are you sure it is your own baby that they are putting back?” (Chinwe, 54yrs, Nigerian, 1<sup>st</sup> attempt)*

*“when I went to see the doctor, and he said it was IVF that I would have, I had to ask him again and again, “are you sure I would be able to breastfeed my baby?” “Are you sure it is my own baby I would carry?” (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

A few other women had heard **myths** about the treatment, which added to their scepticism about it. Some of these myths and notions were perpetuated by stories passed down over decades.

*“They say that some women used to say they are doing IVF, then they would go and pump their stomachs and take injections that make it look like they are carrying pregnancy. But then after, either there would be no pregnancy, or they won’t be able to breast feed the baby” (Ronke, 42yrs, Nigerian, 1<sup>st</sup> attempt)*

*“...actually, somebody advised my husband that we should try IVF, my husband was like “how would I go and do IVF for a woman that her fallopian tubes are okay?”. He said that it’s for only those women that their fallopian tubes are blocked” (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

Among the UK cohorts, most women seemed **knowledgeable** about the treatment. They had either heard about it from the internet or the media, while some others had friends or family who had undergone these treatments themselves:

*“Well there’s usually one story or another in the media about IVF these days...” (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

*“I did have a friend who was going through it as well, a couple months in front of us, so she’d kind of talked to me about the things that happen, so I think we knew what to expect, as in, this is what happens, but [stammers] that’s just knowing something,*

*that's just theory rather than [than] going through it." (Anna, 37yrs, Nigerian, 3<sup>rd</sup> attempt)*

*"...we did most of our own research online, particularly what clinic to choose, I knew we needed help, and even before going to meet my GP for the referral, I kind of already knew that we would be referred for IVF" (Lisa, 35yrs, British, 1<sup>st</sup> attempt)*

Within the Nigerian cohort, a few women had equally mentioned learning about the treatment from family and friends they considered reliable:

*"I only have one nurse, who is my friend, my very good friend, she works at the children's ward. In fact, she is like a mother to me, she was the one that told me about it and she is even the one that brought me here" (Alpha, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

*"One of my aunties, she works in a place where they used to look for solution to treatment, so she called me, because I don't live in this place, so she now talked about it and she said it is one of the options I should try, [...], so that's why I'm here" (Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

#### **4.3.3.3: Reasons for ART**

During the interviews, participants described their reasons for undergoing ART. After they had described their experiences with sub-fertility, and the motives for wanting children, some went on to explain why they eventually decided to have ART.

According to a number of Nigerian women, the decision to undergo IVF or ICSI was determined by their doctor describing their decision as **'doctors' orders'**. The medical profession in Nigeria has remained paternalistic, with patients seeing the doctors as 'gods' of knowledge, whose views, motives or judgements cannot be questioned. Therefore, whatever treatment is prescribed by the doctors is the right one. Examples of statements illustrating this include:

*"...when I went to see another doctor, the doctor now said we should go for IVF, that he doesn't know the reason why I'm not getting pregnant. So that's why we decided to do it." (Ronke, 42yrs, Nigerian, 1<sup>st</sup> attempt)*

*“... the doctor said that we should go for IVF. I was here last year, doctor checked my result, he now said that I have [luteal] fibroids in my womb, he said that the fibroid might disturb the IVF, he said that I have to remove it first, so I did, and now I've come to see him again, if he would allow me do the IVF now.” (Helen, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

A few UK participants equally reported it being what the doctor recommended, which was the reason they decided to have the treatment:

*“...it was just, they can't really find a cause, its unexplained infertility, so it was just what the doctors advised really that we do it.” (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

Some women who were quite knowledgeable about the ART process mentioned that although they wanted to go ahead with an IVF procedure first, were not allowed to, and rather by the **doctors' orders** had to go through a series of IUI treatments first.

*“... we came to see doctor, I now let doctor know that this is the problem oh, he now gave me some drugs, and said I should go and do some tests. I wanted to do the IVF first, but he said we should not do it, [...] We now did the IUI twice now, then he said I can now do IVF.” (Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

A similar view was reported by one UK participant, who unlike the Nigerian participant could not go through any other procedures, but straight to IVF by the **doctors' orders**:

*“...we were told by the doctor that we have to go through IVF, that we couldn't go through any other process, that's just straight to IVF, which was a bit over whelming, cos I felt we could at least have had some IUI done...” (Lucy, 32yrs, British, 3<sup>rd</sup> attempt)*

Within the UK cohort, most of the women had their reasons to undergo ART, which did not necessarily have as much to do with the **doctors' orders**, but were more **personal decisions**, and then went for a consultation. Example:

*“It's just something that we've thought that we've had to do just because, mainly because of his age, we sort of didn't feel we had that sort of many options really [laughs] and we've had to sort of just get on with it and just do it, yeah umm, so we didn't feel that we had that many options in terms of what we could do.” (Paulette, 44yrs, British, 1<sup>st</sup> attempt)*

*“Well, we struggled to have my little boy, eh, obviously eventually we conceived, eh, so we started trying again quite soon after having him, knowing the problems we’d had in the first place, yeah, and just after a few years [...] we just decided that obviously that was the next step for us [was] to have IVF.” (Katy, 31yrs, British, 1<sup>st</sup> attempt)*

Only one Nigerian women had made a personal decision to undergo the treatment for practical reasons, and didn’t really need to be told by a doctor:

*“My husband is usually away, sometimes he comes once a year, sometimes once in eight months, so we just decided to do it because, there’s no time for both of us to stay in one place together” (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

## **Summary**

This chapter described the participant characteristics for the questionnaires and those that participated in the interviews, the stress and anxiety patterns of women in both countries, their experiences with infertility and treatment seeking behaviours.

Socio-demographic characteristics associated with perceived stress among the UK cohort includes marital status, educational status, cause/aetiology of infertility as well as number of attempts at treatment. Among the Nigerian cohort, the duration of infertility and the type of treatment were implicated as significant predictors of stress among these women.

Three themes developed on the basis of participants’ description of their experiences with subfertility, which were **Psychological impact, Stigmatisation, and Guilt or Regret**.

In the first theme ‘**psychological impact**’, the effect and importance of parenthood was evident as participants describe feelings of *desperation* and *stress* over their subfertility.

The second theme **Stigmatisation** was exclusive to the Nigerian cohort. The outcome of living with the *stigma* of childlessness over a sustained period of time was clearly visible in the women’s narratives. The final theme describing participants’ experience with their subfertility was **Guilt or Regret**. The question posed evidently made some participants remember decisions they had made earlier in life and develop a sense of **guilt or regret** towards them. These were essentially in areas of *delayed childbearing* and *abortions*, while a few others felt they were being *unfairly punished* by God.

An additional three themes were developed based on participants descriptions of their knowledge, beliefs and understanding of ART. The three themes were **help-seeking behaviour, knowledge about ART and reasons for ART**.

On the first theme of **help-seeking behaviour**, participants described the **alternative** and **complementary** remedies they sought. Within the Nigerian cohort, this ranged from traditional to spiritual healers, before settling on orthodox medicine. Within the UK cohort, some women equally sought unorthodox remedies and decided to complement it with their treatment. In the second theme **knowledge about the treatment**, some Nigerian participants described having *no knowledge* about the treatment prior to their first consultation. Others who had heard about it expressed *uncertainties* about the working mechanism of the treatment. Most UK participants were *knowledgeable* about the treatment. This led to the third and final theme **reasons for ART**. Here participants described how the decision to undergo treatment was made, which was either a *personal decision*, or by the *doctors' orders*.

After participants had spoken about their knowledge and understanding of the treatment, they were then asked about their funding experience with it. This would be described in the next chapter. Chapter 5 presents data on the affordability of infertility treatment in both countries and participants experiences with funding the treatment.

# **CHAPTER 5: AFFORDABILITY OF ART**



## CHAPTER 5: AFFORDABILITY OF ART

### 5.1: INTRODUCTION

This chapter examines the affordability/cost-burden of ART in the UK with Nigeria, using three different measures of affordability.

The purpose of this chapter is to answer research questions 2a and 2b

2a: what is the cost burden to households accessing ART in the UK and Nigeria?

2b: what are the perceptions and funding patterns exhibited by women seeking ART in both countries?

The objective of this section is to determine the cost burden of ART to the participants, using three different methods of assessing affordability (stated in section 3.10.2). The descriptive analysis of the respondent's income and expenditure distribution are presented here as two different currencies were used.

### 5.2. ECONOMIC/FINANCIAL DISTRIBUTION OF THE STUDY POPULATION

#### *UK Cohorts*

Table 5.1 presents the expenditure and income characteristics of all UK households included in this study, characterised as either self-funded or NHS-funded. As shown in the table, 45% of the NHS-funded and 40% of the self-funded households endorsed having income levels above £40,000, while approximately 8.6% of the self-funded study populations endorsed having income levels less than or equal to £20,000. None of the NHS-funded women endorsed having an income level less than £20,000.

In regard to the monthly expenditure, 8.6% of the self-funded population reported expenditures under £1000. However, the majority of both populations (i.e. NHS=44.8% & self-funded=57.1%) reported expenditure levels between £1000 and £2000. No participant reported monthly expenditures over £5000.

An independent-samples t-test was conducted to compare the annual expenditure for NHS and Self-funded patients. There was no significant difference in expenditure levels for NHS (M= 25655.17, SD= 13017.23) and self-funded patients [M=24685.71, SD=11891.10;  $t(62) = 0.31, p = 0.76$ ]. The magnitude of the difference in the means was very small (eta squared = .006).

Table 5.1: Income and Expenditure distribution of UK cohorts: NHS versus Self-funded

<b>Variable</b>	<b>NHS, n=29 [n (%)]</b>	<b>Self-funded, n=35 [n (%)]</b>
<b>Annual Income</b>		
Under £15,000	-	1 (2.9)
£15000-£20,000	-	2 (5.7)
£20,000-£30000	7 (24.1)	5 (14.3)
£30000-£40000	9 (31.0)	13 (37.1)
Above £40000	13 (44.8)	14 (40.0)
<b>Monthly expenditure</b>		
Under £1000	5 (17.2)	3 (8.6)
£1000-£2000	13 (44.8)	20 (57.1)
£2000-£3000	5 (17.2)	6 (17.1)
£3000-£5000	6 (20.7)	6 (17.1)
Above £5000	-	-
<b>Annual expenditure, £ (M±SD)</b>	25655.17±13017.23	24685.71±11891.10

The total number of participants with their various income and expenditure distributions, socio-economic quintile classifications and the mid-point values used for analysis are presented in Table 5.2a&b. The total annual expenditure was calculated by multiplying the monthly expenditure by 12.

Table 5.2a: Annual income distribution, mid-point values &amp; quintile (UK, n=64)

<b>Income distribution</b>	<b>N (%)</b>	<b>Mid-point value</b>	<b>PPI rate (Mid- point value)</b>	<b>Quintile</b>
Under £15,000	1 (1.6)	£15,000	\$21490	Poorest
£15,000-£20,000	2 (3.1)	£17,500	\$25072	Poor
£20,000-£30,000	12 (18.8)	£25,000	\$35817	Middle
£30,000-£40,000	22 (34.4)	£35,000	\$50143	Rich
Above £40,000	27 (42.2)	£45,000	\$64470	Richest

Table 5.2b: Monthly expenditure distribution, mid-point values &amp; quintile (n=64)

Monthly expenditure	N (%)	Mid-point value	Annual expenditure	PPI rate (Annual expenditure)	Quintile
Under £1000	8 (12.5)	<£1,000	<£12,000	\$17,192	Poorest
£1000-£2000	33 (51.6)	£1500	£18,000	\$25,788	Poor
£2000-£3000	11 (17.2)	£2500	£30,000	\$42,980	Middle
£3000-£5000	12 (18.8)	£4000	£48,000	\$68,768	Rich
Above £5000	-	-	-		Richest

Table 5.2c: Distribution of UK funding sources according to socio-economic quintile

	NHS-funded, n (%)	Self-funded, n (%)	Total
<b>Poorest</b>	5 (17.2)	3 (8.6%)	8
<b>Poor</b>	13 (44.8)	20 (57.1)	33
<b>Middle</b>	5 (17.2)	6 (17.1)	11
<b>Rich</b>	6 (20.7)	6 (17.1)	12
<b>Total</b>	29 (100)	35 (100)	64

### Cost of the treatment (UK cohort)

As stated in section 3.9.6, the cost of the treatment was collected as an open-variable, and participants were asked to provide the cost of their treatment. The cost of the treatment in the UK clinic was dependent on the procedure/type of ART required. Table 5.3 provides the cost distribution stated by the participants. Treatment costs below £1600 were reported by a few participants (3.1%) who were about to undergo IVF, however, had agreed to share their gametes (eggs) with another woman/couple. The cost of the treatment is subsidised for such a patient. Treatment costs of £3,000-£3900 were reported by majority of the patients (60.9%) undergoing IVF procedures, while 35.9% reported treatment costs ranging from £4000-£4500 and over. A few reported costs above £4500, and these were those patients requiring donor gametes along with the ICSI procedure. A continuous mid-point value was created to establish the median cost of each treatment to the participants.

Table 5.3: Distribution of the treatment costs stated by UK cohort (n=64)

<b>Treatment cost</b>	<b>Procedure to undertake</b>	<b>N (%)</b>	<b>Mid-point value</b>	<b>PPI rate (mid-point)</b>
<£1600	Egg-share (IVF)	2 (3.1)	£1600	\$2292.2
£3000-£3900	IVF	39 (60.9)	£3433	\$4918.3
£4000-£4500	ICSI	21 (32.8)	£4250	\$6089
>£4500	ICSI + Donor Gametes	2 (3.1)	£4500	\$6447
<b>Mean IVF cost</b>			<b>£3343.8± 453.1</b>	
<b>Mean ICSI cost</b>			<b>£4121.5± 448.9</b>	
<b>Mean ART cost</b>			<b>£3623± 584.9 (3474.2, 3758.6 95%CI)</b>	

### *Nigerian Cohorts*

The income and expenditure distribution for this cohort is presented in Table 5.4a and 5.4b. The total annual expenditure was calculated by multiplying the monthly expenditure by 12. From the data presented in both tables, more than half of the sample population had combined household incomes above ₦500,000 (51.9%), and majority had monthly expenditures exceeding ₦ 50,000 (34.6%).

Table 5.4a: Annual combined household income distribution and mid-point values (n=52)

<b>Income distribution</b>	<b>N (%)</b>	<b>Mid-point value</b>	<b>PPI rate (Income distribution)</b>	<b>Quintile</b>
Under ₦ 150,000	-	-	-	Poorest
₦ 150,000-₦200,000	3 (5.8)	₦ 175,000	\$1865	Poor
₦ 300,000- ₦ 400,000	13 (25.0)	₦ 350,000	\$3730	Middle
₦ 400,000- ₦ 500,000	9 (17.3)	₦ 450000	\$4795	Rich
Above ₦ 500,000	27 (51.9)	>₦ 500,000	\$5328	Richest

Table 5.4b: Average monthly expenditure and mid-point values (n=52)

Monthly expenditure	N (%)	Mid-point value	Annual expenditure	PPI rate (Annual Expenditure)	Quintile
Under ₦ 10000	-	-	₦ 100,000	-	Poorest
₦ 10000- ₦ 20000	6 (11.5)	₦ 15,000	₦180,000	\$1918	Poor
₦ 20000- <del>₦</del> 30000	12 (23.1)	₦ 25000	₦300,000	\$3197	Middle
₦ 30000- <del>₦</del> 50000	16 (30.8)	₦ 40000	₦480,000	\$5115	Rich
Above ₦ 50000	18 (34.6)	>₦50000	>₦600,000	\$6394	Richest

### Cost of the treatment (Nigerian cohort)

The initial cost of the treatment in the Nigerian clinic is dependent on the age of the patient. Additional costs might be incurred if the ovarian response after stimulation is low. Meaning that if after the woman's ovaries are stimulated, the number of mature follicles does not increase, then additional stimulation is required, which would incur additional costs. However, as the participants were recruited before the start of the cycle,

Table 5.5: Distribution of treatment costs stated by economic quintile for Nigerian cohort (n=52)

Treatment cost	Mid-value	Poor, n (%)	Middle, n (%)	Rich, n (%)	Richest, n (%)	Total, n (%)
<b>Aged 25-39 years</b>						
₦ 700-750 thousand	₦725000	2 (3.8)	6 (11.5)	5 (9.6)	9 (17.3)	22(42.3)
₦ 800-850 thousand	₦825000	-	2 (3.8)	-	1 (2)	3 (5.8)
<b>Aged &gt;40 years</b>						
₦ 900-950 thousand	₦925000	3 (5.7)	1 (2)	4 (7.7)	5 (9.6)	13 (25)
>₦ 950 thousand	₦1000000	1 (2)	3 (5.7)	7 (13.5)	3 (5.7)	14 (26.9)
<b>Mean ART cost</b>	₦848076.92 ± 134660.62 (\$9037.30± \$1434.9)					

### 5.3: CATASTROPHIC EXPENDITURE

The catastrophic expenditure of the treatments (IVF or ICSI) to the patients was calculated using a threshold of 40% above the total household expenditure. The mid-point values for monthly expenditure was used.

To calculate catastrophic expenditure, the formula used was:

$$\frac{\text{Cost of treatment (IVF/ICSI)}}{\text{Total household expenditure (for each quintile)}} \times 100 > 40\%$$

### **UK Cohorts**

To calculate the catastrophic expenditure for each quintile and each treatment, the following calculations were done on each economic quintile and each treatment:

$$\begin{aligned} & \frac{\text{Cost of IVF}}{\text{Household expenditure (for poorest)}} \times 100 > 40\% \\ & = \frac{\pounds 3433}{\pounds 12,000} \times 100 > 40\% \text{ (threshold)} \\ & = \frac{\pounds 3433}{\pounds 12,000} \times 100 > 40\% \text{ threshold} \\ & = 0.286 \times 100 > 40\%, = 28\% > 40\% \text{ threshold} \end{aligned}$$

The total household expenditure on IVF expressed per-expenditure based quintile is presented in Figure 5.1. From the graph, it is observed that the cost of IVF at £3433, accounted for approximately 28% of household expenditure for the patients within the ‘poorest’ quintile. Meaning that 8.6% of the self-funded participants spent approximately 28% of their annual expenditure on one IVF treatment cycle. This however did not reach the 40% threshold which would account for catastrophic expenditure within this study. For participants within the ‘poor’ and ‘middle’ economic groups, they spent approximately 19% and 11% of their annual household non-food expenditure on an IVF cycle respectively. Participants within the rich and richest quintiles spent approximately 7% and 6% of the annual expenditure on an IVF treatment cycle. This study recorded no participants within the richest quintile.

The result indicates that out of the 19 self-funded IVF participants within the UK cohort, 15.8% of the participants spent at least 28% of their household non-food expenditure on their IVF cycle.

From the results in Figure 5.1, ICSI costs within the poorest quintile in the UK cohort accounts for 35.4% of the annual household expenditure. Some authors have considered this to be a significant effect (Shrime et al., 2015). However, it did not reach the threshold

established for this study, and therefore, participants within this quintile cannot be said to have incurred a catastrophic expenditure.

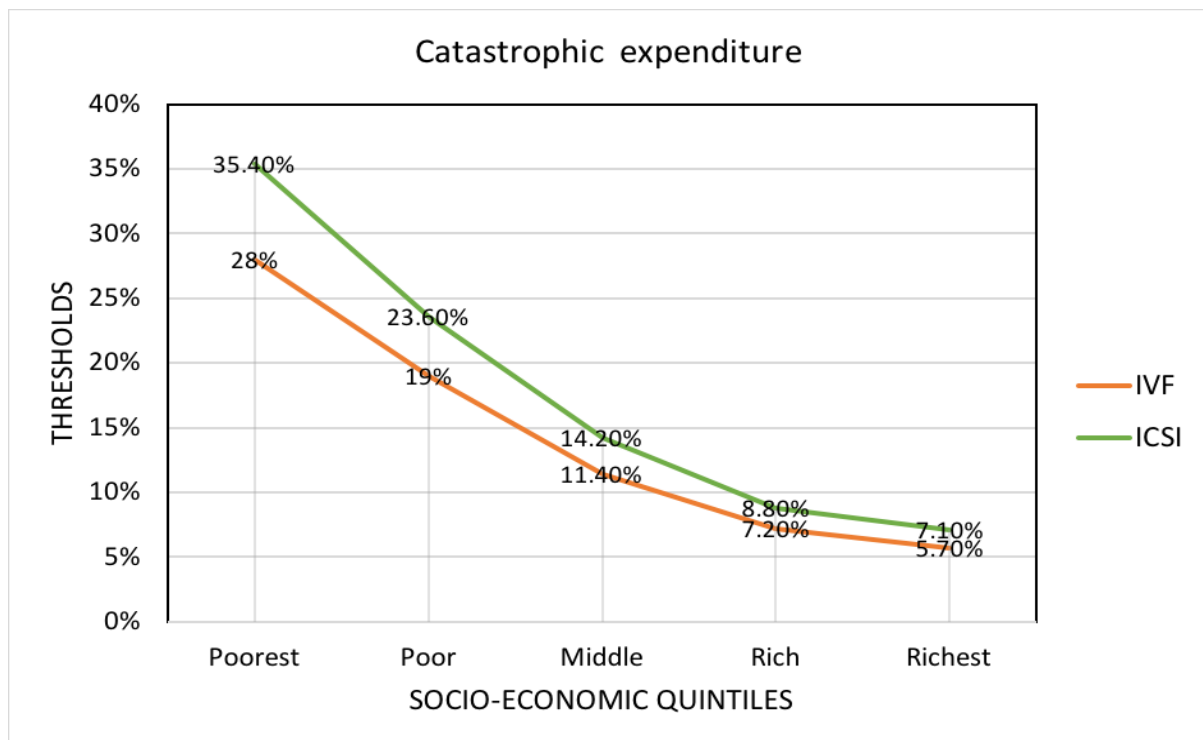


Figure 5.1: Catastrophic expenditure values for the various UK economic quintiles

For participants within the poor and middle quintile groups, they spent approximately 24% and 14% of their annual household expenditure on an IVF cycle respectively. Similar thresholds were observed between the rich (8.8%) and richest quintiles (7.1%). As there were no participants within the richest quintile, it is inferred that for the 12 (18.8%) patients within the rich quintile with monthly expenditures of approximately £4000, the cost of an ICSI procedure would account for approximately 9% of their annual household expenditure.

### ***Nigerian Cohort***

An examination of the income and expenditure distribution within this cohort (Table 5.4a, b) showed that using the household annual expenditure to calculate catastrophic payment expenditure would be ineffective. This is because the cost of the treatment was above the estimated household annual expenditure for each quintile and therefore constitutes a catastrophic expenditure in itself. Therefore, the catastrophic overshoot (see section 3.10.2.1) was estimated instead.

The equation for the calculation of household overshoot is:

$$\text{Overshoot} = \varepsilon \left( \frac{\text{Cost of treatment}}{\text{Annual expenditure}} \right) - Z$$

Where:

$\varepsilon$  is an indicator; such that  $\varepsilon=1$ , if  $\left( \frac{\text{Cost of treatment}}{\text{Annual expenditure}} \right) > z$ , and otherwise zero

Z = Threshold i.e. 40%

Therefore, overshoot for patients 25-39 years in the *poor* quintile

$$\text{Overshoot} = 1 \left( \frac{\text{₦}725,000}{\text{₦}180,000} \times 100 \right) - 40\%$$

$$\text{Overshoot} = 1 (4.027 \times 100) - 40\%$$

$$\text{Overshoot} = 402.7 - 40 = 362.7$$

$$\text{Mean overshoot} = \frac{\text{Overshoot}}{\text{Number of households}}$$

$$\text{Mean overshoot} = \frac{362.7}{6} = 60.5\%$$

The aim of assessing the catastrophic mean overshoot graphically was to visualise just how much the economic quintiles exceeded the threshold, and by what percentage difference. Figure 5.2 shows how much more than the 40% threshold was exceeded, depending on the economic status of the households. The varying differences support the increasing cost of treatment, as well as the differences in economic quintile (Figure 5.2). The results show that the two (2) households in the ‘poor’ economic quintile (see Table 4.9), that have to fund a ₦725000 ART cycle exceeded the 40% threshold by more than 60%, while the nine (9) households within the ‘richest’ economic quintile that have to fund the same cycle at the same cost, exceeded the 40% threshold by 4.4%.



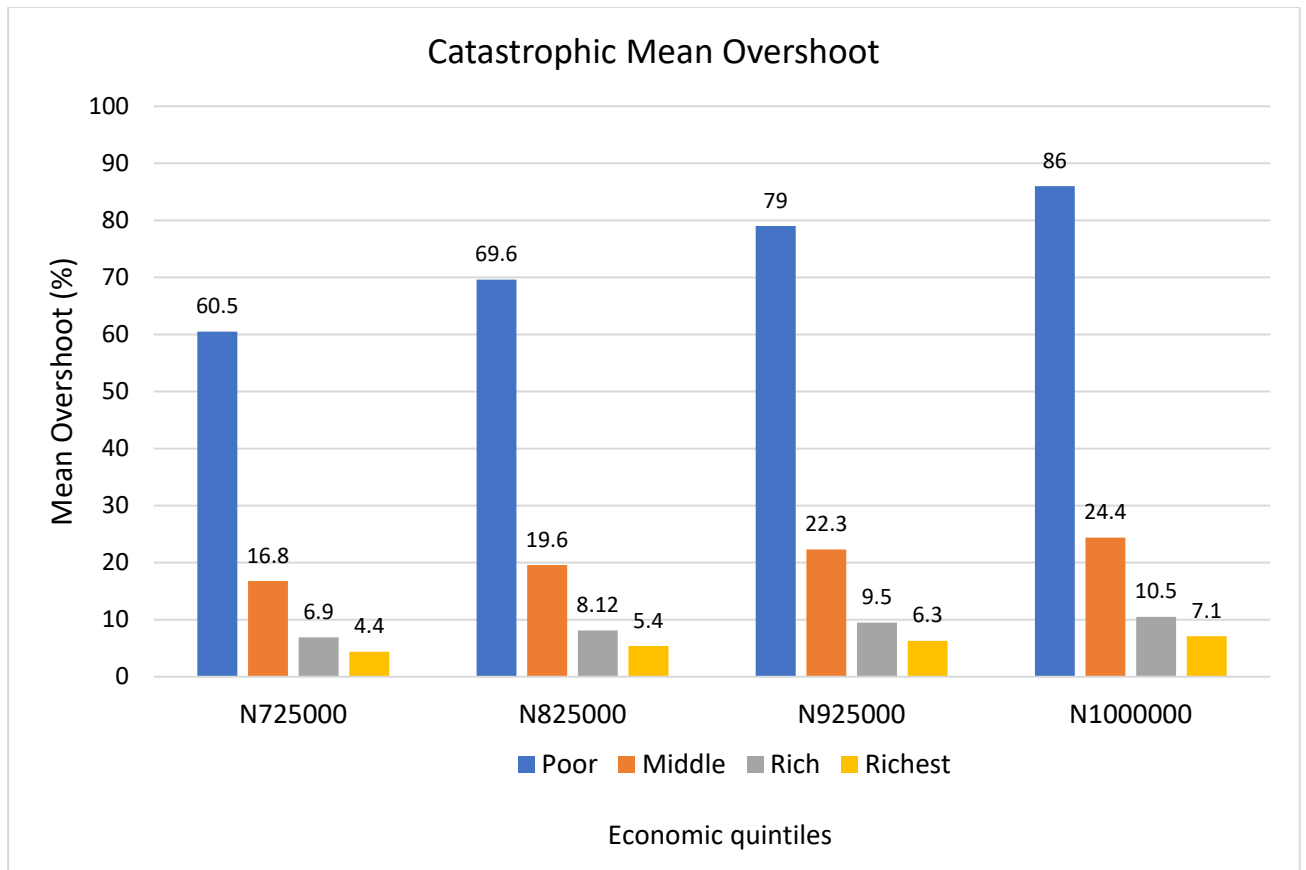


Figure 5.2: Catastrophic mean overshoot for households in the various economic quintiles

Similarly, the three households in the poor economic quintile who had to pay N 925,000 for a single IVF or ICSI cycle exceeded the 40% threshold established for catastrophic expenditure by 79% the only household in the middle quintile exceeded the threshold by 22.3%, the 4 households in the rich quintile by 9.5%, while the richest household by 6.3%.

#### ***Comparison of both cohorts***

There was a significant difference ( $p < 0.001$ ) in catastrophic expenditure between UK and Nigerian cohorts. With the Nigerian cohort incurring more catastrophic payments than UK households that self-funded the treatment.

#### **5.4. SUBJECTIVE FINANCIAL WELL-BEING EVALUATION**

A single question was used to measure subjective financial well-being by asking individual perception of income adequacy to meet the needs for the treatment. The results are presented in Figure 5.3a, 5.3b, 5.4 and 5.5.

### UK Cohorts

An initial frequency distribution analysis showed that majority (35.9%) of the participants endorsed 'moderately' having enough money to meet their treatment needs, followed by 28.1% of respondents endorsing 'mostly' having enough money to meet the treatment needs. Few women (6.3%) endorsed 'not at all' and a similar number endorsed having 'a little' money to meet their needs. From the bar chart presented in Figure 5.3a, majority (20.3%) of the 'poor' households reported 'moderately' having enough money to meet their treatment needs, while households within the 'rich' economic quintile reported moderately (7.81%), mostly (7.81%) and completely (3.13%) having enough money to meet their treatment needs.

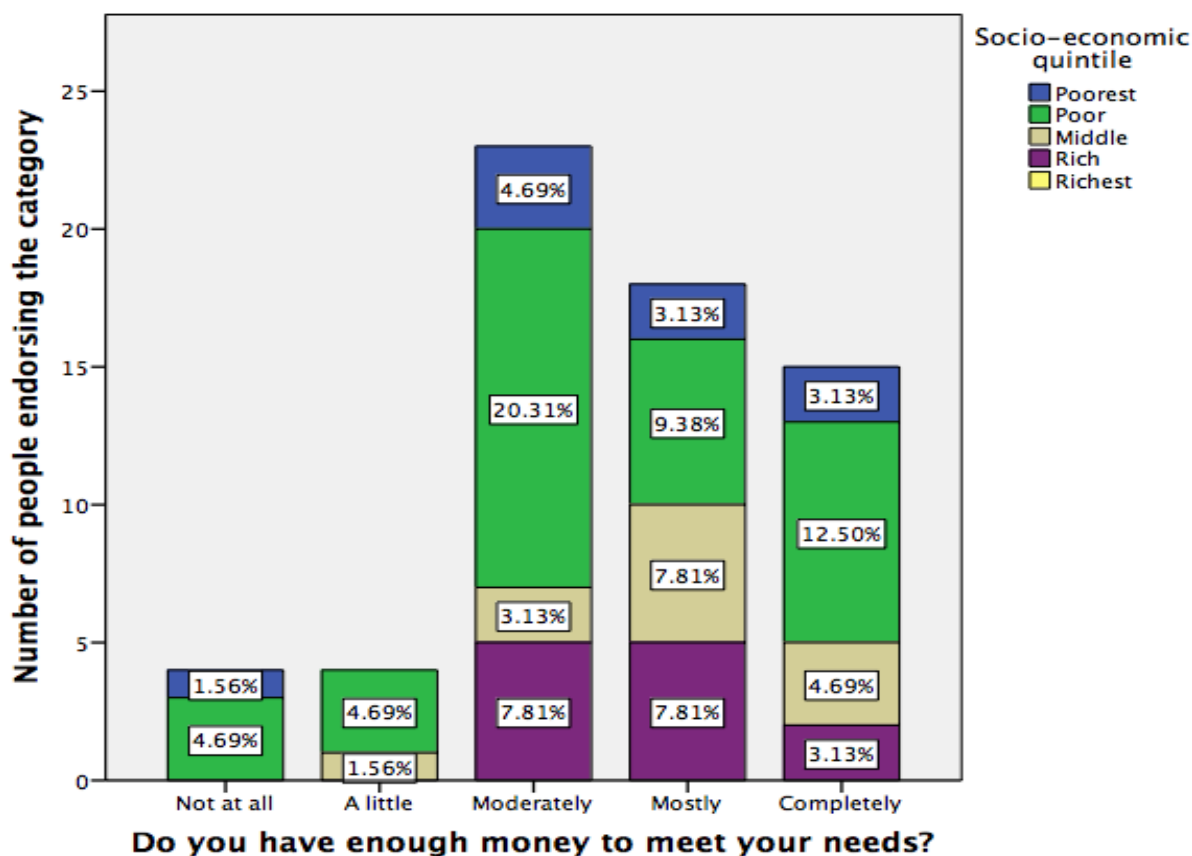


Figure 5.3a: Economic quintiles reporting subjective financial well-being (UK cohort).

The comparison between NHS-funded and self-funded UK women are presented in Figure 4.3b. The majority of Self-funded women endorsed 'moderately' having enough money (45.7%) to meet their needs, however, majority of NHS-funded women endorsed

'mostly' having enough money (31%) to meet their needs. In comparison, more NHS-funded women endorsed not having enough money to meet their needs (10.3%) compared to the self-funded women (2.9%). An independent samples t-test was conducted to compare the financial well-being scores for NHS and Self-funded UK women. There was no significant difference in scores for NHS ( $M=3.59, SD=1.26$ ) and Self-funded women [ $M=3.54, SD=0.98; t(62)=0.15, p=0.87$ ]. The magnitude of the difference in the means was very small ( $\eta^2 = .0004$ ).

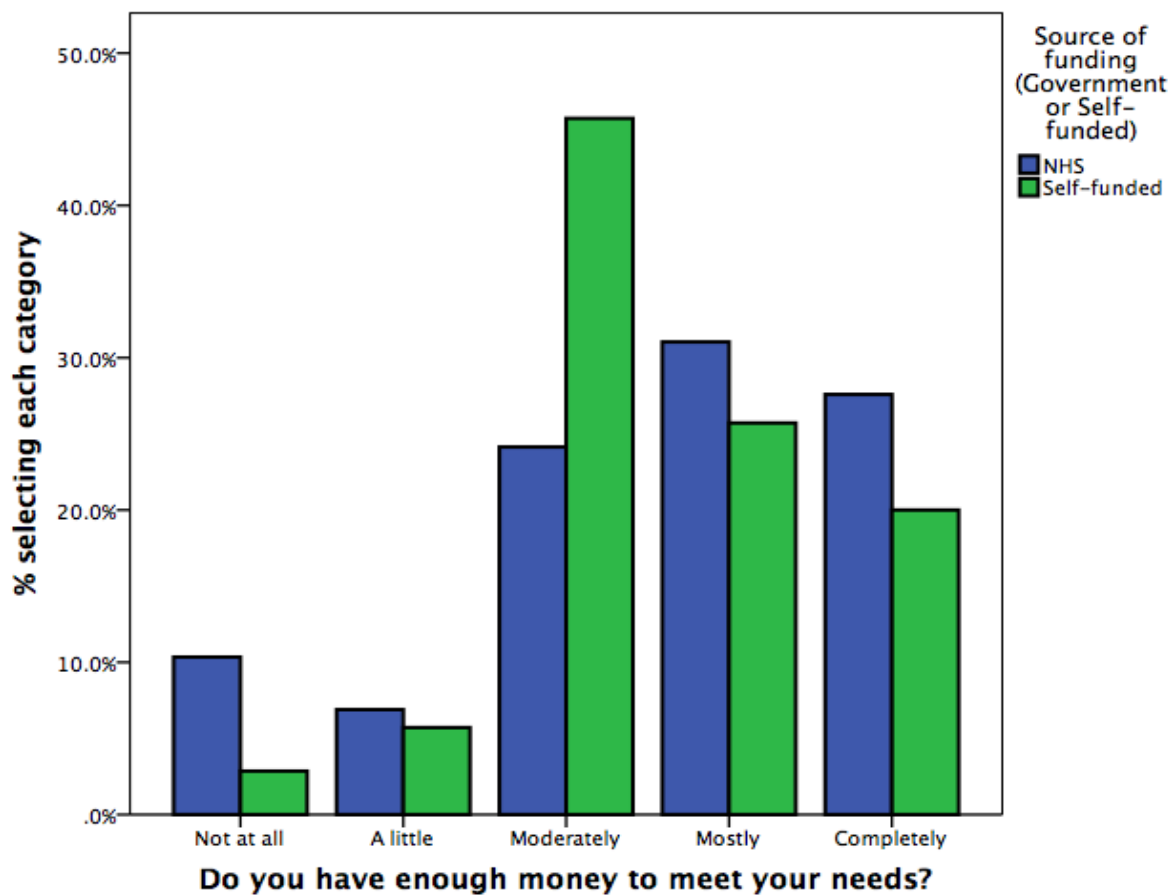


Figure 5.3b: Subjective financial well-being comparison between NHS and Self-funded women

#### 5.4.1. Socio-demographic predictors of financial satisfaction in UK cohort

A standard linear multiple regression was applied to calculate the individual contributions of the socio-demographic variables on the subjective financial well-being question. Preliminary assumption testing was conducted to check for normality, linearity, outliers, and multicollinearity, with no serious violations noted. Then taking into account the literature on financial well-being, and accounting for the confounding factors of age

and education, the other variables (cost of the procedure, annual household income, funding source, number of attempts and cause of subfertility) were entered for the regression analysis. The first step was to enter all the variables and the main outcome (subjective financial well-being) into the regression analysis. The model outcome was not significant  $F(5,58) = 1.96, p=0.09$ . This first model explained 14.5% of the variance in subjective poverty  $R^2 = 0.145, p=0.09$ . Then using a backward elimination method, non-significant covariates were excluded from the model. This was done one at a time, and each time a covariate was removed, a new test was run, with the final model including only covariates with p-values of 0.05 or less (shown in Table 5.6a).

Table 5.6a: Showing predictors of subjective financial wellbeing among UK cohort

Variables	$\beta$	B	SE B	$p$	95%CI for B
<b>Model 1</b>					
Cost of the procedure	.12	.00	.12	.34	[.00, .001]
Annual household income	.25	.31	.25	.04*	[.01, .62]
Cause of subfertility	-.24	-.32	-.25	.06	[-.65, .01]
Funding source	-.02	-.03	-.01	.90	[-.59, .53]
Number of attempts	-.05	-.07	-.05	.73	[-.47, .34]
<b>Model 2</b>					
Cost of the procedure	.12	.00	.00	.34	[.00, .001]
Annual household income	.26	.31	.15	.04*	[.01, .62]
Cause of subfertility	-.24	-.32	.16	.05*	[-.64, .00]
Number of attempts	-.05	-.07	.19	.70	[-.48, .32]
<b>Model 3</b>					
Cost of the procedure	.11	.00	.00	.36	[.00, .001]
Annual household income	.26	.15	.15	.03*	[.02, .62]
Cause of subfertility	-.25	.15	.16	.04*	[-.64, -.02]
<b>Model 4</b>					
Annual household income	.24	.29	.14	.04*	[.01, .59]
Cause of subfertility	-.24	-.31	.15	.04*	[-.63, -.00]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p < 0.05$

The final model was significant  $F(2, 61) = 4.58, p=0.01$ , and accounted for 13.1% of the variance  $R^2 = 0.131$  in subjective poverty response. The exclusion of most of the other variables did not create any significant change to the final model  $\Delta F(1, 60) = 0.82, p=0.368$ , and  $\Delta R^2 = -.012$ . The results in Table 4.7a, shows that for this regression model, the  $\beta$  of 0.244 for annual household expenditure,  $t(61) = 2.03, p=0.04$  and Cause of subfertility,  $t(61) = -2.02, p=0.04$  with  $\beta = -.243$  are the largest and the most highly statistically significant of the regression coefficients. With an increase in annual income

associated with having enough money to meet ones needs. While from the way the scoring was done for the aetiology/cause of infertility, female factor infertility associated with having enough money to meet ones needs.

### Nigerian Cohorts

An initial frequency distribution analysis presented in Figure 5.4 showed that majority of the women endorsed ‘mostly’ having enough money (28.8%) to meet their needs. However, almost as many women endorsed not having enough money (26.9%) and having little money (25%). Only a small number of women endorsed ‘completely’ (5.8%) having enough money for their needs. From the results presented in Figure 5.4, majority (13.4%) of the respondents in the *richest* quintile reported not having any money, while 7.69% reported having a little money to meet their needs. Few (3.85%) reported moderately and completely having enough money. A similar number of women (3.85%) in the *poor* economic quintile endorsed ‘a little’, ‘moderately’ and ‘mostly’ having enough money to meet their needs. None of the participants in this economic quintile (poor) endorsed ‘not at all’ as a response.

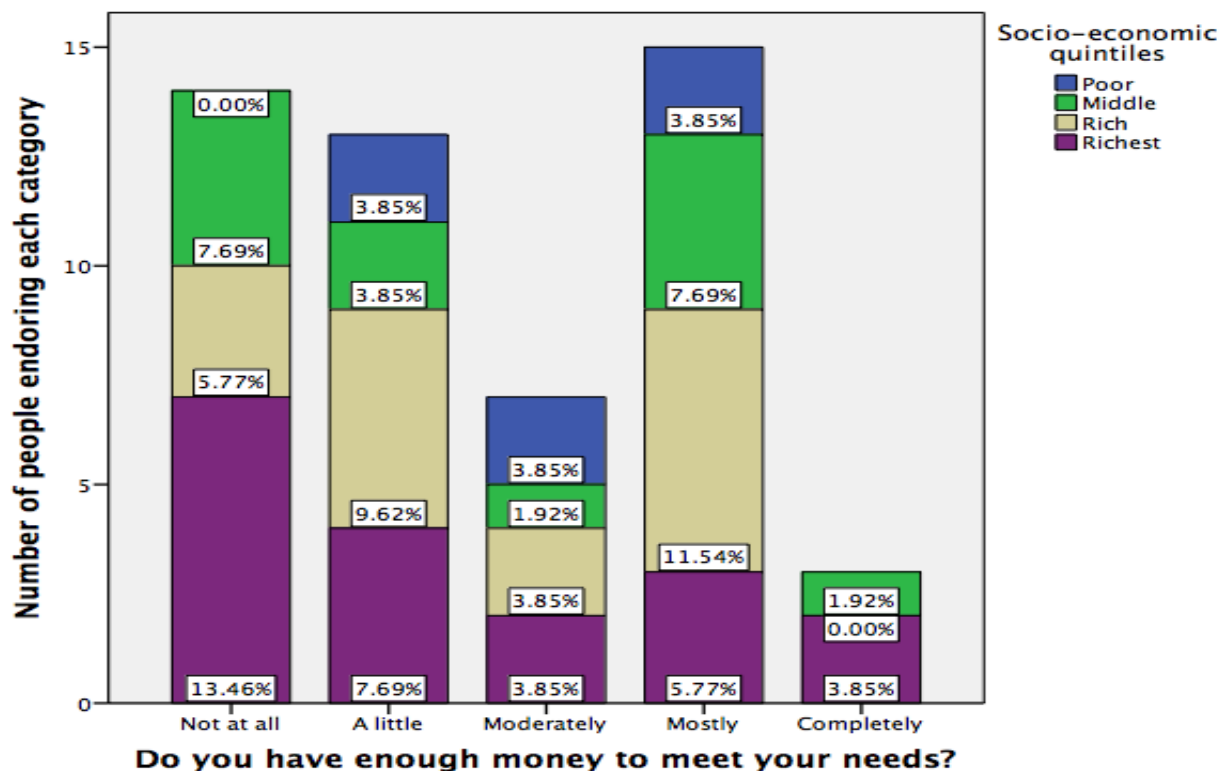


Figure 5.4: Economic quintiles reporting subjective financial well-being (Nigeria)

#### 5.4.2. Socio-demographic predictors of subjective financial well-being in Nigerian cohort

A similar standard multiple regression analysis (method enter) was done to determine the socio-demographic predictors of subjective financial well-being within the Nigerian cohort. In the first step, all the variables (cost of the procedure, annual household income, cause of subfertility and number of attempts) and the main outcome (subjective financial well-being response) were entered into the regression analysis. The model outcome was not significant  $F(4,47) = 0.74, p=0.56$ . This model explained 5.9% of the variance in subjective poverty  $R^2 = 0.059, p=0.56$  (Table 5.6b). The analysis showed that none of the major variables (documented in literature) were significant predictors of subjective financial well-being ( $p>.05$ ) among this cohort.

Table 5.6b: Showing correlates of subjective financial wellbeing among Nigerian cohort

<b>Variables</b>	<b><math>\beta</math></b>	<b>B</b>	<b>SE B</b>	<b><i>p</i></b>	<b>95%CI for B</b>
Cost of the procedure	.09	.00	.00	.54	[.00, .00]
Annual household income	-.12	-.15	.19	.42	[-.54, .23]
Cause of subfertility	.13	.12	.13	.36	[-.14, .39]
Number of attempts	-.16	-.57	.51	.27	[-1.61, .46]

SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval

#### ***Comparison between both cohorts***

A descriptive comparison between both countries shows that the majority of the UK women reported moderately having enough money, while the majority of the Nigerian women reported mostly having enough money to meet their needs (Figure 5.5). More UK women reported 'completely' having enough money than Nigerian women, while more Nigerian women endorsed not having enough and having little money compared to UK women. An independent samples t-test was conducted to compare the responses to the subjective financial well-being question for UK and Nigerian participants. There was a significant difference between responses for UK ( $M=3.53, SD=1.09$ ) and Nigerian cohorts [ $M=2.62, SD=1.32; t(99.2) = -4.01, p<0.001$ ]. The magnitude of the differences in the means was large (eta squared = 0.146).

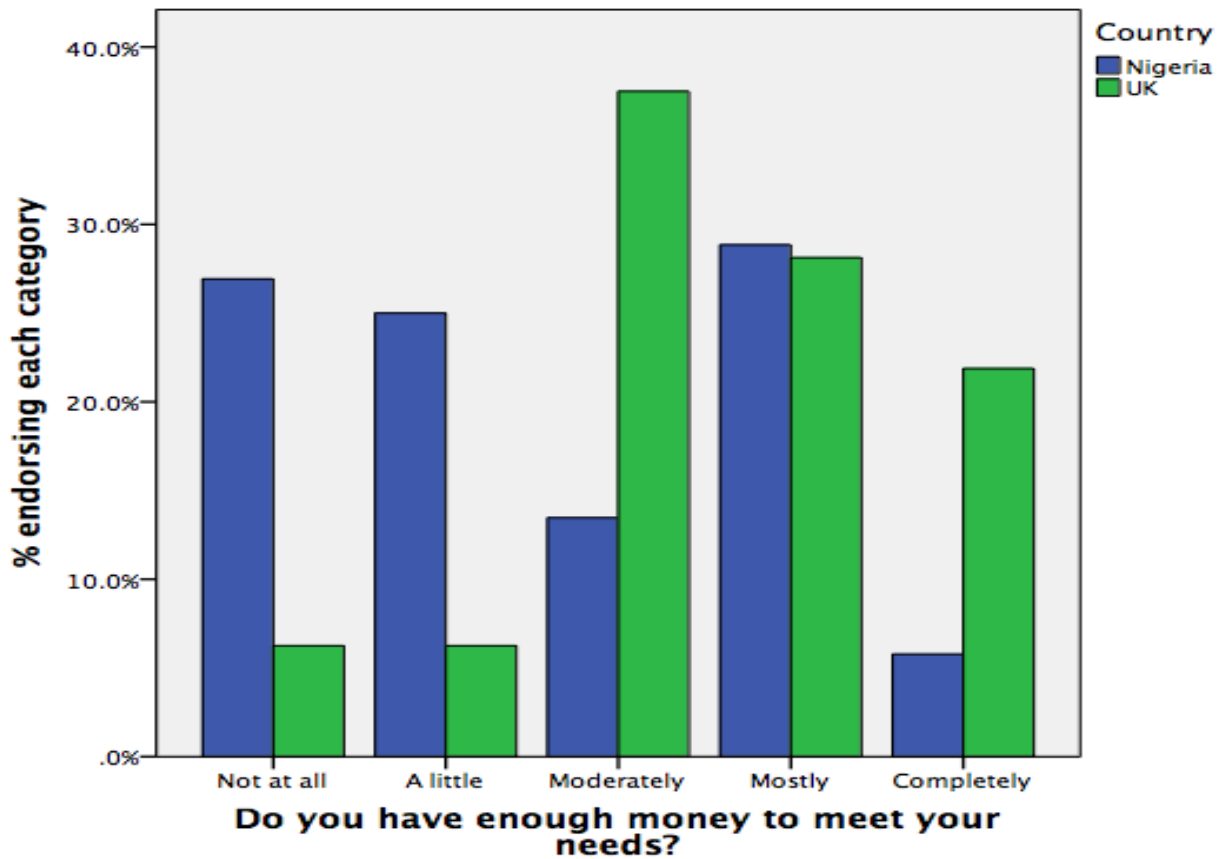


Figure 5.5: Subjective financial well-being comparison between UK and Nigerian cohorts

## 5.5. WHO/HAI METHOD OF AFFORDABILITY

### *UK Cohort*

In the UK (based on 2016-2017 tax year), the hourly wage of the lowest paid unskilled government worker was £7.20 per hour (\$10.30). This was multiplied by a 7.5 working hours per day, which is **£54.00** a day. £54 per day multiplied by 5 working days per week, gives a weekly pay of £270 (\$386.8) and a monthly salary of £1,170 (\$1676.2).

Using a day's wage of £54 (\$77.3) and an average IVF cost of £3433 (\$4918.3), the lowest paid unskilled government worker would require:

Cost of IVF /a day's pay = £3433/£54 = 63.5 days' wages. Which is approximately 2months and 4 days wages for a single cycle of IVF in the Sheffield clinic in the UK.

### *Nigerian Cohort*

In Nigeria (based on 2016-2017 tax year), a monthly salary of **₦19800** (\$210) is the minimum wage and the monthly salary of the lowest paid unskilled government worker.

Using a minimum wage/monthly salary of ₦19800 (\$210) and an average IVF cost of ₦775,000 (\$8258.5), the lowest paid unskilled government worker would require:

$$\text{₦775,000}/\text{₦19800} = 39 \text{ months' pay.}$$

This means that the lowest paid unskilled government worker would require approximately 3 years and 3 months' salary to fund a single IVF cycle in the Benin clinic in Nigeria.

### ***Comparison between both cohorts***

For comparability, the 2016 PPP values obtained from the international monetary fund (IMF) database for both countries are used and are shown below:

$$\text{UK (2016 PPP)} = \$0.698, \text{ Nigeria (2016 PPP)} = \$93.842$$

Using the CCEMG-EPPI cost converter, to convert the cost estimate of the Nigerian monthly salary to the UK currency and price year (2016); the local currency is divided by the PPP (Nigeria) factor to get the US equivalent, then the US equivalent is multiplied by the PPP (UK) to get the UK equivalent:

$$\text{₦19800}/93.84 = \$210.99 \text{ (US equivalent)}$$

$$\$210.99 \times 0.698 = \text{£}147.27 \text{ (UK equivalent)}$$

The UK equivalent of ₦19800 is £147.27. This means that in Nigeria, ₦19800 would allow you to buy the same things you would buy with £147.27 in the UK.

Using the IVF costs for this study, the UK equivalent of ₦775,000 (cost of an IVF cycle in Nigeria for women 25-39yrs) is £5764.59, which is actually higher than the cost of an average ICSI procedure in the Sheffield clinic. However, it is not far-fetched from the cost of ART in certain fertility clinics in other UK cities such as London. To obtain a single IVF cycle in Sheffield at £3433, the Nigerian equivalent would be ₦467,000, which is a little less than 2 years' salary for the lowest paid unskilled government worker.

## **5.6. FUNDING THE TREATMENT**

Although access to the treatment is likely to involve some degree of hope, most participants expressed some issues and fears they had over funding the treatment. The themes that have been developed from the interviews describe patient's experiences



with funding the treatment, and are presented as ‘**concerns over funding**’, ‘**obtaining funds**’ and ‘**Quality of life**’. These are summarised in Table 5.7 and described in detail.

Table 5.7: Patients experiences with funding the treatment

Theme	Sub-theme	Participants descriptions
CONCERNS OVER FUNDING	<i>Pressure, worries &amp; stress, frustrations, fears, additional costs, God</i>	Participants describe their worries about funding the treatment, the frustrations and pressure when its unsuccessful
OBTAINING FUNDS	<i>Savings, loans, contributions, extra-work/overtime, Gifts, husband’s responsibility</i>	Participants describe how funds were sought for their treatment
QUALITY OF LIFE	<i>No effect, relationship strain, effects (opportunity cost, change in habits), Coping</i>	Participants describe how their quality of life is affected by the aftermath of funding the treatment

### 5.6.1: CONCERNS OVER FUNDING

The pinnacle of reasons for the concern about funding the treatment was the fact that it could be unsuccessful, and they might have to fund it again. Several UK participants described their *worries* and *stress* on this issue and interestingly there were a lot of similarities between the NHS-funded and self-funded patients with regards to these concerns. Examples among a few NHS funded participants include:

*“I do think, what happens after the next cycle, how do I afford it?” (Lucy, 32yrs, British, 3<sup>rd</sup> attempt)*

*“It does add stress to it because I’m very aware that I’ve got a 1 in 10 chance and it’s a lot of money to have to pay out if my one and only chance doesn’t work, you know, my one and only free chance. [Exhales] I’m stressed about a lot of things, but I’m more stressed about that. So, all the worry that you can pay for yourself and another round, it’s no more guaranteed than this one, then what do you do, and how many times do you do that before you have no savings left.” (Sarah, 41yrs, British, 1<sup>st</sup> attempt)*

Similar examples among some self-funded participants include:

*“Probably my [stutters] biggest worry is the fact that, it’s not paying for the treatment, cos I’ve got money to one side, its if it is unsuccessful then, which I hope it won’t be, then its afterwards that it [will] wipe out all my savings. Hopefully it would work, and then if it doesn’t, and then that’s when the flipside, if it doesn’t, then you’ve got no savings and no child” (Lisa, 35yrs, British, 1<sup>st</sup> attempt)*

*“...but then if we are unsuccessful, and there’s another cycle then of course that’s the biggest stress is, or if there’s something wrong with me and it has to get cancelled [...] so we are paying for a gamble basically” (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

One participant mentioned having a partner who she intends to marry, however, certain life goals needed to be achieved first. The text that follows is an excerpt from the interview:

**Q:** Your mum helping with the cost of the treatment is great, any additional concerns?

**Lucy:** *I am, I am quite concerned, yeah because ehm, well Dave and I, we’ve actually planned to get married next year.*

**Q:** Okay?

**Lucy:** *Yeah, we went to look at a wedding venue yesterday, so we’ve decided on the venue, but we aren’t going to get married until after this process. Because we feel if it doesn’t work on the third try, we’d have to fund it ourselves and we can’t really justify getting married without having a child. So, we’ve got to wait until obviously this works before we run to getting married (Lucy, 32yrs, British, 3<sup>rd</sup> attempt).*

A few other women mentioned the added **pressure** they felt about having a few cycles funded by the NHS, and the rest by themselves:

*“I think it adds a huge amount of pressure that you get one cycle free, therefore there is much more added pressure to the idea that it has to work, because it is going to be obviously very expensive to keep, having cycles.” (Eleanor, 34yrs, British, 1<sup>st</sup> attempt)*

*“I think it makes you feel a lot more pressure because you know that you’ve only got so many left that you can fund, and it definitely makes you feel more pressure. And then you also worry that if it doesn’t work, umm, if then all your savings that you*

*can't really enjoy the rest of your life together. It's like an added disappointment really." (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

Some pointed out the **frustrating** aspect of having to fund more cycles:

*"...then I guess you start feeling like it could be spending money on or wasting money really on something that's never going to work "(Fiona, 36yrs, British, 2<sup>nd</sup> attempt).*

*"... but how long would you carry on putting money into something, and it isn't, if it doesn't work or, it doesn't keep working, then, that's a [stammers] that's another conversation isn't it?" (Anna, 37yrs, British, 3<sup>rd</sup> attempt)*

Among the Nigerian cohort, some women expressed their **fears** about funding the treatment, which was mainly about the probability of an unsuccessful cycle:

*I'm afraid because, looking at the cost one is going to put into this process, it's going to be painful if you do it and its not successful. (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

*"If it was like 100% guarantee, then yes! people would not be discouraged or a bit uncomfortable about the costs. But just the 'we are not even sure', 'it's just 50-50', 'you might take in, you might not' that is the scariest aspect." (Ijeoma, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

Some other women expressed their **worries** about the cost of the treatment:

*"But 700 thousand naira, isn't the money too much? Haba! Where do they think someone can get that kind of money from? (Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)*

*"My husband and I were supposed to pay for the treatment, but now he is kind of financially down, you get it, that's actually why we are getting this delay. He is kind of financially down, so now we have to pull our heads together to look for how to raise the total sum. They told me 900 or 950 thousand, it's on the high side, very high, that's almost a million oh!" (Bose, 49yrs, Nigerian, 2<sup>nd</sup> attempt)*

A few women expressed their concerns about some indirect **additional costs** they had to pay for before the treatment, and how these depleted their initial treatment funds. These situations are presented:

*"I came in 2013 with my money; they said I have to do a myomectomy before they would do the procedure. I did the myomectomy, complications came in, sepsis and all the others, I was re-admitted. Eventually I was admitted thrice, I spent all the money I had, trying to save my soul. So that was how that cycle ended that time. I had to go back again and look for money. You know for a classroom teacher, here in Nigeria, we're not well paid, and money is minimal (...), so it makes it even more difficult" (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt).*

She went on to say:

*"So, since that 2013, I had to go and start looking for money again, saving up all over again, looking for how I would get loans and (hiss). I got the money again, when I came in here with 700 thousand, they said the money has already increased to at least 850 thousand, I said okay. I went to borrow the remaining money to complete it, we started the programme. Only half way into the cycle now, they said I cannot continue that they are not accessing my endometrial cavity. I cannot continue. I should go and do a hysteroscopy, which is another 280 thousand naira. My money has already finished now?" (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

Another woman said:

*"I had the intention of doing the treatment last year, but the doctor now discovered that I have small fibroids. It's not big, but they are plenty, so he suggested that I should go for surgery, to which I did. So, after the surgery I now told my doctor that my menstrual flow is not all that much anymore, that it's just like drops, so he now said that I should go and do HSG<sup>15</sup>. So, when I did that one, then they now discovered that the tubes were blocked, and I had to go in for another surgery, where they would open the tubes. All this one is money I have been spending even before the IVF treatment oh!" (Helen, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

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<sup>15</sup> HSG or Hysterosalpingography is a radiology procedure used for the diagnosis of blocked fallopian tubes ([www.webmd.com](http://www.webmd.com))

Other women did not really express their *fears* or *worries* but instead believed that '**God would provide**' the funds they needed, as illustrated by the following examples:

*"The bible says, "the path of the righteous is a shining light", I believe definitely he will provide the money for us" (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

*"...but it's just God, its God. I still believe God would still provide. He would provide the means, as long as He has said that this is what we should do" (Onyiye, 39yrs, Nigerian, 1<sup>st</sup> attempt).*

Evidently, the costs of the treatment can contribute to the stress and frustrations experienced by couples who are already burdened by their subfertility.

### **5.6.2: OBTAINING FUNDS**

The second theme observed was '**obtaining funds**', i.e. basically how funds were sought. Within both cohorts it was apparent that there was a high demand for the treatment and couples were willing to go extra miles to raise the money for it. A few UK participants mentioned having sought for *loans* to fund the treatment.

*"Yeah, we struggled, struggled a lot, we had to borrow it and pay back monthly [out] with wages, still have no idea how we are getting it all yet..." (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

*"we've talked to [...] had some family contributing and people helping us out with money, if we should need another cycle, but obviously we're going to pay them back" (Eleanor, 34yrs, British, 1<sup>st</sup> attempt)*

A similar method was mentioned by a Nigerian woman, who also expressed having sought a loan for her treatment:

*"Well, me I've asked for a loan from my bank, but they equally were saying that maybe before the 1st or 2nd week of this June, it may come..." (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

A few UK women mentioned using their *savings* to fund the treatment. A few UK participants illustrated this:

*“I think for us, we knew we’d be able to save up a certain amount, and it was worth doing that, because we felt that we wanted to give it every chance that we could.”*  
(Anna, 37yrs, British, 3<sup>rd</sup> attempt)

*“That part has been quite stressful, and we haven’t actually got that money just at hand, we’ve have to save up, you know, we’ve have to physically save up to be able to afford to have treatment”* (Sheree, 37yrs, British, 1<sup>st</sup> attempt)

This was also mentioned by Bose (Nigerian), who describes how she saved part of her monthly income in order to raise the funds for the treatment:

*“What I did was, from that my salary of about 60 thousand, now it’s just moving to 70 thousand, I saved up 50 thousand each month for a little more than 1 year in other to raise the money. That was how I gathered all the money together”* (Bose, 49yrs, Nigerian, 2<sup>nd</sup> attempt)

A few women, mentioned getting **contributions** from colleagues at work. One informant describes how she sought the funds for her treatment through contributions made by colleagues:

*“I decided instead of going for a loan, I will rather just, you know, go into this kind of ‘osusu’<sup>16</sup> that we do in Nigeria here, that you enter with other people. In our group the contribution is 40 thousand naira. So, every time they give me my own money, I will save it. I prefer to go into that one, when it’s my turn I take, and when its somebody else’s turn, I will also give too.”* (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)

Within the UK cohort, some respondents described having to work **overtime** in order to fund the treatment:

*“Basically, over time for me at work, and that came through as a lump sum and that’s just a little bit short of one cycle. But it was excess of my normal salary...”* (Zoe, 32yrs, British, 1<sup>st</sup> attempt)

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<sup>16</sup> ‘Osusu’ is a form of micro financial capital accumulation practised in Africa where a small group of 5-10 people come together to help each other. For example, 10 people put 1000 naira in a pot and then one of the 10 takes the resulting 10,000 naira for his/her use, promising to put in 1000 at the next group meeting to continue the process.

*"Well, I've gone full time back to work for 6 months just to earn a little bit more to help cover for it" (Katy, 31yrs, British, 1<sup>st</sup> attempt)*

For a few women who felt quite lucky, the funds for their treatment were given as **gifts**:

*"I'm quite lucky because my mum has said she would help me pay for it". (Lucy, 32yrs, British, 3<sup>rd</sup> attempt)*

*"I've been quite fortunate in a way, my uncle got left some money and he gave me some, not towards this, he didn't know it was towards this, but I've got sort of £5000 put to one side which I'm going to use for this, so I've been lucky" (Lisa, 35yrs, British, 1<sup>st</sup> attempt)*

Although most of these women had mentioned how they had either sought or intended to seek the funds for the treatment if needed, Vanessa and Sadia had a different opinion about the whole idea of seeking funds. Vanessa says:

*"If we were in a position where we couldn't fund it then, I won't look at doing it anyway, because of the practicalities of it. If you can't afford the funding for this, then could you afford a child anyway? So, I think that would put a stop to that, if we didn't have the money" (Vanessa, 40yrs, British, 1<sup>st</sup> attempt)*

And Sadia says:

*I wouldn't ask for anyone else's financial support, I just wouldn't. I probably wouldn't go through it if I didn't have the money (Sadia, 37yrs, British, 1<sup>st</sup> attempt)*

Contrary to Vanessa and Sadia's convictions about seeking funds, Barbara and Racheal felt very strongly about it and the heights they would go to seek the funds as illustrated in the following:

*"I would go as far as getting a loan from the bank, I would get a loan, I would ask family or friends, I would do anything..." (Barbara, 41yrs, British, 1<sup>st</sup> attempt)*

*"If I really wanted it, and I had to get an extra job, then yeah, I would do that. I'd do anything really." (Rachel, 40yrs, British, 1<sup>st</sup> attempt)*

Within the Nigerian cohort some women were of the opinion that it was their **husband's responsibility** to fund the treatment, probably due to the cultural connotations associated with the man being the head of the home.

*"Ah! It's my husband now, he is the one that will pay for it, after all he is the man of the house" (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

*"...who else can I turn to if not my husband? He is the one that will pay for it now. It is not easy, but God would help him" (Helen, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

### 5.7. Summary

This chapter has presented data on the affordability of ART in both the UK and Nigeria. The purpose of the analysis was to identify whether or not ART treatment in the UK or Nigeria, is affordable to the households of the patients seeking treatment. This was done using three different measures of affordability: catastrophic expenditure, subjective financial well-being and WHO/HAI method.

Key findings on the cost burden/affordability of the treatment and the perceptions and funding patterns exhibited by infertile women in both cohorts are:

1. None of the UK households incurred catastrophic expenditure as a result of funding the treatment. However, the Nigerian households incurred catastrophic expenditures from funding the treatment, using their annual income and expenditure as reference points.
2. Majority of the UK respondents reported 'moderately' having enough money to meet their treatment needs and annual income was the significant predictor. However, majority of the Nigerian respondent reported mostly having enough money to meet their treatment needs, but annual income had no relationship.
3. The lowest paid unskilled government worker in the UK requires approximately two months and four days wages to purchase a standard IVF treatment cycle. In contrast, in Nigeria, this equated to about three years and three months wages.
4. Sub-fertile women in both cohort had similar worries about funding the treatment.
5. Within both cohorts, funds were sought in various ways. These include loans, savings, contributions, extra work/overtime and a few fortunate enough received the funds as gifts from family and relatives.



**CHAPTER 6:**  
**SOCIAL SUPPORT**  
**&**  
**QUALITY OF LIFE**

## **CHAPTER 6: THE ROLE AND EFFECT OF SOCIAL SUPPORT IN WOMEN**

### **ACCESSING ART**

#### **6.1: INTRODUCTION**

This chapter presents the results describing the social support behaviours of the study participants as well as the impact on their quality of life. This chapter would answer two of the research questions posed, which are:

3. Does social support moderate the relationship between perceived stress and quality of life, and, what are the social support behaviours exhibited by the women in both countries and how does social support contribute to how women cope?

4. What socio-demographic factors predict quality of life of sub-fertile women in both countries, and to what extent is the quality of life experienced by women in both countries affected by funding the treatment?

#### **6.2 SOCIAL SUPPORT**

The difference in support availability and satisfaction between the UK and Nigerian women is illustrated in Table 6.1a & b. To better capture which items were reported to a greater extent by the population, proportions reporting 'no-one', 'one person' and '6-9 people' are presented in this section.

##### ***UK Cohorts***

14.1% of women reported that they had 'no one' to console them when they were very upset, while 10% reported that they had 'no one' to make them feel relaxed when they were under pressure. Only one person reported that she had 'no one' to care about her regardless of what was happening to her and she was fairly dissatisfied with it.

On the items in which only one person was recorded as the sole source of support, 60% of the women recorded their husband/partner, 30% recorded a family member (usually the mother or sister) and 10% reported a friend or colleague.

37.5% reported that they had more than six people to count on when they were in need of help, while 26.6% of the women had over six people who accepted both their best and worst points.

### ***Nigerian Cohorts***

25% of women reported that they had 'no one' to count-on to help them feel better when they were generally down in the dumps and an equal percentage had 'no one' to help them feel more relaxed under pressure. Only one participant reported having 'no one' to care for her regardless of what's happening, and an equal number had 'no one' who accepted 'her' totally including best and worst points.

On the items in which only one person is reported to be available for support, 40% of the women indicated that their husband/partner was the only source of support, 30% recorded 'God' as their sole source of support, 13% recorded a parent, 12% reported a sibling, 3% recorded a friend and 2% a spiritual adviser (such as a pastor or Imam).

On questions regarding the number of people that can be counted on to be dependable when in need of help and can help 'you' feel relaxed when under pressure, no woman reported up to six people. Also, no woman reported having up to six people to console her when she was very upset.

### ***Comparison of both cohorts***

Spearman's rho was used to determine the correlation between the two scores (Number/availability & Satisfaction) of the social support questionnaire. There was a moderate positive correlation observed between the two subscales ( $r_s=0.429$ ,  $p<.001$ ). This is comparable to Saranson et al (1987) that reported a moderate positive correlation of both scores in a sample of 182 university students ( $r_s=0.33$ ,  $p<.001$ ) (Sarason et al., 1987a).

A Mann-Whitney U test was conducted to determine the difference between UK and Nigerian cohorts, in terms of their availability and satisfaction with social support. The Mann-Whitney test was used because of the ordinal scale and skewed distribution of the SSQ data. Results of the analysis indicated that availability of social support was significantly greater for UK women (Mdn=3) than for Nigerian women (Mdn=1.2),  $U=529.0$ ,  $p=0.001$ ,  $r=0.58$ . However, the test indicated that the satisfaction with social support was the same between UK women (Mdn=5.7) and Nigerian women (Mdn=5.3),  $U=1470.0$ ,  $p=0.27$ ,  $r=0.10$ .

Additionally, there was no difference between availability ( $U=486.5$ ,  $p=0.96$ ) of, or satisfaction ( $U=425.5$ ,  $p=0.36$ ) with social support, between NHS-funded and Self-funded UK women.

Table 6.1a: Social support availability scores (SSQ\_N) for the UK and Nigerian cohorts

Item	Description	No one n (%)		1 Person Only n (%)		2-5 people n (%)		6-9 people n (%)	
		NIG	UK	NIG	UK	NIG	UK	NIG	UK
	<b>Whom can you really count on:</b>								
<b>1a</b>	To be dependable when you need help?	5 (9.6)	-	11 (21.2)	3 (4.7)	36 (69.2)	37 (57.8)	-	24 (37.5)
<b>2a</b>	To help you feel more relaxed when you are under pressure	13 (25.0)	7 (10.9)	21 (40.4)	13 (20.3)	18 (34.6)	36 (56.3)	-	8 (12.5)
<b>3a</b>	Who accepts you totally, including both your worst and your best points?	1 (1.9)	2 (3.1)	36 (69.2)	15 (23.4)	14 (26.9)	29 (45.3)	1 (1.9)	17 (26.6)
<b>4a</b>	To care about you, regardless of what is happening to you?	1 (1.9)	1 (1.6)	28 (53.8)	12 (18.8)	22 (42.3)	35 (54.7)	1 (1.9)	15 (23.4)
<b>5a</b>	To help you feel better when you are feeling generally down-in-the dumps	13 (25.0)	4 (6.3)	29 (55.8)	13 (20.3)	9 (17.3)	34 (53.1)	1 (1.9)	12 (18.8)
<b>6a</b>	To console you when you are very upset?	11 (21.2)	9 (14.1)	23 (44.2)	12 (18.8)	18 (34.6)	36 (56.3)	-	6 (9.4)

Table 6.1b: Social support satisfaction scores (SSQ\_S) for Nigeria &amp; UK cohorts

Item	Description	Very Dissatisfied n (%)		Fairly dissatisfied n (%)		A little dissatisfied n (%)		A little satisfied n (%)		Fairly satisfied n (%)		Very satisfied n (%)	
		NIG	UK	NIG	UK	NIG	UK	NIG	UK	NIG	UK	NIG	UK
<b>1b</b>	How satisfied are you?	2 (3.8)	-	-	-	3 (5.8)	1 (1.6)	2 (3.8)	3 (4.7)	15 (28.8)	22 (34.4)	30 (57.7)	38 (59.4)
<b>2b</b>		4 (7.7)	2 (3.1)	5 (9.6)	4 (6.3)	2 (3.8)	3 (4.7)	3 (5.8)	-	14 (26.9)	16 (25.0)	24 (46.2)	37 (57.8)
<b>3b</b>		-	-	1 (1.9)	1 (1.6)	-	1 (1.6)	3 (5.8)	2 (3.1)	17 (32.7)	25 (39.1)	31 (59.6)	33 (51.6)
<b>4b</b>		-	-	-	1 (1.6)	-	1 (1.6)	4 (7.7)	2 (3.1)	18 (34.6)	19 (29.7)	30 (57.7)	40 (62.5)
<b>5b</b>		7 (13.5)	2 (3.1)	1 (1.9)	1 (1.6)	5 (9.6)	4 (6.3)	1 (1.9)	7 (10.9)	11 (21.2)	14 (21.9)	27 (51.9)	35 (54.7)
<b>6b</b>		6 (11.5)	2 (3.1)	2 (3.8)	1 (1.6)	2 (3.8)	2 (3.1)	4 (7.7)	10 (15.6)	9 (55.8)	18 (28.1)	29 (55.8)	30 (46.9)

### **6.3. QUALITY OF LIFE**

#### ***UK Cohorts***

An item-by-item evaluation of the WHOQOL-BREF observed that 25% of the women within this cohort evaluated their overall quality of life as 'very good', 51.6% as 'good', 17.2% as 'neither poor nor good' and 6.3% as poor. No one evaluated their quality of life as 'very poor'. On the overall question of how satisfied the women are with their health, 18.8% of the women reported that they were 'very satisfied', 45% were 'satisfied', 15.6% were 'neither satisfied nor dissatisfied', 17.2% were dissatisfied, and 3.1% were 'very dissatisfied' with their health (Table 6.2). These results could be attributed to the sub-fertility diagnosis of these women, and their interpretation of the question in regard to that diagnosis.

#### ***Nigerian Cohorts***

An item-by-item analysis of the scale observed that 9.6% of the women within this cohort evaluated their overall quality of life as 'very good', 50% as 'good', 32.7% as 'neither poor nor good' and 7.7% as poor (Table 6.2). No one evaluated their quality of life as 'very poor'. On the analysis of how satisfied the women were with their health, 5.8% of the women reported that they were 'very satisfied', 50% were 'satisfied', 26.9% were 'neither satisfied nor dissatisfied', 11.5% were dissatisfied, and 5.8% were 'very dissatisfied' with their health.

#### ***Comparison of both cohorts***

An independent t-test was conducted to compare the QOL domain scores for the UK and Nigerian cohorts. There were no significant differences in the physical, psychological and overall perceived health domains of UK and Nigerian women. However, there was significant differences in the social, environmental and overall QOL domains between the UK and Nigerian women as shown in Table 6.3. The highest average score of satisfaction was found in the environmental domain in both countries, while the lowest was found in the physical domain.

Table 6.2: Item-by-item distribution of responses in the WHOQOL-BREF scores in both countries, n (%)

		<b>Very poor</b>		<b>Poor</b>		<b>Neither poor nor good</b>		<b>Good</b>		<b>Very good</b>	
		<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>
<b>1</b>	How would you rate your quality of life?	-	-	4 (7.7)	4 (6.3)	17 (32.7)	11 (17.2)	26 (50.0)	33 (51.6)	5 (9.6)	16 (25.0)
		<b>Very dissatisfied</b>		<b>Dissatisfied</b>		<b>Neither satisfied nor dissatisfied</b>		<b>Satisfied</b>		<b>Very satisfied</b>	
		<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>
<b>2</b>	How satisfied are you with your health?	3 (5.8)	2 (3.1)	6 (11.5)	11 (17.2)	14 (26.9)	10 (15.6)	26 (50.0)	29 (45.3)	3 (5.8)	12 (18.8)
		<b>Not at all</b>		<b>A little</b>		<b>A moderate amount</b>		<b>Very much</b>		<b>An extreme amount</b>	
		<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>
<b>3</b>	To what extent do you feel pain prevents you from doing what you need to do?	34 (65.4)	37 (57.8)	7 (13.5)	19 (29.7)	6 (11.5)	5 (7.8)	3 (5.8)	3 (4.7)	2 (3.8)	-
<b>4</b>	How much do you need any medical treatment to	30 (57.7)	45 (70.3)	5 (9.6)	10 (15.6)	6 (11.5)	3 (4.7)	11 (21.2)	6 (9.4)	-	-

	function in daily life?										
<b>5</b>	How much do you enjoy life?	6 (11.5)	9 (14.1)	22 (42.3)	30 (46.9)	18 (34.6)	22 (34.4)	3 (4.7)	6 (11.5)	-	-
<b>6</b>	To what extent do you feel your life to be meaningful?	11 (21.2)	13 (20.3)	23 (44.2)	31 (48.4)	13 (25.0)	11 (17.2)	4 (7.7)	7 (10.9)	1 (1.9)	2 (3.1)
		<b>Not at all</b>		<b>A little</b>		<b>A moderate amount</b>		<b>Very much</b>		<b>Extremely</b>	
		<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>
<b>7</b>	How well are you able to concentrate?	-	-	2 (3.8)	7 (10.9)	18 (34.6)	25 (39.1)	32 (61.5)	30 (46.9)	-	2 (3.1)
<b>8</b>	How safe do you feel in your daily life?	-	-	1 (1.9)	2 (3.1)	5 (9.6)	9 (14.1)	44 (84.6)	41 (64.1)	2 (3.8)	12 (18.8)
<b>9</b>	How healthy is your physical environment?	-	-	-	-	7 (13.5)	15 (23.4)	43 (82.7)	37 (57.8)	2 (3.8)	12 (18.8)
		<b>Not at all</b>		<b>A little</b>		<b>Moderately</b>		<b>Mostly</b>		<b>Completely</b>	
		<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>	<b>NIG</b>	<b>UK</b>
<b>10</b>	Do you have enough energy for everyday life?	1 (1.9)	-	1 (1.9)	3 (4.7)	11 (21.2)	23 (35.9)	33 (63.5)	27 (42.2)	6 (11.5)	11 (17.2)



<b>11</b>	Are you able to accept your bodily appearance?	1 (1.9)	3 (4.7)	2 (3.8)	6 (9.4)	16 (30.8)	18 (28.1)	23 (44.2)	27 (42.2)	10 (19.2)	10 (15.6)
<b>12</b>	Have you enough money to meet your needs?	14 (26.9)	4 (6.3)	13 (25.0)	4 (6.3)	7 (13.5)	23 (35.9)	15 (28.8)	18 (28.1)	3 (5.8)	15 (23.4)
<b>13</b>	How available to you is the information that you need in your day-to-day life?	-	-	1 (1.9)	2 (3.1)	31 (59.6)	18 (28.1)	20 (38.5)	29 (45.3)	-	15 (23.4)
<b>14</b>	To what extent do you have the opportunity for leisure activities?	3 (5.8)	-	17 (32.7)	16 (25.0)	15 (28.8)	23 (35.9)	15 (28.8)	20 (31.3)	2 (3.8)	5 (7.8)
		<b>Very poor</b>		<b>Poor</b>		<b>Neither poor nor good</b>		<b>Good</b>		<b>Very good</b>	
		NIG	UK	NIG	UK	NIG	UK	NIG	UK	NIG	UK
<b>15</b>	How well are you able to get around?	-	-	2 (3.8)	3 (4.7)	12 (23.1)	6 (9.4)	34 (65.4)	17 (26.6)	4 (7.7)	38 (59.4)
		<b>Very dissatisfied</b>		<b>Dissatisfied</b>		<b>Neither satisfied nor dissatisfied</b>		<b>Satisfied</b>		<b>Very satisfied</b>	
		NIG	UK	NIG	UK	NIG	UK	NIG	UK	NIG	UK
<b>16</b>	How satisfied are you with your sleep?	4 (7.7)	4 (6.3)	5 (9.6)	7 (10.9)	7 (13.5)	14 (21.9)	32 (61.5)	34 (53.1)	4 (7.7)	5 (7.8)

<b>17</b>	How satisfied are you with your ability to perform your daily living activities?	-	-	2 (3.8)	-	7 (13.5)	14 (21.9)	41 (78.8)	34 (53.1)	2 (3.8)	16 (25.0)
<b>18</b>	How satisfied are you with your capacity for work?	-	1 (1.6)	1 (1.9)	-	7 (13.5)	14 (21.9)	44 (84.6)	39 (60.9)	-	10 (15.6)
<b>19</b>	How satisfied are you with yourself?	-	2 (3.1)	8 (15.4)	4 (6.3)	6 (11.5)	11 (17.2)	33 (63.5)	33 (51.6)	5 (9.6)	14 (21.9)
<b>20</b>	How satisfied are you with your personal relationships?	-	-	6 (11.5)	4 (6.3)	9 (17.3)	9 (14.1)	37 (71.2)	31 (48.4)	-	20 (31.3)
<b>21</b>	How satisfied are you with your sex life?	7 (13.5)	6 (9.4)	10 (19.2)	6 (9.4)	15 (28.8)	17 (26.6)	17 (32.7)	22 (34.4)	3 (5.8)	13 (20.3)
<b>22</b>	How satisfied are you with the support you get from your friends?	3 (5.8)	-	14 (26.9)	2 (3.1)	13 (25.0)	23 (35.9)	18 (34.6)	26 (40.6)	4 (7.7)	13 (20.3)
<b>23</b>	How satisfied are you with the conditions of your living place?	-	-	1 (1.9)	-	10 (19.2)	10 (15.6)	37 (71.2)	24 (37.5)	4 (7.7)	30 (46.9)
<b>24</b>	How satisfied are you with your access to health services?	2 (3.8)	-	5 (9.6)	3 (4.7)	19 (36.5)	12 (18.8)	24 (46.2)	27 (42.2)	2 (3.8)	22 (34.4)
<b>25</b>	How satisfied are you with your transport	3 (5.8)	1 (1.6)	6 (11.5)	3 (4.7)	10 (19.2)	5 (7.8)	29 (55.8)	31 (48.4)	4 (7.7)	24 (37.5)

		Never		Seldom		Quite often		Very often		Always	
		NIG	UK	NIG	UK	NIG	UK	NIG	UK	NIG	UK
<b>26</b>	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	4 (7.7)	2 (3.1)	21 (40.4)	19 (29.7)	10 (19.2)	31 (48.4)	11 (21.2)	10 (15.6)	6 (11.5)	2 (3.1)



Table 6.3: Distribution and differences in means and standard deviations of QOL scores

	UK	Nigeria	Mean Difference		
	M±SD	M±SD		95% CI	p-value
<b>Physical</b>	55.8±9.4	55.0±7.8	-0.8±1.6	-4.1, 2.4	0.62
<b>Psychological</b>	62.7±11.8	61.6±9.4	-1.0±2.0	-5.0, 2.9	0.61
<b>Social</b>	69.3±20.2	56.3±17.0	-12.9±3.5	-19.9, -5.9	<0.001
<b>Environmental</b>	74.1±13.6	62.5±8.6	-11.5±2.1	-15.6, -7.4	<0.001
<b>Q1</b>	3.9±0.8	3.6±0.7	-0.3±0.2	-0.6, -0.04	0.03
<b>Q2</b>	3.6±1.1	3.4±0.9	-0.2±0.2	-0.5, 0.2	0.28

Q1= Overall QOL, Q2= Overall health, CI= Confidence interval, M= Mean, SD=Standard Deviation

### 6.3.1. Socio-demographic predictors of quality of life

A standard linear multiple regression (method enter) was applied to calculate the individual contribution of the socio-demographic and fertility variables to each domain of the WHOQOL-BREF. The model included age, educational level, marital status, duration of subfertility, type of ART, source of funding, number of attempts and monthly expenditure as independent variables. These particular independent variables were selected because they represent important demographic variables and have been widely reported in several studies (Fekkes et al., 2003, Lau et al., 2008, Chachamovich et al., 2010, Ragni et al., 2005).

The results of the regression analysis are presented in Table 6.4a for the UK cohorts and 6.4b for Nigerian cohorts.

#### *UK Cohorts*

After adjusting for the other covariates in the model, age ( $\beta=.31$ ) was only significantly associated with physical quality of life, with an increase in age associated with an increase in physical quality of life scores (Table 6.4a). Similarly, annual income was also relevant, predicting the scores in two domains; physical ( $\beta=.29$ ) and environmental ( $\beta=.26$ ). Finally, duration of infertility was negatively associated with psychological quality of life, and based on how this variable was scored, a shorter duration of infertility (<5years) was associated with better psychological quality of life, than higher durations. Equally significantly predictive of psychological quality of life was educational level ( $\beta=.32$ ), with

a higher educational level associated with better psychological quality of life. Educational level was equally shown to be positively associated with environmental quality of life, however, this did not reach statistical significance.

### ***Nigerian Cohorts***

After adjusting for the other covariates in the model, cause of subfertility ( $\beta=.35$ ) was significantly associated with physical quality of life. Additionally, annual income was associated with social ( $\beta=.42$ ) and environmental quality of life ( $\beta=.41$ ) (Table 6.4b).

Table 6.4a: Multiple regression for each WHOQOL-BREF domain in UK women (n=64)

Variables	DOM1			DOM2			DOM3			DOM4		
	B	SE B	$\beta$	B	SE B	$\beta$	B	SE B	$\beta$	B	SE B	$\beta$
Age	.69	.27	<b>.31*</b>	.17	.35	.06	.73	.62	.15	.26	4.2	.08
Educational level	1.02	.74	.18	2.25	.96	<b>.32*</b>	1.43	1.69	.12	2.05	1.14	.25
Marital status	-4.20	2.37	-.21	-4.73	3.07	-.19	-5.86	5.41	-.14	-4.16	3.65	-.15
Duration of subfertility	-1.20	.88	-.18	-2.79	1.14	<b>-.33*</b>	.77	2.01	.05	-1.79	1.35	-.18
Source of funding	3.98	2.32	.21	2.14	3.01	.09	7.57	5.29	.19	.57	3.57	.02
Number of attempts	-1.20	1.66	-.09	1.23	2.16	.07	2.43	3.80	.08	.96	2.56	.05
Annual income	2.98	1.31	<b>.29*</b>	1.86	1.70	.15	5.59	3.00	.26	3.79	2.02	<b>.26*</b>
<b>Model R<sup>2</sup>, F, p-value</b>		<b>R<sup>2</sup>=0.24, F=2.52, p=0.02</b>			<b>R<sup>2</sup>=0.183, F=1.79, p=0.11</b>			<b>R<sup>2</sup>=0.13, F=1.23, p=0.29</b>		<b>R<sup>2</sup>=.126, F=1.15, p=0.34</b>		

\* Correlation is significant at the 0.05 level (2-tailed), SE- Standard error,  $\beta$  - Regression coefficient, DOM1-Physical domain, DOM2- Psychological domain, DOM3- Social domain, DOM4-Environmental domain

Table 6.4b: Multiple regression for each WHOQOL-BREF domain in Nigerian women (n=52)

Variables	DOM1			DOM2			DOM3			DOM4		
	B	SE B	$\beta$	B	SE B	$\beta$	B	SE B	$\beta$	B	SE B	$\beta$
Age	.04	.22	.04	.27	.28	.20	.56	.47	.23	.26	.25	.21
Educational level	-.41	.66	-.09	.68	.86	.13	.78	1.44	.08	1.04	.76	.22
Marital status	4.55	3.83	.17	7.73	5.01	.24	8.75	8.32	.15	2.91	4.38	.10
Duration of subfertility	3.64	2.63	.21	1.74	3.44	.08	4.20	5.72	.11	-1.16	3.01	-.06
Cause of subfertility	1.92	.87	<b>.35*</b>	1.04	1.13	.16	1.01	1.88	.08	1.11	.99	.19
Number of attempts	-3.31	3.00	-.16	1.40	3.92	.05	-8.88	6.51	-.19	-.43	3.43	-.02
Annual income	.69	1.23	.09	.27	1.61	.03	7.07	2.67	<b>.42*</b>	3.43	1.41	<b>.41*</b>
<b>Model R<sup>2</sup>, F, p-value</b>	<b>R<sup>2</sup>= 0.222 F=, 1.79 p=0.11</b>			<b>R<sup>2</sup>=0.081 F=0.55 p=0.79</b>			<b>R<sup>2</sup>=0.216 F=1.73 p=0.12</b>			<b>R<sup>2</sup> =0.140 F=1.02 p=0.43</b>		

\* Correlation is significant at the 0.05 level (2-tailed), SE- Standard error,  $\beta$  - Regression coefficient, DOM1-Physical domain, DOM2- Psychological domain, DOM3- Social domain, DOM4-Environmental domain



#### 6.4.: THE EFFECT OF FUNDING THE TREATMENT ON QUALITY OF LIFE (QUALITATIVE)

The views of the women were also sought on the effects of the treatment costs to their quality of life. The results from this theme was used to answer the second qualitative research objective of this study: “to what extent does the quality of life experienced by women in both countries affected by funding the treatment?” When asked if they felt the cost of the treatment might affect their household expenditures in the upcoming months, the views expressed by some of the UK women were **not much effects**, as illustrated by the following:

*“but we are fortunate enough, we are sort of both in jobs where we have got, sort of reasonably good jobs, so it wouldn’t knock us down too much” (Sheree, 37yrs, British, 1<sup>st</sup> attempt)*

*“...it’s not, sort of, stopped us from doing what we normally do. It’s not stopped us generally socialising...” (Anna, 37yrs, British, 3<sup>rd</sup> attempt)*

This sub-theme was also exhibited by a few Nigerian women, and more importantly women on their second cycle of ART were asked about this. The responses from two participants were:

*“it’s something we had planned for a long time ago, and we had started gathering the money some time ago, so, it wouldn’t really be a financial strain for us.” (Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

*“I think we’re quite lucky, and that’s how I’m trying to look at it, that you know, compared to other people, this is nothing and we can do it, particularly because we both have good jobs” (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

Furthermore, within both cohorts, a few participants mentioned the fact that the changes to their quality of life might not necessarily be in terms of the financial aspects, but more on the **strain to the relationship**. Within the UK cohort, this is illustrated below:

*“...we’ve just been working really hard to pay for it, so we haven’t seen each other much, [James] has been away quite a lot doing the over time, so it has had a lot of stress on our relationship” (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

*“I think it changes quality of life in terms of trying to conceive, not really financially, although that’s also part of it. It’s more about the stress it puts on our relationship as a couple” (Paulette, 44yrs, British 1<sup>st</sup> attempt)*

Similarly, within the Nigerian cohort the **strain on the relationship** was observed by some of the Nigerian women and was exhibited as fears towards the unpredictable reactions of their husbands to an unsuccessful treatment. Examples include:

*“...if this treatment does not work, my husband travels out a lot, he might even travel and not come back. Me, I cannot remain like this...” (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

*“You know how men are, when they start spending so much on you, when they are writing their will, they will be calculating those things. My husband would say, ‘this is how this woman has been wasting my money, this is what I’ve been spending my money on’...” (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

Once the decision is made to pursue treatment by most couples, significant adjustments tend to be made to their lifestyles. Participants widely described the effects funding the treatment had on them in relation to **changes in habits** and **opportunity costs** they had to implement to help with saving towards the treatment. Examples among the UK cohorts include:

*“I suppose we don’t go out as much, don’t spend as much money on like the theatre or going out for food but then, there all kind of luxuries anyways. I won’t be able to get a new car” (Sadia, 37yrs, Nigerian, 1<sup>st</sup> attempt)*

*“It affects job choices, it affects everything, you know, whether you should move to a new house or not, particularly because of the one free cycle you tend to have to think about what if it doesn’t work” (Barbara, 41yrs, British, 1<sup>st</sup> attempt)*

*"I'm at the moment paying all the bills, and the mortgage, so I guess, thinking about quality of life, its more just not being able to have things that kind of would be needed at some point, and also missing out on I guess social life, which would help to kind of de-stress you sometimes." (Fiona, 36yrs, British, 2<sup>nd</sup> attempt)*

Similar views were shared by a few Nigerian women, where the fertility treatment supersedes other aspects of their lives, which in some gets postponed or dismissed entirely in others:

*"...we were looking at the money like, we may not be able to do anything else oh! Some other projects were suspended to raise it, but we knew that the cost of doing this would cause the suspension to those other ones, because this one is a capital project for me" (Onyiye, 39yrs, Nigerian, 1<sup>st</sup> attempt)*

For others, it was difficult to concentrate on long-term goals while recovering from procedures and dealing with mood fluctuations, as a result of her treatment and so she had them cancelled.

*"I started doing my masters, but I had to stop it because I could not concentrate. Juggling between all the appointments, recovering from the first hyper-stimulation I had and all the mood swings, I just had to stop it oh" (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

Some UK participants described how these opportunity costs to their quality of life resulted in the modification and in some cases cancellations to **holiday plans**:

*"...even booking holidays and things like that, that you're going to spend money on or life choices, you know, it goes through your mind whether you should, or you shouldn't." (Rachel, 40yrs, British, 1<sup>st</sup> attempt)*

*"It's obviously put a strain on things we can do, because we've not obviously been able to have a holiday this year, because of saving up" (Sheree, 37yrs, British, 1<sup>st</sup> attempt)*

*"I've heard it's about 3-4 thousand, so you know, that's a, that's a holiday, that's what I tend to spend anyway on holidays in a year. So, it would affect that. You know, I'd have to choose between my holiday or my treatment." (Sarah, 41yrs, British, 1<sup>st</sup> attempt)*

Although Sarah agreed funding the treatment would have an effect on her social quality of life in terms of having to go on holidays, she felt she would not let it affect her overall quality of life by adding:

*“...we worked our socks off for our money, and I'm not prepared to spend it all on this because then, we'll have no, you know, we'll have no life” (Sarah, 41yrs, British, 1<sup>st</sup> attempt)*

For most of the Nigerian participants the desperation to have a child outweighed the effects such costs would have on their household and quality of life. None of the participants who could not afford the treatment decided to forfeit it. Although they did not have the financial means to fund the treatment, they were willing to suffer financial hardship and to **cope with it** as illustrated by these examples:

*“I don't care how much it costs, we'll find the money and pay it. As long as we are able to have a child from it, that is all that matters to me” (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

*“...by the time the money is complete, they would do the IVF for me. Then if there's any money left we can see what we would use to eat.” (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

*“...but there's nothing you can do when you really need something. You have to accept anything that comes out of it, including the cost” (Margaret, 36yrs, Nigerian, 1<sup>st</sup> attempt)*

Unlike a few of the UK cohorts who had established that they would rather forfeit the treatment than incur debt or outrageous expenditures, a few of the Nigerian participants were unperturbed about incurring catastrophic expenditures due to their desperation to have a child. Could this be due to impeccable financial support from family and friends? The social support behaviours exhibited by the women and the role social support plays with how these women cope with ART related stress could be determined by the way they communicate their treatment and infertility issues with their family and broader social networks, which is the focus of section 6.5.

## **6.5. RELATIONSHIP BETWEEN PSYCHOLOGICAL DISTRESS AND SOCIAL SUPPORT VARIABLES**

The association between social support and psychological distress (determined by the BAI & PSS), was examined, using the Spearman's Rho correlation (see Table 6.5)

### ***UK Cohort***

The results from the correlation matrix (Table 6.5) presents the relationship between anxiety and number of available social support and suggests no correlation between the two variables [ $r_2=0.03$ ,  $n=64$ ,  $p=0.78$ ]. The correlation between anxiety and satisfaction with social support equally suggests no correlation [ $r_2=-0.11$ ,  $n=64$ ,  $p=0.38$ ] between both variables. The correlation analysis between perceived stress and number of available social support recorded no association between both variables [ $r_2=-0.17$ ,  $n=64$ ,  $p=0.17$ ], while the relationship between perceived stress and satisfaction with support recorded a weak negative correlation [ $r_2=-0.23$ ,  $n=64$ ,  $p=0.06$ ], however, this did not reach statistical significance.

### ***Nigerian Cohort***

The relationship between anxiety and number of social support was investigated and the results suggest no correlation between the two variables [ $r_2=-0.04$ ,  $n=52$ ,  $p=0.77$ ] (Table 6.5). The table equally shows no correlation between anxiety and satisfaction with social support [ $r_2=-0.18$ ,  $n=52$ ,  $p=0.19$ ]. The relationship between perceived stress and number of social support recorded a significant negative association between both variables [ $r_2=-0.28$ ,  $n=52$ ,  $p=0.04$ ], with high levels of perceived stress associated with low numbers of people available for support. The relationship between perceived stress and satisfaction with support recorded a significant negative correlation [ $r_2=-0.41$ ,  $n=52$ ,  $p<0.01$ ], with high perceived stress levels associated with low satisfaction with available support.

Table 6.5: Correlation matrix of all the scales and sub-scales used in this study

	<b>BAI</b>	<b>PSS</b>	<b>SSQ_N</b>	<b>SSQ_S</b>	<b>Q1<sup>a</sup></b>	<b>Q2<sup>b</sup></b>	<b>DOM1</b>	<b>DOM2</b>	<b>DOM3</b>	<b>DOM4</b>
<b>BAI</b>	1	.574**	.035	-.110	-.104	-.205	-.259*	-.203	.164	-.177
<b>p-value</b>		<0.01	0.78	0.38	0.41	0.10	0.04	0.10	0.19	0.16
<b>PSS</b>	.680**	1	-.171	-.236	-.158	-.145	-.139	-.184	-.043	-.106
<b>p-value</b>	<0.01		0.17	0.06	0.21	0.25	0.27	0.14	0.73	0.40
<b>SSQ_N</b>	-.042	-.284*	1	.386**	.085	.226	-.006	.106	.397**	.319*
<b>p-value</b>	0.77	0.04		<0.01	0.50	0.07	0.96	0.40	<0.01	0.01
<b>SSQ_S</b>	-.182	-.405**	.594**	1	.205	.234	.015	.031	.365**	.279*
<b>p-value</b>	0.19	<0.01	<0.01		0.11	0.06	0.90	0.80	<0.01	0.03
<b>Q1<sup>a</sup></b>	-.018	-.407**	.411**	.225	1	.477**	.250*	.366**	.281*	.429**
<b>p-value</b>	0.89	<0.01	<0.01	0.11		<0.01	0.05	<0.01	0.02	<0.01
<b>Q2<sup>b</sup></b>	-.534**	-.560**	.366**	.326*	.619**	1	.321*	.430**	.374***	.390**
<b>p-value</b>	<0.01	<0.01	<0.01	0.01	<0.01		0.01	<0.01	<0.01	<0.01
<b>DOM1</b>	.227	-.047	-.056	.133	.494**	.116	1	.376**	.128	.308*
<b>p-value</b>	0.11	0.74	0.69	0.34	<0.01	0.41		<0.01	0.32	0.01
<b>DOM2</b>	-.202	-.396**	.258	.440**	.112	.137	0.082	1	.453**	.461**
<b>p-value</b>	0.15	<0.01	0.06	<0.01	0.43	0.34	0.56		<0.01	<0.01
<b>DOM3</b>	-.105	-.421**	.509**	.580**	.316*	.230	.204	.237	1	.566**
<b>p-value</b>	0.45	<0.01	<0.01	<0.01	0.02	0.10	0.15	0.09		<0.01
<b>DOM4</b>	-.192	-.254	-.029	.198	.198	.247	.202	.248	.382**	1
<b>p-value</b>	0.17	0.07	0.84	0.16	0.16	0.07	0.15	0.07	<0.01	

Correlations above the diagonal are for UK cohorts, correlations below the diagonal (in blue) are for Nigerian cohorts.

\*\* Correlation is significant at the 0.01 level (2-tailed). \* Correlation is significant at the 0.05 level (2-tailed). BAI-Beck Anxiety Inventory, PSS-Perceived Stress Scale, SSQ\_N- Number of available support, SSQ\_S- Satisfaction with support, Q1<sup>a</sup>-How would you rate your quality of life? Q2<sup>b</sup>- How satisfied are you with your health? DOM1-Physical domain, DOM2-Psychological domain, DOM3- Social domain, DOM4-Environmental domain.

### 6.5.1. Relationship between perceived stress, social support and anxiety

The vast literature on the moderating effects of social support on perceived stress and anxiety (Cohen, 2004, Hyde et al., 2011, Thoits, 2011, Habif and Lahey, 1980) led the researcher to posit two hypotheses that would examine its role in this dataset. With the premise that high levels of perceived stress increase the risk for an individual to develop anxiety, the role of social support in moderating the effects of perceived stress on anxiety was examined.

**Hypothesis 1:** *Number of people available to support the woman moderates the relationship between perceived stress and anxiety, with a higher number of people available for support buffering the effects of perceived stress on anxiety.*

**Hypothesis 2:** *Satisfaction with available support moderates the relationship between perceived stress and anxiety, with higher satisfaction with support buffering the effects of perceived stress on anxiety.*

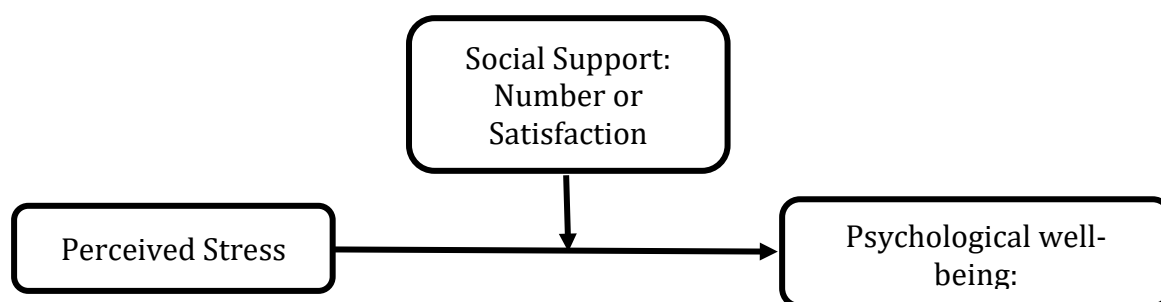


Figure 6.1: Proposed model of the relationship between perceived stress, social support and anxiety.

A moderated<sup>17</sup> multiple regression analysis was conducted to ascertain if social support (number or satisfaction) interacted to buffer/cushion the effects of perceived stress on anxiety levels in both cohorts. The moderation effect was assessed through the construction of an interaction term, composed of the predictor variable (perceived stress) multiplied by the moderator (social support number or satisfaction) variable. The product of perceived stress and social support number/satisfaction is not the interaction; instead, the perceived stress by social support number/satisfaction interaction is ‘carried by’ the multiplicative product of both variables.

<sup>17</sup> A moderator is “a variable that alters the strength of the relationship between a predictor variable and an outcome variable” (Pidgeon et al. 2014).

The equation necessary to assess the interactional hypothesis is presented below:

$$Y = B_1X_1 + B_2X_2 + B_3X_1X_2 + A$$

where

Y = the predicted value of the outcome variable

X<sub>1</sub> = the perceived stress variable

X<sub>2</sub> = the number of/ satisfaction with available social support

X<sub>1</sub>X<sub>2</sub> = the product of perceived stress and social support number/satisfaction variables

To help reduce issues of multicollinearity both the predictor variable and moderators were standardised/centred, and two regression models were developed. The first model investigated whether the number of available support moderated the relationship between perceived stress and anxiety, while the second model investigated whether satisfaction with support moderated the relationship between perceived stress and anxiety.

The development of the model was performed in three steps and is described briefly. In each model, the fertility variables (cause of subfertility, duration, number of attempts) were entered at step 1 as covariates to control for on the outcome variable. At step two, the standardised predictor and moderator were entered into the regression analysis simultaneously, and at step three, the interaction variable (product of predictor and moderator) was entered. The regression analysis was re-run at each step, and the results presented below.

### ***UK Cohort***

**Model 1:** At step 1, marital status, cause of subfertility, duration of subfertility and number of attempts, were entered into the regression equation as covariates to control for the effects of socio-demographic and fertility variables on the outcome variable, and the overall model was not significant,  $F(4, 57) = 1.20, p = 0.32$ . The model explained 7.8% of the variance in anxiety  $R^2 = 0.078$ . At step 2, after controlling for the effects of the socio-demographic and fertility variables, the centred perceived stress and number of available support were entered into the regression equation simultaneously, and the model was significant,  $F(6, 55) = 7.67, p < 0.001$ . Perceived stress and number of available support accounted for 45.6% of the variance in anxiety  $R^2 = 0.456, p < 0.001$ . At this step, perceived stress was a significant positive contributor to anxiety,  $\beta = 0.71, p < 0.001$ , indicating that



at a 1SD increase in perceived stress resulted in a 0.71 increase in anxiety. The number of available support at this step was a non-significant predictor of anxiety,  $\beta=0.12$ ,  $p=0.25$  (Table 6.6).

Table 6.6: Model 1 investigating the number of social support as a moderator of perceived stress and anxiety in the UK cohort

	$\beta$	<i>B</i>	<i>SE B</i>	<i>p</i>	95%CI for <i>B</i>
Constant		3.25	4.53	.47	[-5.83, 14.69]
Marital status	.05	1.13	1.89	.55	[-2.65, 4.50]
Cause of subfertility	.19	1.02	.66	.12	[-0.36, 2.30]
Duration of subfertility	.20	1.04	.67	.13	[-0.31, 2.39]
Number of attempts	-.05	-.54	1.35	.69	[-3.24, 2.16]
Constant		8.06	3.70	.03	[0.64, 15.49]
Perceived stress	0.71	5.04	0.82	<.01*	[3.40, 6.68]
No. of social support	0.12	0.89	0.78	.25	[-0.66, 2.44]
Constant		9.96	3.66	.01	[7.24, 20.38]
Perceived stress x No. of SS	0.23	1.95	0.85	.02*	[0.24, 3.67]

Note: No.= Number, SS = Social support. SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p<0.05$

At step 3, the perceived stress x number of available social support interaction was added to the regression equation, and the overall model was significant,  $F(7, 54) = 7.83$ ,  $p < 0.001$ . Consistent with the hypothesis, the perceived stress x number of available support interaction term was significantly predictive of anxiety levels, explaining an additional 4.8% of the variance ( $R^2 = 0.504$ ) in BAI scores,  $\Delta F(1, 54) = 5.24$ ,  $p = 0.02$ . Therefore, the predictive relationship between perceived stress and anxiety scores varied according to the number of available support.

To further explore the significant interaction effect of perceived stress x number of available support, a simple slope analysis was conducted to examine the exact nature of the conditionality that exists between anxiety levels and perceived stress scores. Using the 'Process Procedure for SPSS v.3 add-on, a comparison of high (+1SD), average (0) and low (-1SD) numbers of available support was calculated and assessed.

The analysis revealed that when the number of available social support was few,

perceived stress levels were significantly predictive of anxiety scores,  $\beta=0.19$ ,  $t(58) = 2.21$ ,  $p=0.03$ . For an average number of available social support, perceived stress was equally significantly predictive of anxiety levels  $\beta=0.69$ ,  $t(58) = 5.81$ ,  $p<.001$ , and at high numbers of available social support, perceived stress was still significantly predictive of anxiety scores.  $\beta=0.97$ ,  $t(58) = 5.61$ ,  $p<.001$ . The generated data for visualising the conditional effect of the focal predictor was used to plot the simple slope. The graphical representation of the interaction is displayed in Figure 6.2

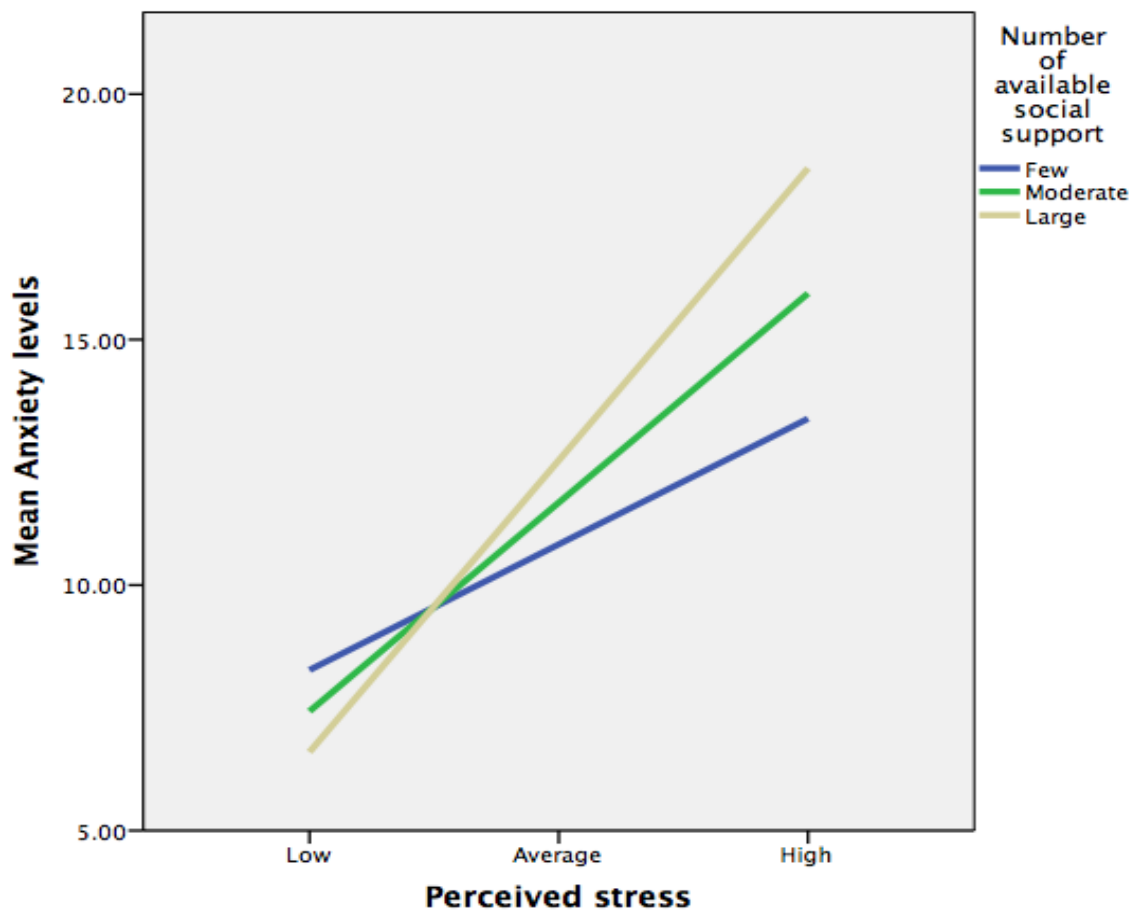


Figure 6.2: Number of available social support moderated the relationship between perceived stress and anxiety

As such, the nature of the interaction appeared to be that large numbers of available support had a more significant effect on anxiety levels than low or average. Thus, hypothesis 1 is accepted.

**Model 2:** Similarly, after controlling for the effects of socio-demographic and fertility variables, at step 2, the centred perceived stress and satisfaction with support were entered simultaneously into the regression model and the model was significant,  $F(2, 59) = 16.83, p < 0.001$ . At this step, perceived stress was a significant positive predictor of anxiety,  $\beta = 0.61, p < 0.001$  (Table 6.7), indicating that a 1 SD increase in perceived stress resulted in a 0.61 SD increase in anxiety. Satisfaction with available support at this step was a non-significant predictor of anxiety,  $\beta = -0.50, p = 0.64$ . At step 3 of the analysis, the satisfaction with support x perceived stress interaction term was added to the regression equation, and the overall model was significant,  $F(3, 58) = 11.03, p < 0.001$ . Inconsistent with the hypothesis, the satisfaction with support x perceived stress interaction term was not predictive of anxiety, explaining no further variance in scores on anxiety,  $\Delta F(1, 58) = 0.002, p = 0.96$ . Therefore, the predictive relationship between perceived stress and anxiety did not vary according to satisfaction with support.

Table 6.7: Model 2 investigating satisfaction with social support as a moderator between perceived stress and anxiety in the UK cohort

	$\beta$	<i>B</i>	SE <i>B</i>	95%CI for <i>B</i>	p-value
Constant		11.30	0.73	[9.83,12.77]	<.001
Perceived stress	.61	4.36	0.76	[2.83, 5.89]	<.001**
Satisfaction with SS	.05	0.35	0.76	[-1.17, 1.89]	0.64
Constant		11.29	0.77	[9.75, 12.83]	<.001
Perceived stress x Satisfaction SS	-.005	-.04	0.79	[-1.61, 1.55]	0.96

Note: SS= Social Support, SE- Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*\*  $p < 0.01$

### ***Nigerian Cohorts***

Similar moderating regression analysis as with the UK cohorts was performed on the dataset of the Nigerian cohorts, with the same hypothesis.

**Model 1:** At step 1, cause of subfertility, duration of subfertility, type of ART and number of attempts, were entered into the regression equation as covariates to control for the effects of fertility variables on the outcome variable, and the overall model was not significant,  $F(4, 47) = 1.79, p = 0.14$ . The model explained 13.3% of the variance in anxiety

$R^2=0.133$ . However, at this step, the duration of subfertility was significant  $\beta=.35$ ,  $p=0.02$ . Thus, duration of subfertility (0=<5years, 1=>5years) was significantly predictive of anxiety scores, such that women with subfertility durations exceeding 5years have greater anxiety scores than women with subfertility durations less than 5 years.

At step 2, the centred perceived stress and number of available support were entered simultaneously into the regression model, and the overall model was significant  $F(6, 45) = 9.75$ ,  $p < 0.001$ . Perceived stress and number of available support accounted for 56.5% of the variance in anxiety scores  $R^2 = 0.565$ ,  $p < 0.001$ . At this step, perceived stress was a significant positive contributor to anxiety,  $\beta=0.74$ ,  $p < 0.001$ , indicating that at a 1SD increase in perceived stress resulted in a 0.77 increase in anxiety. The number of available support at this step was equally a significant predictor of anxiety,  $\beta=0.25$ ,  $p=0.02$  (Table 6.8).

Table 6.8: Model 1 Investigating number of social support as a moderator between perceived stress and anxiety in the Nigerian cohort

	$\beta$	<i>B</i>	<i>SE B</i>	95%CI for <i>B</i>	p-value
Constant		16.35	7.63	[1.00, 31.71]	0.03
Duration of subfertility	.35	6.32	2.75	[0.78, 11.86]	0.02*
Cause of subfertility	.054	.30	.86	[-1.43, 2.04]	0.72
Type of ART	-.29	-4.82	2.72	[-10.29, 0.65]	0.09
Number of attempts	-.08	-1.69	2.94	[-7.61, 4.23]	0.56
Constant		14.35	5.64	[2.98, 25.72]	0.02*
Perceived stress	0.74	6.11	0.91	[4.27, 7.95]	<0.001**
No. of social support	0.25	2.05	0.90	[0.24, 3.86]	0.03*
Constant		14.93	5.65	[3.53, 26.32]	0.01
Perceived stress x No. of SS	0.13	0.62	0.56	[-0.51, 1.76]	0.27

No.-Number, SS-Social support, CI-Confidence intervals, SE-Standard error,  $\beta$ -Regression coefficient, \* $p < 0.05$ , \*\* $p < 0.01$

At step 3, the perceived stress x number of available social support interaction was added to the regression equation, and the overall model was significant,  $F(7, 44) = 8.58$ ,  $p < 0.001$ . Inconsistent with the hypothesis, the perceived stress x number of available support interaction term was not significantly predictive of anxiety, explaining no further

variance in scores on anxiety,  $\Delta F (1,44) = 1.22, p=0.27$ . Therefore, the predictive relationship between perceived stress and anxiety scores did not vary according to the number of available support.

**Model 2:** After controlling for the fertility variables, at step 2, the centred perceived stress and satisfaction with support were entered simultaneously into the regression model and the overall model was significant,  $F (2, 49) = 23.58, p < 0.001$ . Perceived stress and satisfaction with support accounted for 49% of the variance in anxiety. At this step, perceived stress was a significant positive predictor of anxiety,  $\beta = 0.77, p < 0.001$ , indicating that a 1 SD increase in perceived stress resulted in a 0.77 SD increase in anxiety. Satisfaction with available support at this step was a non-significant predictor of anxiety,  $\beta = -0.20, p = 0.11$  (Table 6.9).

Table 6.9: Model 2 investigating satisfaction with social support as a moderator between perceived stress and anxiety

	$\beta$	<i>B</i>	SE <i>B</i>	95%CI for <i>B</i>	p-value
Constant		12.65	0.83	[10.98, 14.32]	<0.001
Perceived stress	.77	6.36	0.96	[4.43, 8.29]	<0.001**
Support satisfaction	.19	1.56	0.96	[-.36, 3.50]	0.11
Constant		12.57	0.95	[10.66, 14.48]	<0.001
Perceived stress x Satisfaction with SS	-.02	-.17	0.93	[-2.03, 1.69]	0.85

SS-Social support, CI-Confidence intervals, \*\* $p < 0.01$ , SE-Standard error,  $\beta$ -Regression coefficient

At step 3 of the analysis, the satisfaction with perceived stress x satisfaction with support interaction term was added to the regression equation, and the overall model was significant,  $F (3, 48) = 15.43, p < 0.001$ . Inconsistent with the hypothesis, the perceived stress x satisfaction with support interaction term was non-significantly predictive of anxiety, explaining no further variance in scores on anxiety,  $\Delta F (1, 48) = 0.04, p = 0.85$ . Therefore, within the Nigerian cohort, the predictive relationship between perceived stress and anxiety did not vary according to satisfaction with available support.

### **6.5.2. Relationship between Social Support and Quality of Life variables**

The relationship between social support and QOL was assessed using the four domains of the WHOQOL-BREF scale and the two subscales of the SSQ-6. Association was investigated using Pearson product-moment correlation coefficient.

#### ***UK Cohorts***

Among the UK women in this study, a moderate positive correlation was observed between the number of available support and the social quality of life domain [ $r=.39$ ,  $n=64$ ,  $p<0.01$ ] and environmental quality of life [ $r=.32$ ,  $p=0.01$ ], with high numbers of people available for support associated with higher levels of social and environmental quality of life (see Table 6.5). Equally, significant positive correlations were observed between satisfaction with support and social quality of life [ $r=.36$ ,  $n=64$ ,  $p=.003$ ], while a weak positive correlation was observed between the environmental quality of life and satisfaction with social support [ $r=.28$ ,  $n=64$ ,  $p=.025$ ]. With increased satisfaction with available support associated with increased social and environmental quality of life (see Table 6.5).

#### ***Nigerian Cohorts***

Among the Nigerian women, there was a strong positive correlation between the number of available support and social quality of life [ $r=.53$ ,  $n=52$ ,  $p<.001$ ] (see Table 6.5), with low numbers of support associated with low levels of social quality of life and vice versa. Additionally, the number of available support was significantly associated with the psychological quality of life [ $r=.34$ ,  $n=52$ ,  $p=.015$ ], with high number of people available for support associated with better psychological quality of life, and vice versa. Satisfaction with social support was strongly positively associated with social quality of life [ $r=.53$ ,  $n=52$ ,  $p<.001$ ], with low satisfaction with social support associated with low levels of social quality of life. Additionally, a moderate positive correlation was observed between the psychological quality of life and the satisfaction with social support [ $r=.37$ ,  $n=52$ ,  $p=.008$ ] with low satisfaction with support associated with low psychological quality of life (see Table 6.5).

### **6.5.3. Relationship between Psychological distress and Quality of Life**

#### ***UK Cohorts***

The relationship between psychological distress (as measured by the BAI and PSS) and quality of life (WHOQOL-BREF) domains was investigated using Pearson product correlation coefficient. There was a weak negative correlation between the anxiety levels and physical quality of life [ $r = -.26$ ,  $n=64$ ,  $p=0.04$  (see Table 6.5), with high levels of anxiety associated with lower physical quality of life. There were no other significant associations between psychological well-being and quality of life domains within this cohort.

#### ***Nigerian Cohorts***

The relationship between psychological distress (as measured by the BAI and PSS) and quality of life (WHOQOL-BREF) domains was investigated using Pearson product correlation coefficient. There was a strong negative correlation between the anxiety levels and overall health [ $r = -.53$ ,  $n=52$ ,  $p<.001$ ] (See Table 6.5), with high levels of anxiety associated with lower overall health and vice versa. Additionally, moderate to strong negative correlations were observed between perceived stress and overall quality of life [ $r=-.41$ ,  $p<0.01$ ], overall health [ $r=-.56$ ,  $p<0.01$ ], psychological domain [ $r=-.39$ ,  $p<0.01$ ] and social domain [ $r=-.42$ ,  $p<0.01$ ] (see Table 6.5). High levels of perceived stress were associated with lower levels of overall quality of life, lower overall health, lower psychological and social quality of life.

### **6.5.4. Relationship between psychological distress, social support and quality of life**

Although this study provides evidence of a moderate to a strong positive correlation between social support and quality of life domains, the process by which it occurs is still ill-understood. The overwhelming evidence of the correlation coefficients (shown in Table 6.5) is not to be ignored. However, it is somewhat subjective and accounts for a relatively small proportion of the total variance. Given the same overall quality of life, different individuals evaluate the different aspects/domains to their quality of life differently and equally experience different stress levels. This could be as a result of (as is the case with most sub-fertile women), various biological, physical, psychological and situational factors, which interact in various intricate patterns to determine an

individual's state of psychological well-being (Wilcox, 1981, Lazarus, 1966, Lazarus and Opton Jr, 1966). Furthermore, as stated in the literature review, social support has received growing recognition as a variable that potentially moderates the stress → quality of life relationship (Wilcox, 1981) by protecting the individual from the influence of potentially stressful events (Cohen and Wills, 1985). Therefore, with the observation that sub-fertile women experience increased stress levels, the ability to mobilise support should be associated with less stress and improve quality of life. To explore this phenomenon further within this study, the following hypothesis was posited:

**Hypothesis 1:** *Social support number/satisfaction moderates the relationship between perceived stress and quality of life domains. Higher numbers of social support would buffer/cushion the effects of perceived stress on quality of life.*

**Hypothesis 2:** *Number of/satisfaction with available social support moderates the relationship between anxiety levels and quality of life domains. Higher satisfaction with available support would buffer/cushion the effect of anxiety on each quality of life domain.*

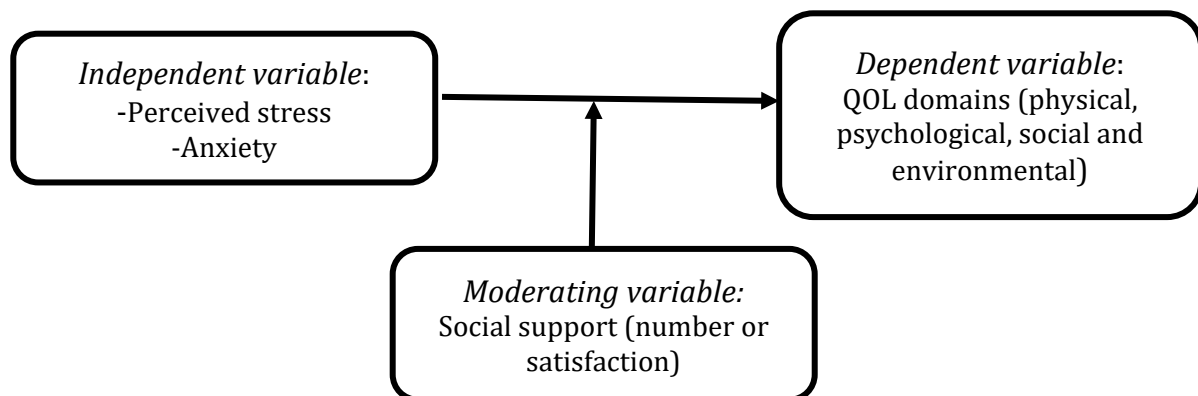


Figure 6.3: Graphical representation of the effect of perceived stress/ anxiety on quality of life domain

Quite similar to the interaction steps and models in section 6.5.1, a series of moderated multiple regression analysis were performed, in this case the quality of life domains (physical, psychological, social, environmental) were the outcome variables, the social support subscales were moderators, and the psychological distress variables (PSS & BAI) predictors. To test the hypothesis, the moderator and predictor variables were trichotomized (low, average and high). Regression models and interaction analyses that



were not significant ( $p>0.05$ ) ranged from 0.146 to 0.897. Table 6.10 and 6.11, shows the regression analysis for all the four domains of quality of life in both cohorts.

Table 6.10: Showing correlations (r) between variables and QOL domains, Beta, and R2 in the regression analysis for the UK cohort (n=64)

Variables	DOM1			DOM2			DOM3			DOM4		
	r	$\beta$	R <sup>2</sup>	r	$\beta$	R <sup>2</sup>	r	$\beta$	R <sup>2</sup>	r	$\beta$	R <sup>2</sup>
<b>Predictor variables</b>												
Anxiety (BAI)	-.24	-.21		-.18	-.13		.19	.22		-.14	-.08	
Number of support	.02	.06	.111	.10	.05	.083	.38	.30*	.284	.36	.26*	.213
Satisfaction with SS	-.06	-.12		.05	.02		.37	.24		.33	.21	
<b>Constant</b>												
Anxiety x SS Number	-.23	-.21	.136	-.05	.03	.083	-.16	-.06	.286	-.24	-.08	.217
<b>Constant</b>												
Anxiety x Satisfaction	-.16	-.09	.143	-.03	-.05	.086	-.06	-.10	.294	.26	.34*	.305
<b>Predictor variables</b>												
Perceived stress (PSS)	-.16	-.20		-.20	-.22		-.06	.10		-.14	-.04	
Number of support	.02	.04	.104	.13	.06	.110	.37	.32*	.240	.36	.26*	.211
Satisfaction with SS	-.06	-.14		.06	-.003		.37	.24		.33	.21	
<b>Constant</b>												
P. Stress x SS Number	-.14	-.09	.111	.00	.04	.112	.005	.06	.243	-.06	.005	.211
<b>Constant</b>												
P. Stress x Satisfaction	-.14	-.15	.128	.00	-.08	.117	.05	-.15	.257	.07	.08	.215

DOM1- Physical, DOM2- Psychological, DOM3- Social, DOM4- Environmental, SS-Social support, P- Perceived, \* $p < 0.05$

Table 6.11: Showing QOL domains, Beta, and R<sup>2</sup> in the regression analysis for the Nigerian cohort (n=52)

Variables	DOM1			DOM2			DOM3			DOM4		
	r	$\beta$	R <sup>2</sup>	r	$\beta$	R <sup>2</sup>	r	$\beta$	R <sup>2</sup>	r	$\beta$	R <sup>2</sup>
<b>Predictor variables</b>												
Anxiety (BAI)	.23	.16		-.20	-.12		-.10	-.02		-.19	-.12	
Number of support	-.05	-.12	.231	.25	.02	.236	.51	.30*	.464	-.03	-.24	.168
Satisfaction with SS	.13	.23		.44	.43*		.58	.37*		.19	.29	
<b>Interaction</b>												
Anxiety x SS Number	.21	.04	.232	-.01	.02	.236	-.11	-.03	.465	-.03	-.13	.181
<b>Interaction</b>												
Anxiety x Satisfaction	.22	.07	.236	.18	.08	.242	.05	-.03	.465	.27	.34*	.261
<b>Predictor variables</b>												
Perceived stress (PSS)	-.04	-.16		-.39	-.24		-.42	-.16		-.25	-.23	
Number of support	-.05	-.12	.224	.25	-.03	.262	.51	.27*	.481	-.03	-.28	.192
Satisfaction with SS	.13	.11		.44	.36*		.58	.30*		.19	.23	
<b>Interaction</b>												
P. Stress x SS Number	.19	.08	.229	-.02	.005	.262	-.09	.08	.485	.05	-.09	.197
<b>Interaction</b>												
P. Stress x Satisfaction	.24	.05	.230	.16	-.09	.266	.18	-.04	.486	.17	.19	.215

DOM1- Physical, DOM2- Psychological, DOM3- Social, DOM4- Environmental, SS-Social support, P- Perceived, \* $p < 0.05$

### 6.5.5. Interactions between Anxiety & Satisfaction with Social Support on environmental quality of life

Both models for the environmental quality of life domain in the UK and Nigerian cohort identified positive interactions between anxiety (BAI-scores) and satisfaction with social support (Table 6.10 & 6.11). This would be explored further in this section. The researcher chose not to exclude findings with a  $p < 0.2$  from the regression equation. Variance inflation Factor (VIF) was inspected for multicollinearity in each model, results were presented as  $R^2$  and standardised beta values.

#### UK Cohort

**Model 1:** At step 1, anxiety scores and satisfaction with social support were entered into the regression model, and the model was significant,  $F(2, 59) = 4.07, p = 0.02$ . Anxiety and satisfaction with social support accounted for 12.1% of the variance in environmental quality of life domain  $R^2 = 0.121, p = 0.02$ . At this step, satisfaction with social support was a significant positive contributor of environmental quality of life,  $\beta = 0.32, p = 0.01$ . Anxiety at this step was a non-significant negative contributor of environmental quality of life,  $\beta = -0.12, p = 0.38$  (Table 6.12).

Table 6.12: Multiple regression investigating satisfaction with social support as a moderator between anxiety and environmental quality of life

	$\beta$	B	SE B	95%CI for B	p-value
Constant		74.36	1.62	[71.12, 77.61]	<0.01
Anxiety	-0.10	-1.45	1.65	[-4.75, 1.85]	0.38
Social support Satisfaction	0.32	4.26	1.64	[0.98, 7.54]	0.01**
Constant		74.61	1.61	[71.39, 77.84]	<0.01
Anxiety x SS satisfaction	0.18	2.33	1.55	[-0.76, 5.44]	0.13

SS-Social Support, SE- Standard error,  $\beta$ -Regression coefficient, CI-Confidence interval, \*  $p < 0.05$

At step 2, the anxiety x satisfaction with social support interaction was added to the regression equation and the overall model was significant,  $F(3, 58) = 3.53, p = 0.02$ . The anxiety x social support satisfaction interaction term was predictive of environmental quality of life, explaining an additional 3.3% of the variance ( $R^2 = 0.033$ ),  $\Delta F(1, 58) = 2.27$ , although it did not reach theoretical statistical significance  $p = 0.13$ . Therefore, the

relationship between anxiety and environmental quality of life is not dependent on the satisfaction with available support.

However, because  $p < 0.2$  were not excluded from the regression, it was interesting to assess the nature of the conditionality that exists between environmental quality of life and anxiety levels. Dawson's simple slope analysis was conducted, using the 'Process Procedure for SPSS v.3 add-on, a comparison of high (+1SD), average (0) and low (-1SD) numbers of available support was calculated and assessed, and the graphical representation of the conditionality is presented in Figure 6.4.

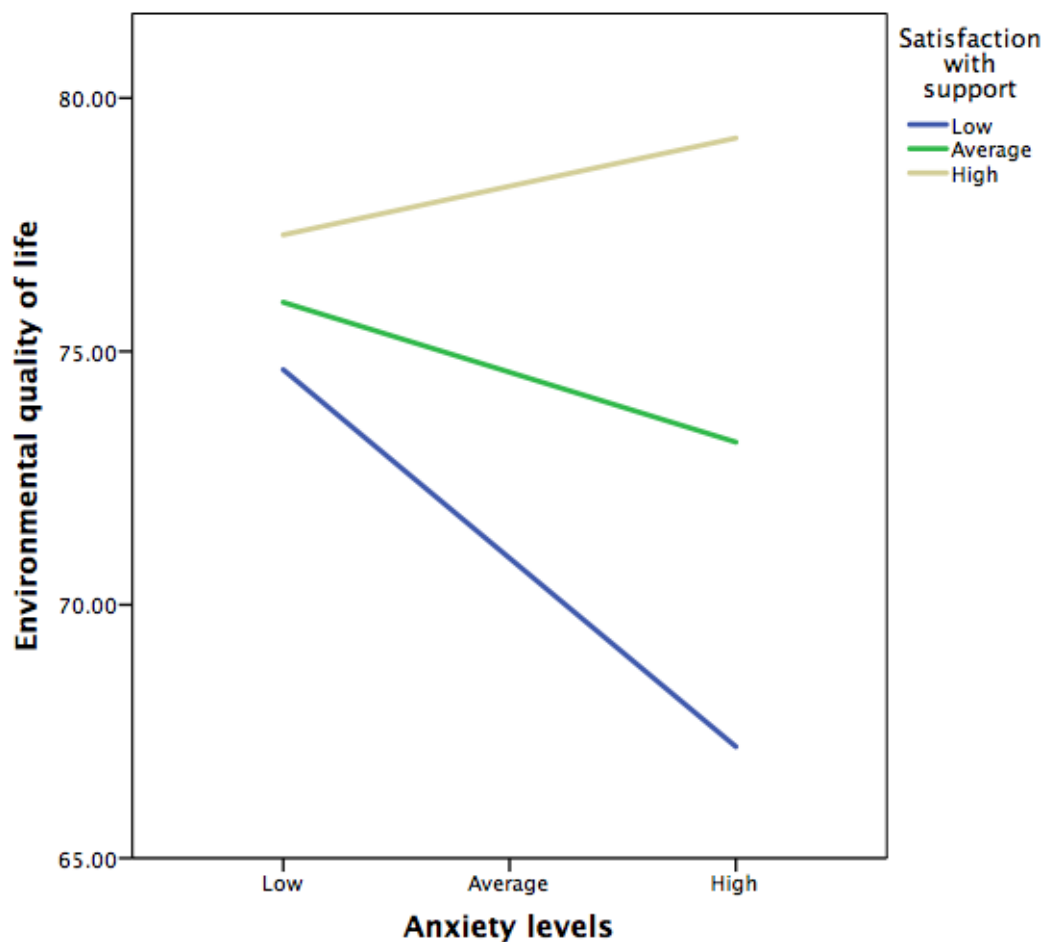


Figure 6.4: Satisfaction with available social support moderated the relationship between anxiety and environmental quality of life.

The findings revealed that when satisfaction available social support was low, anxiety levels were predictive of environmental quality of life scores, although this did not reach statistical significance  $\beta = -0.27$ ,  $t(58) = -1.67$ ,  $p = 0.09$ , for an average satisfaction with social support, anxiety was not predictive of environmental quality of life,  $\beta = -0.10$ ,  $t(58)$

=-0.85,  $p=0.4$ , and at high satisfaction levels, anxiety was equally not predictive of environmental quality of life.  $\beta=0.07$ ,  $t(58)=0.42$ ,  $p=0.67$ . Therefore, although the results did not reach statistical significance, probably due to a low sample size, it can be inferred that low satisfaction with support at high anxiety levels resulted in lower environmental quality of life. This result demonstrates that when there's a low satisfaction with available support for sub-fertile UK women, anxiety levels become high, and their environmental quality of life is reduced.

### ***Nigerian Cohort***

At step 1, anxiety scores and satisfaction with available support were entered into the regression model and the model was not significant,  $F(2, 49) = 1.67$ ,  $p=0.19$ , and accounted for only 6.4% of the variance ( $R^2 = 0.064$ ). At step 2 of the analysis, the satisfaction with support x anxiety interaction term was added to the regression equation, and the overall model did not reach statistical significance,  $F(3, 48) = 2.47$ ,  $p=0.07$ . However, consistent with the hypothesis, the satisfaction with support x anxiety interaction term was significantly predictive of environmental quality of life, explaining a further 7% ( $\Delta R^2 = 0.070$ ) of the variance in scores,  $\Delta F(1, 48) = 3.87$ ,  $p=0.05$  (Table 6.13). Therefore, the predictive relationship between anxiety and environmental quality of life is not dependent on the satisfaction with social support per se, but rather on the anxiety by social support satisfaction interaction.

Table 6.13: Multiple regression investigating satisfaction with social support as moderating the relationship between anxiety and environmental quality of life

	$\beta$	B	SE B	95%CI for B	p-value
Constant		62.53	1.17	[60.17, 64.91]	<0.001
Anxiety levels (BAI)	-0.16	-1.37	1.21	[-3.80, 1.05]	0.26
Social support satisfaction	0.16	1.44	1.21	[-0.98, 3.87]	0.24
Constant		63.15	1.18	[60.76, 65.53]	<0.001
Anxiety x SS Satisfaction	0.28	3.30	1.68	[-0.07, 6.68]	0.05*

SS-Social Support, BAI-Beck Anxiety Inventory, SE-Standard error,  $\beta$  - Regression coefficient, CI- Confidence interval, \*  $p=0.05$

The findings revealed that when the satisfaction with social support x anxiety interaction was low, anxiety levels were significantly predictive of environmental quality of life

scores,  $\beta=-0.59$ ,  $t(48)=-2.3$ ,  $p=0.03$ , for an average interaction, anxiety level was predictive of environmental quality of life,  $\beta=-0.21$ ,  $t(48)=-1.52$ ,  $p=0.13$ , and at high satisfaction with social support x anxiety interactions, anxiety was not predictive of environmental quality of life.  $\beta=0.17$ ,  $t(48)=-0.79$ ,  $p=0.50$ . Therefore, low satisfaction by anxiety interaction, had a bigger effect on environmental quality of life than average or high. The nature of the conditionality is shown in Figure 6.5

The nature of this interaction appeared to be that there is no overall effect of either anxiety or satisfaction with social support, but there is a cross over interaction. The effect of satisfaction with social support on environmental quality of life is opposite, depending on the anxiety levels.

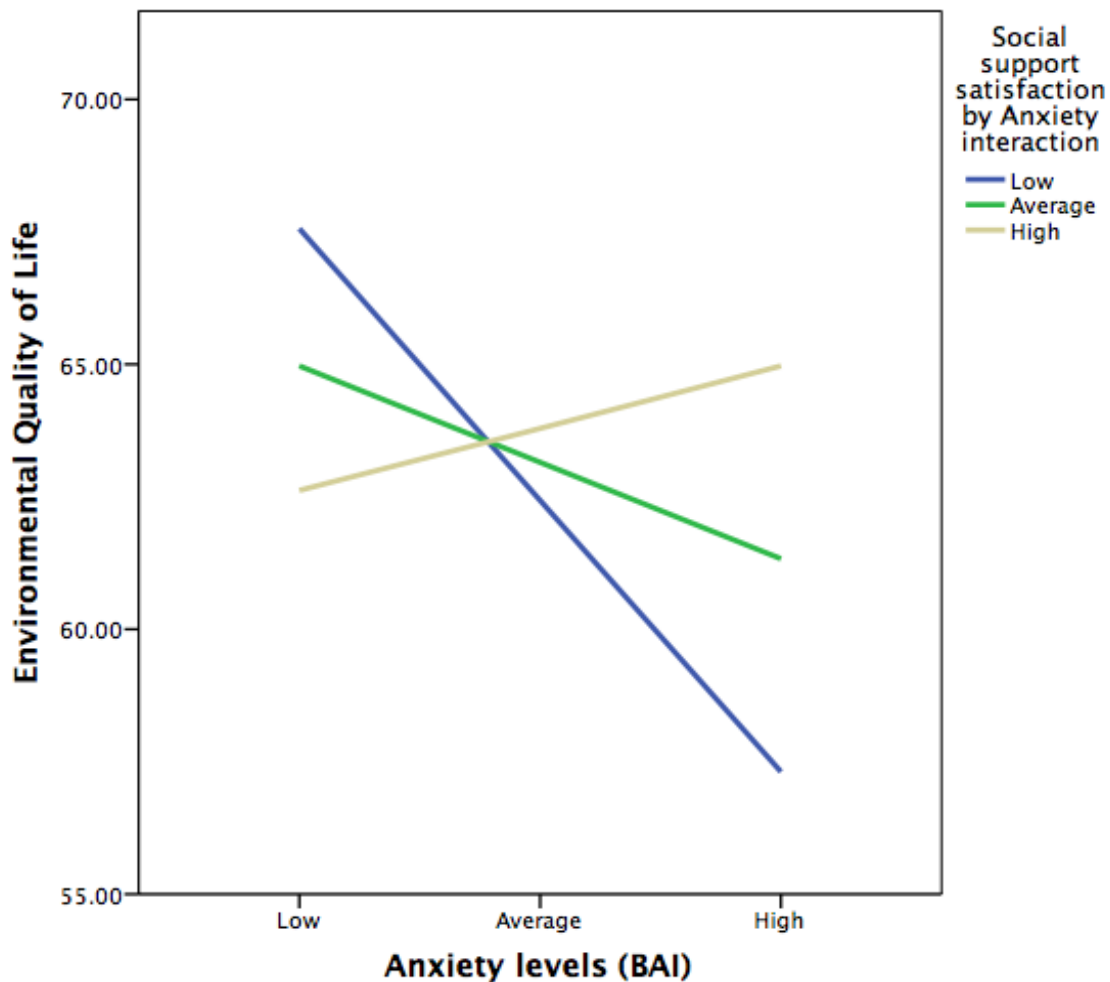


Figure 6.5: The satisfaction with social support by anxiety interaction effect moderated the relationship between anxiety and environmental quality of life.

## 6.6: SOCIAL SUPPORT BEHAVIOURS EXHIBITED BY WOMEN IN BOTH COUNTRIES

Previous research has suggested that, to understand the reception of social support by sub-fertile couples, there is a need to examine their communicative behaviours (Steuber and High, 2015). Within both cohorts, participants had different ideologies about disclosing their subfertility status or treatment. Some preferred to keep the entire topic private, others preferred to share it with their family or friends, and a few with work colleagues. But all for different and specific reasons. These people (family, friends, colleagues) and the particular reasons for informing them, explains the social support patterns or behaviours exhibited by the sub-fertile women in both countries and would be illustrated further in this section.

When participants from both cohorts were asked about their perceptions on the sources of social support they had or have received, six major themes were identified: **PRIVACY, FAMILY, PARTNER, FRIENDS, WORK COLLEGUES & HEALTH CARE PROVIDER**. These are summarised in Table 6.6 and described in detail.

Table 6.14: Participants behaviours for disclosing information about the treatment

<b>Theme</b>	<b>Sub-themes</b>	<b>Participants description</b>
PRIVACY	<i>Lack of discretion, don't want to be asked, conception doesn't need to be advertised</i>	Participants describe why they'd rather not inform anyone about their issues or treatment
FAMILY	<i>Emotional support, dearth of understanding, financial support, lack of financial support</i>	Participants describe the reasons they informed their family and relatives and the type of support they received
PARTNER	<i>Emotional support, frustrations, marital disputes, lack of financial support</i>	Participants describe the type of support they got from their partners and the issues that arose from accessing the treatment
FRIENDSHIPS	<i>Guidance, acceptance, learning experience, spiritual support, lack of quality support</i>	Participants describe their reasons for informing their friends and why those particular people needed to know
WORK & HCP <sup>18</sup>	<i>Cover for you, job security, emotional support, lack of empathy</i>	Participants describe their reasons for informing their work colleagues about the treatment. Additionally, support from health care providers were also discussed

<sup>18</sup> HCP - Health Care Providers



### 6.6.1. PRIVACY

Although studies have shown that effectively communicating or disclosing their subfertility status or experience might positively impact the quality of support a sub-fertile woman receives and ultimately her psychological and social well-being, most Nigerian participants preferred to have their status and treatment remain a private affair. The text that follows is an excerpt from an interview with one respondent who felt it unnecessary to inform her friends about her treatment due to a **lack of discretion** on their part:

**Q:** Have you told any of them that you are going for this procedure?

**Happiness:** *No, it's just between me and my husband.*

**Q:** Can you tell me a bit more about your reasons for that?

**Happiness:** *Ah! why would I be announcing it now? How would I go and be telling my friend that I want to go and do IVF, for what? This country we are in, I can tell my friend, my friend would take it to somebody else and they will be saying it outside, so there's no point, it's between me and my husband only. (Happiness, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

A similar view of privacy was shared by a few other participants (UK), not necessarily for lack of discretion but because they **don't want to be asked about it**, especially if it wasn't going too well:

*"I haven't really told anyone, I've kept it to myself, I think it's quite a private thing, just because I think, if you tell people what you're doing, then people ask how it's going and either way you don't really want to say" (Lisa, 35yrs, British, 1<sup>st</sup> attempt)*

*"I just have to keep as private as possible, I don't really want to discuss it with anyone, until it's actually done, and then maybe I could, I just don't want to jinx it." (Sadia, 37yrs, British, 1<sup>st</sup> attempt)*

An aspect some sub-fertile women described that was a difficulty in social settings, such as dealing with feelings of jealousy and envy when learning about pregnancies from their friends. One respondent, Fiona, had friends that conceived naturally, and did not want to share her struggles with them. She mentioned finding it difficult to deal with the notion

of not being able to get pregnant when everyone else around her seemed to be doing it quite easily, and so preferred not to talk about it, so she **doesn't get asked about it**.

*"I've had friends who are sort of the same age as me, that have just got pregnant straight away, sometimes without even trying, and that's quite hard to deal with when you've been trying for 3 years and nothing seems to be working [sobs]. And obviously I wouldn't wish what I'm going through on them, but it just makes it difficult [sniffs]. So, I suppose I've sort of stopped telling people about it cos I don't really want to be asked about it." (Fiona, 36yrs, British, 2<sup>nd</sup> attempt)*

Another school of thought on the reasons for privacy was shared by Karen, who felt that the method of **conception does not need to be advertised**. She said it was unnecessary to inform friends or family about the process because couples who try to conceive naturally do not have to inform anyone about it, and so neither should a couple trying to conceive through ART.

*"I think if you were trying for a baby you know, naturally, then you won't probably tell all your family and friends, so I think this isn't any different in that way..." (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

### **6.6.2: FAMILY**

The pinnacle of reasons for informing family members about the treatment was for **"emotional support"**. Most UK participants reported informing their mothers and sisters about the treatment because of the emotional support they were assured they would receive:

*"It's only my mother and my sister that [I've told], that know. My mum is just very supportive about it all, and I can go and just talk to her about how I'm feeling and know I'm safe." (Lucy, 32yrs, British, 3<sup>rd</sup> attempt)*

*"I have told my sisters, I have two sisters who already have children and they conceived naturally, they are really supportive." (Barbara, 41yrs, British, 1<sup>st</sup> attempt)*

Among the Nigerian participants, a few women equally shared this view. One respondent, Onyiye, had lost her father to cancer right before the start of her treatment. She described how she had to cancel that treatment because she was in such a raw emotional state she knew it would be a waste of time and resources to go forward with it. However, she believed that if her father were alive, he would have provided emotional support:

*"I want to believe that if my daddy were alive, he would have been able to help me to an extent. I know my parents would not lead me astray. I would have been able to run to my daddy, rest my head on his shoulders and say, 'Daddy, see what I'm going through'." (Onyiye, 39yrs, Nigerian, 1<sup>st</sup> attempt)*

A few participants within the UK cohort felt that although their families were supportive about their decision to undergo treatment, there was a **dearth of understanding** as they could not really empathise with the depth of their despair as a couple, and so the advice they got from their families were not particularly encouraging:

*"...not a lot of people understand it and a lot of the responses you get from family is 'oh it will happen' or 'just don't stress and it'll just happen for you' because obviously there not going to want to say, 'keep trying'" (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

*"Both families are very supportive, and we've been talking about it quite openly with them, but sometimes, the advice you'd get from them is not necessarily the best..." (Rachel, 40yrs, British, 1<sup>st</sup> attempt)*

This was equally evident in the Nigerian cohort. Some participants equally felt that although family members think they are being supportive and helpful, particularly when giving advice, there was a **dearth of understanding**. This is illustrated by Felicia's experience with her family and in-laws, who kept advising her to leave her husband if she wanted to conceive:

*"...family too are worrying me, some would say I should just leave the marriage, that was how that other woman left and when she married another man, she was having kids. The family members from his side are telling me to leave him, some of my own too are also telling me to leave him. But leave him and go where?" (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

The second reason participants reported for informing family members about the treatment was for **“financial support”**. One respondent, Alpha (Nigerian), described her reason for informing her younger brother about her treatment. She explained how she wanted to keep it private and try to raise the funds herself but then he had surprised her by not only suggesting the treatment, asked that she find out the cost and agreed to help with part of the funds.

*“I’ve only told my younger brother, because he is the one that said, ‘Sister, I want you to go and do all those IVF things that people are doing in the hospital. Just go and find out how much it is, I can assist your husband in the payment...” (Alpha, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

However, Alpha’s situation is rather unique. Some other women reported having a complete **lack of financial support** from their family and relatives.

*“It’s not like there are not people to ask, it’s just that if you ask someone for big money like this, after a while when the person see’s your calls, they won’t even pick up. They would start to say ‘Oh! she has come again to disturb me!’ So sometimes you don’t even bother.” (Ijeoma, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

*“When you have siblings or relatives who are capable of assisting but are not willing to, then what’s the essence?” (Ola, 32yrs, Nigerian, 1<sup>st</sup> attempt)*

*“I have a half-brother who would have been able to assist, but even when I was going to school, he had never assisted me [...]and most times I’ve gone to him, his wife is a nurse, she knows what my situation is. She just tells me that I should go and meet their pastor, so I just left them. I decided to manage my life like that.” (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

Within the UK cohort, some participants had reported asking family members and relatives for financial support in the form of loans, contributions and gifts as presented in section 7.5.2, however, a good number of the participants preferred to ‘save-up’ instead of ‘borrowing’ from their family or relatives. No UK respondent reported a lack of

financial support from their family, most felt that either the family members were financially incapable, or their pride would get in the way.

### 6.6.3: PARTNER

The third theme that emerged from the interviews was support from their **partners**. Within the both cohorts, most women were happy and satisfied with the **emotional support** they received from their partners, as illustrated below:

*“My husband decided that we should come to this hospital, that it would be cheaper than private hospitals. He has just been the one helping me through all this our issues” (Onyiye, 39yrs, Nigerian, 1<sup>st</sup> attempt)*

*“I just thank God for the Kind of man I married. He doesn’t pressure me” (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

A similar view was expressed by some UK women:

*“...and my husband has been really supportive” (Sadia, 37yrs, British, 1<sup>st</sup> attempt)*

*“[James] has just been wonderful, I really feel like we’re in this together” (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

However, a few UK women were not quite as pleased. Some women expressed **frustrations with their partners**. One respondent, Barbara, had some issues with her husband because the nature of their subfertility was diagnosed to be ‘psycho-sexual dysfunction’. According to Barbara, the only issue they have as a couple was the fact that her husband did not enjoy their sexual experience.

*“it’s a shame really, [that] the only reason I have to go through this treatment is because my husband doesn’t enjoy sex. It’s quite frustrating really...” (Barbara, 41yrs, British, 1<sup>st</sup> attempt)*

Another respondent, Fiona, was equally not very pleased with her partner because she felt he didn’t quite understand how important having a child was for her and rather liked to do things at his time.

*“My partner he’s 42, and he is probably not as keen about having a child as I am, ‘cos of his age, and also, he’s got friends that haven’t got kids. And so, he has things that he likes to do at his time. So, I’d admit he is a bit selfish at times and isn’t as encouraging as I’d like him to be.” (Fiona, 36yrs, British, 2<sup>nd</sup> attempt)*

Within the Nigerian cohorts, a few women expressed having significant **marital disputes** particularly in regard to the decision to undergo the treatment. Not all couples who are diagnosed with infertility actually pursue medical treatment. This could be for various reasons, including but not limited to, socio-cultural beliefs, fear of exploitation and the high treatment costs. Two interview excerpts are presented to illustrate this.

In the first interview excerpt with Joy, the **marital dispute** arose because the couple had to confront a new issue, which was introducing a third party (using donor eggs) to the already traumatic reproductive process. This created some psychological distress for her partner:

***Joy:** ...they said that I would need donor eggs. At first my husband did not agree, but then the doctor now explained it to him very well.*

**Q:** Why didn’t your husband initially agree to the use of donor eggs?

***Joy:** He was very angry with me. He said that I did not tell him, that I was hiding it.*

**Q:** Hiding what?

***Joy:** That I was not having any ovaries. It caused a lot of trouble in our house oh. Every time it is one fight or another, and every time he will bring it up. He would say that ‘of all the women in the world, he married the woman that does not have any ovaries’. So, we had to come and see doctor to explain it to him.*

(Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)

In the interview with Felicia, the **marital dispute** arose because her husband was already traumatised from an earlier experience with an unsuccessful IVF cycle with a previous partner and was not willing to pay for another one.

**Q:** Is your husband a doctor?

***Felicia:** He is not oh!*

**Q:** Then why was it his recommendation that you don't do IVF?

***Felicia:** He had a lady before me. He was dating the lady for about 8 years before we met, and that lady, the two of her fallopian tubes were blocked. So, he paid for her to*

*do IVF, and it did not work, but eventually she got pregnant. So, since then he has been so scared and said he doesn't want to waste so much of his money on it again.*

*(Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

This unwillingness to pay for the treatment elicits another aspect that equally provoked **marital disputes** which was '**lack of financial support**' from their partners. As stated by a few participants, arguments between husband and wife is not uncommon. However, when infertility is added, the relationship can get very uncommunicative and volatile quickly. The issues seemed to be more severe when the aetiology was female-related. For a few women, their partners felt no responsibility towards funding the treatment:

*"He said I shouldn't disturb him with the money issue, as long as he is not the cause of the problem, I should not disturb him with it. So, I knew I had to face it myself."*

*(Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

*"My husband was very angry when doctor told us how much it would cost. He said that since I'm the one that does not have any ovaries, that I should pay for it" (Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)*

One felt the woman needed to equally contribute to the cost of the treatment:

*"... he said that I must put 200 thousand naira, since it is my fault. That if I don't contribute, he would not. But me I cannot even gather the 200 thousand" (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

Another did not want to pay again for the treatment after an already unsuccessful cycle:

*"At first my husband said no! That there's no use to waste money on that again, that God would just help us this year." (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

The issues were not very different in the case of male-related subfertility. Previous research suggests that men equally experience some distress (especially with social stigma) when faced with subfertility, and it is likely greater in men with male-factor subfertility (Eke et al., 2011, Folkvord et al., 2005, Inhorn, 2013, Kowalcek et al., 2001, Zorn et al., 2008). Although the men were more eager to pay for the treatment, the **marital disputes** were equally as verbal and, in some cases, even violent. One respondent reported having a violent altercation with her husband about his subfertility in which she poured 'hot water' on him, after he had beaten her up.

*“The problem is from his side [...], my husband beat me eh, I thought I was going to die. When he now went to lie down, I just went to the kitchen, boiled hot water, put it inside bucket and poured it on him. I decided that the two of us would die today. It was our neighbours that had to come and separate us oh” (Rosemary, 28yrs, Nigerian, 1<sup>st</sup> attempt)*

The above comments from this theme illustrates that, the burden of an infertility diagnosis is borne by the women even when the reproductive impairment lies with the man. Especially in a patriarchist society like Nigeria. It is therefore no surprise that these women would compensate by doing all they can to alleviate this burden.

#### **6.6.4: FRIENDSHIPS**

The fundamental reason most UK participants had for informing friends about the treatment was to **‘provide Guidance’**. A number of participants acknowledged that they would prefer to speak to people who have actually been through the experience. They felt those people better understand not just what the treatment entails, but also how to deal with the aftermath of an unsuccessful procedure.

*“Sometimes I feel it would be nice to speak to people that have or are going through it or have been through it. Because they’ll understand that it’s not just about psyching yourself up for going through IVF, its psyching yourself up for the chance that this might not happen. And you have to go through the rest of your life not having a child when it’s the only thing you want.” (Zoe, 32yrs, British, 1<sup>st</sup> attempt)*

A few participants reported being friends with and talking to people who have been through the ART procedure, to find out about their experiences with it:

*“I did meet [...] a friend, cos she went through quite a lot of disappointments with IVF, and I met her once. But I know that I can call her again, ‘cos it was really nice, and really good to sort of listen to, and speak to someone who has actually been through it” (Eleanor, 34yrs, British, 1<sup>st</sup> attempt)*

*“...friends who’ve had IVF as well. To find out from them what their experiences with the treatment was like?” (Vanessa, 40yrs, British, 1<sup>st</sup> attempt)*



Among the Nigerian participants, only a few women reported having friends they could tell about the treatment, and it was equally imperative that these women had undergone the treatment too. From examining how crucial it was that the friend had experienced the treatment, a second sub-theme emerged, which together with **providing guidance** was **'acceptance'**. The quality of feeling accepted by a friend was paramount for these women. Most of them felt that only a person who had experienced what they were going through would understand and empathise with them nonjudgmentally. This feeling of acceptance by their friends was evident in their responses and evoked verbal and non-verbal cues like 'smiling', when these people were talked about:

*"I'm close friends with a lady who has been through all this before, so I let her know, purely because she can understand what I'm going through better than anybody else, even my husband" (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

*"My bosom friend is the one that had this issue too [...], she knows what this is like, she also had IVF and got pregnant after the third time of doing it, so she knows, she really knows...." (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

Where some women had gained **guidance and acceptance** from informing their friends, others had developed a more rational understanding based on the perceived consequences of the treatment from others, especially in regard to funding it. A few UK participants reported it being a **'learning experience'** for them in which they could now make informed decisions about their financial commitments to the treatment.

*"I know people who have gone through it in different circumstances and for different reasons, and err, I know how it affected their life, and actually, my friend is quite traumatised from it, and I can see [why] now, because she lost so much money and, to go through all that and to loose babies as well, must be horrendous. So, we decided to give it two goes, and that's it" (Rachel, 40yrs, British, 1<sup>st</sup> attempt)*

It was apparent from the interviews that speaking to individuals or couples that have experienced the treatment was more productive for the participants as opposed to speaking to friends who can't really empathise with their situation. This was evidenced by a comment made by Fiona:

*“I think people that haven’t been through it, don't really understand or empathise, well you think you're empathising, cos I thought I was understanding of my friend that went through it. But then I realised when I was going through it myself, that it was pretty horrible, and I really didn’t understand her at all” (Fiona, 36yrs, British, 2<sup>nd</sup> attempt)*

One woman who had received support before and during her treatment recognised how important it was and was now happy to be a leading example of support to other women:

*“It’s surprising the number of couples that we know and friends of ours who have gone through the actual experience that we’ve gone through, and now we’ve got friends who are starting to go through the treatment, and we are tending to be their support.” (Anna, 37yrs, British, 3<sup>rd</sup> attempt)*

Another reason a few women had for informing their friends was for **‘spiritual support’**. One UK respondent, Vanessa, felt that it was important to have the spiritual support of her friends from church in the form of prayers:

*“Well, I suppose as Christians, an important aspect for us is prayer, and having people to pray for us on our behalf and to give us emotional support was important. So, we felt like we could only have that if we were honest with them about what we are going through...” (Vanessa, 40yrs, British, 1<sup>st</sup> attempt)*

This was a similar view shared by one other Nigerian woman who shared her experience with a friend from church:

*“A friend of mine from church just called me this morning to say, “I’m praying for you” and I thought, ‘Ah with all your own problems, you can remember me? Thank you oh.” (Ijeoma, 38yrs, Nigerian, 1<sup>st</sup> attempt)*

Some Nigerian respondents commenting on **friendships** said they had none, and rather **‘God’ was their major source of support**, as was depicted in the comments below:

*“Ah, it’s just God oh! Its only Him I can lean on and know that He will not disappoint me” (Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)*

*“It’s just me and my bible oh, no friend, no husband, nobody, just God” (Ronke)*

*"It's like the devil just uses my husband to tempt me, I have no friends oh, it's just me and my God..." (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

For some that did have friends, they did not discuss/disclose anything about their treatment or diagnosis with them. The main concerns most women had was **lack of discretion** (referred to in section 5.16.1) and **lack of tangible support** by friends. When asked about the possibility of friends providing **financial support**, one participant said:

*"No, I don't have friends, I don't like keeping friends, they talk too much. They don't even have money. They don't have, they would still come and ask you for money..." (Joy, 30yrs, Nigerian, 1<sup>st</sup> attempt)*

Another said:

*"As for friends, ah! there is no friend oh. Is it the friends that have their own problems, and are also looking to you for support?" (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

While most participants reported not having friends, there was one participant who did mention having some friends. Felicia described having a few friends from school who were quite concerned about her childlessness as illustrated by the following quote:

*"Even my friends, the ones we went to school together, some would say, "Ah! But you were not like that now, even the girls that were the spoilt type during our school days, they have children now, what is happening to you?" (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

The **lack of tangible support** mentioned by most women was equally present in Felicia's description of her friendships. She felt that although they seemed genuinely concerned about her issue, she sometimes found herself questioning the type of advice she got from them.

*"Last week, one of my course mates said that I should leave my husband, that I should try somebody else if I want children. I was now asking him 'where would I start from? If you want me to leave my husband where would I start from?' I'm not young again. Should I go and start dragging other women's husbands and abandon my own?" (Felicia, 41yrs, Nigerian, 1<sup>st</sup> attempt)*

### 6.6.5: WORK PLACE SUPPORT & HEALTH CARE PROVIDERS

Most UK participants who were currently employed agreed that there was a need to inform their colleagues at work about the treatment. The foremost reason reported by most participants was the need to have **someone to cover for you**. It was important for most of the professional women that they informed their superiors and colleagues at work about the treatment, because the colleague could help provide an excuse or explanation when they (the participant) need to take some time off work. The following statements express this issue:

*“...a lot of my friends don't actually know that this is going on. Surprisingly, quite a few of my work colleagues do, but that's because when you work as a doctor, we sometimes work in shifts. And so, if I'm in clinic by myself covering, it means that if I turn up late for that clinic, due to an appointment or something, then the clinic would run late straight from the start and patients would be waiting.” (Fiona, 36yrs, British, 2<sup>nd</sup> attempt)*

*“We've spoken to quite a few people, essentially work colleagues, cos it's going to involve time off work” (Vanessa, 40yrs, British, 1<sup>st</sup> attempt)*

Again, the importance of speaking to people who have experienced the procedure was cited here. Participants expressed that it's a lot easier for someone who has experienced the procedure to **cover for you**, because the person understands what it entails at every point, and so when you need to take some time off, they know when a replacement needs to be made or when jobs need to be scheduled around your time.

*“Quite a few people at work have had IVF, some consultants have gone through it, so they've offered their support which actually has been quite useful cos I did work with one of them, so she totally understood if, I needed a bit of time, or why I might be turning up late” (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

Not everyone was convinced they needed to tell their colleagues at work about the treatment, and the need for **privacy** was still evident. However, a few believed that although they wanted it to be private, it was important that their bosses and managers knew about it.

*“My line manager and sort of bosses have been really quite supportive. I’ve not really sort of shared it wider than sort of just the important people at work, just because we’re quite private people” (Paulette, 44yrs, British, 1<sup>st</sup> attempt)*

Similarly, among the Nigerian participants, hesitantly, a few equally felt it important to mention it to their superiors/supervisors, essentially for **job security**.

*“I’ve obviously had to, [hesitates] I’ve had to tell my branch manager, you know, just to save my job, but umm, I don’t want it to be like public knowledge” (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

Another reason less favoured by most participants in both cohorts for informing work colleagues was for **‘emotional support’**. However, one UK participant described her reason for informing her work colleagues:

*“I’ve told the company that I’m having a procedure done at some point, but obviously [...] there might be some days (laughs) that I might need to break down and cry and walk out of work, so that’s why I’ve told [a] few people there.” (Rachel, 40yrs, British, 1<sup>st</sup> attempt)*

In addition to the support provided by work colleagues, some women mentioned receiving support from their health care providers. This is not far-fetched, owing to the extensive nature of the infertility treatments and the constant contact between the patient and the health care providers, considering the nurses and physicians a source of support is reasonable.

A few UK women reported receiving **tangible support** from their health care team

*“I found the appointments came really quick, for Sheffield at Jessops, everything was quick which was great. My doctor actually pushed me through a bit quicker, which I found great, and he was really supportive” (Lucy, 32yrs, British, 3<sup>rd</sup> attempt)*

*“The Jessops team have been really great to us and so supportive” (Karen, 36yrs, British, 3<sup>rd</sup> attempt)*

Some Nigerian women reported receiving **emotional support** from the nurses and physicians in the clinic:

*“I like nurse [Agnes], she understands, she always asks me how I'm feeling every time I see her, and she always gives me hope” (Kemi, 43yrs, Nigerian, 1<sup>st</sup> attempt)*

*“The matron has really helped me, when I talk to her, I feel like I'm talking to my mother” (Chioma, 37yrs, Nigerian, 2<sup>nd</sup> attempt)*

*“My doctor is a very funny man oh [...]. I don't know whether he is not taking me seriously, or that's just his nature. He always makes me laugh every time I come here” (Faith, 34yrs, Nigerian, 2<sup>nd</sup> attempt)*

A few other women reported a complete **lack of empathy** from their health care providers, especially with regards to funding the treatment:

*“I saw it as an insult when my consultant told me that am I the poorest person coming to this clinic that I'm saying I cannot raise the money? He said that I'm not serious with the treatment that's why. He doesn't understand what I'm going through” (Ohine, 40yrs, Nigerian, 1<sup>st</sup> attempt)*

## **Summary**

This chapter has described and analysed the socio-demographic predictors of quality of life of the infertile women in both countries and the effect funding the treatment had on their quality of life. Additionally, section 6.5 presented evidence on social support behaviour exhibited by these women, and how it helps them cope with their infertility and treatment related stress. The key findings are that:

1. Within the UK women, good quality of life scores was associated with increased age, higher educational level, durations of infertility greater than 5 years and increased annual income. However, good quality of life scores among the Nigerian women was reported only when male factor aetiology of infertility was reported.
2. Some participants report no effect of funding the treatment to their quality of life, others reported the strain it put on their relationship and others the opportunities forgone in the bid to fund the treatment.
3. There were similarities between social support behaviours exhibited by the women in both countries principally with how they disclose information about their treatment.

# **CHAPTER 7: DISCUSSION OF FINDINGS**

## **CHAPTER 7: DISCUSSION**

### **7.1: KEY FINDINGS**

This chapter uses the quantitative and qualitative findings to provide new insight into the stress and affordability of women presenting for assisted reproductive treatment. The key findings for each research question are discussed below, before section 7.2 highlights what the current research contributes to the existing knowledge of stress and affordability of ART.

#### **7.1.1: Stress patterns of infertile women accessing ART in both UK & Nigeria, and the socio-demographic variations**

Of considerable interest was the participant's endorsement of the individual items in both the stress and anxiety scales. As can be expected of people living with a serious and potentially psychologically challenging diagnosis, the items endorsed by the highest number of participants in the UK for the BAI were "nervous", "unable to relax" and "fear of the worst happening". Nigerians, similarly, endorsed "fear of the worst happening" and "nervous", which are symptoms considered to reflect the subjective neurophysiological aspects of self-reported anxiety (Beck et al., 1988, Beck and Steer, 1990). The scores of half the sample in both the UK and Nigerian cohorts fell into categories of the BAI that were above the minimal range, indicating that anxiety for many sub-fertile women may be a psychological experience that features prominently in their lives. This finding is similar to previous reports. Fatoye et al. (2008) sought to determine the relationship between socio-cultural factors and infertility-related stress among Nigerian women. The authors reported that the rates of significant anxiety were observed in 39.4% of the infertile population compared to 11.1% in the control group; and their mean anxiety scores were equally higher (Fatoye et al., 2008). The increased anxiety and stress scores in the Nigerian cohort, compared to the UK cohort could be attributed to the psychological burden infertile women in that part of the world go through.

One of the aims of this study was to identify, in a sample of Nigerian and UK sub-fertile women, the clinical and socio-demographic variables associated with



psychological distress, measured by the stress and anxiety scores. I believe that one crucial initial step in developing cross-cultural studies on a complex construct like 'stress' is to describe in detail its determinants in as many cultures as possible.

From the analysis of predictors of perceived stress among the UK cohort, *marital status* was observed to be a significant predictor of perceived stress, with unmarried/cohabiting women experiencing higher levels of stress than the married ones. The effect of marital status on stress/anxiety/distress has been reported in many studies, with inconsistent findings (Caron and Liu, 2011, Jorm et al., 2005, Bijl et al., 1998, Thapa and Hauff, 2005). Some studies report a protective effect of being married, compared to being single, separated, widowed or divorced in reducing the effects of psychological stress (Thapa and Hauff, 2005, Bijl et al., 1998). While others suggest that the significant association between marital status and psychological stress was limited to those in age groups less than 44 years of age (McDonough and Strohschein, 2003). Caron et al. (2011), reported a positive interaction effect between gender and marital status, with married males and unmarried females reporting the highest stress levels. The authors, however, attributed this effect to the various roles in marriage that could be associated with psychological distress. Similarly, Bahadur Thapa and Hauff (2005) observed that only among female participants living without a partner were the levels of distress increased. Conversely, Jorm et al. (2005) reported a non-significant effect between marital status and psychological stress. The findings from this study that unmarried/cohabiting women exhibited higher stress levels than married women can, therefore, be said to be consistent with the literature.

Additionally, within the UK cohort, this study observed a negative association between educational level and perceived stress, with higher educational levels associated with lower perceived stress levels. In other words, women with low educational levels had higher perceived stress scores, than women with higher educational levels. A number of studies have equally reported the protective effect of higher education on psychological stress/distress (Jorm et al., 2005, Barnett and Baruch, 1985, Prevention, 2004, Caron and Liu, 2011), which is consistent with the findings in this study. However, factors such as the relatively small sample size of the data could explain why this variable did not reach statistical significance in the analysis.

Regarding the fertility variables, the cause of subfertility and the number of attempts were implicated as significant predictors of perceived stress among the UK cohort, with the cause of subfertility being a more significant predictor. Inconsistent results have also been reported in the literature. A few studies that explored the effect of an infertility diagnosis on women's psychological status have shown that when the cause of the couple's infertility is female-related, women experience a lot more stress than when the cause is male-related, mixed or idiopathic (Lee et al., 2001). A study by Lee et al. (2001) is of particular interest. The authors sought to examine the effect of an infertility diagnosis on treatment-related stress and observed no significant differences in stress between wives experiencing male infertility with their husbands, and wives with female infertility only. However, they equally report that wives with female infertility only experienced more stress due to infertility than wives with mixed or idiopathic infertility (Lee et al., 2001). Conversely, some studies such as one by Lykeridou et al. (2009), in which the authors sought to examine the impact of an infertility diagnosis on the psychological status of women undergoing ART. The authors reported that participants with unknown factor (idiopathic/unexplained) infertility experienced higher anxiety and social stress levels than those with female, mixed or male-factor infertility (Lykeridou et al., 2009).

The number of attempts was a significant positive predictor of perceived stress in the UK cohort, with an increased number of attempts associated with increased stress levels. This result was equally consistent with Lee et al. (2001), in which the authors observed a positive correlation between the number of IVF procedures and the wives stress levels. Among the Nigerian cohort, none of the demographic variables were predictors of perceived stress. However, the type of ART, particularly women having IVF treatment were observed to be more stressed than women having an ICSI procedure although this did not reach statistical significance.

From the analysis of the predictors of anxiety within the UK cohort, neither the socio-demographic characteristics nor the fertility characteristics were observed to predict anxiety scores. Similarly, among the Nigerian cohort, none of the socio-demographic characteristics were implicated as predictors of anxiety. However, the duration of subfertility and the type of ART were both observed to be significant

predictors of anxiety, with the duration of subfertility being the most significant predictor. This finding was also consistent with the study by Lee et al. (2001), in which the authors reported positive correlations between the duration of infertility, and wives stress levels. They observed that the longer the couples were married, the more stress the wives experienced (Lee et al., 2001), which is consistent with the findings of this study. Additionally, the type of ART (either IVF or ICSI) was implicated to be a predictor of anxiety. This finding is consistent with the results reported by Beutel et al. (1999), in which the authors sought to compare treatment-related stresses and depression in couples undergoing assisted reproductive treatment by IVF or ICSI. The clinical history of the participants classed them into two groups; women into the IVF group, and men into ICSI. The authors reported that women in the IVF group had the highest ratings of distress, due to their subjective feelings of responsibility for their childlessness (Beutel et al., 1999). This could equally explain the results in this study.

Thus, these findings indicated that certain fertility characteristics such as treatment types, infertility duration and aetiology influence the stress and anxiety experienced by infertile women before treatment. These results were similar to those from previous research that report specific fertility and sociodemographic characteristics are significantly related to the stress and anxiety levels experienced by sub-fertile women (Halman et al., 1994, Lee et al., 2001, Beutel et al., 1999, Bijl et al., 1998, Thapa and Hauff, 2005, Caron and Liu, 2011).

### **7.1.2: The experiences of infertile women in both countries**

The results of this study provide essential information about the experiences of sub-fertile women in two different countries, their treatment seeking behaviour, beliefs and knowledge about ART. Three themes developed from participants description of their experiences with subfertility, which was stigmatisation, desperation to have a child and guilt or regret after being diagnosed with infertility.

In the first theme, the effect and importance of parenthood were evident as participants described feelings of desperation and stress over their subfertility. The findings are in keeping with the plethora of quantitative and qualitative literature about infertility being a very stressful and overwhelmingly negative experience (Abbey et al.,

1992, Andrews et al., 1991b, Andrews et al., 1991a, Beutel et al., 1999, Adetoro and Ebomoyi, 1991b, Aduloju et al., 2018, Fatoye et al., 2008, Hollos et al., 2009, Iliyasu et al., 2013, Inhorn, 1998, Dyer et al., 2002b, Dyer et al., 2002a, Dyer et al., 2004, Dyer, 2007), which increases as the duration of infertility and number of treatment attempts increase (Fassino et al., 2002, Verhaak et al., 2005a, Verhaak et al., 2005b, Schmidt et al., 2005a, Johansson et al., 2009). Given their desperation, in both cohorts, some women expressed their willingness to try 'anything' to resolve their situation, others mentioned their need to save their dignity and marriage and one woman expressed suicidal thoughts at the notion of a failed cycle. Previous studies in Nigeria have reported that infertile Nigerian women can go to any length to have children (Ahamefule and Onwe, 2015, Hollos, 2003, Ibisomi and Mudege, 2014, Okonofua et al., 1997, Orji et al., 2002, Umezulike and Efetie, 2004, Araoye, 2003). Araoye (2013) reported that in some cultures in Nigeria, the infertile woman would 'marry' another woman who would help her bear children for her husband to save her marriage.

Within the UK cohort, some women expressed how their infertility has affected certain life decisions. An example is a woman who was planning to get married but stated that she might not go ahead with it because they (she and her fiancé) could not justify getting married if they were unable to have children. Similarly, within the Nigerian cohort, a few women mentioned putting a stop to their educational pursuits due to their inability to conceive. Some other women mentioned feeling very stressed due to the duration of their subfertility. This finding is similar to those reported in some quantitative studies which have shown that the more years a woman is childless, the more her stress and anxiety levels increase (Hashemieh et al., 2013, Ramezanzadeh et al., 2004, Lee et al., 2001).

Stigmatisation was exclusive to the Nigerian cohort. For most women, their infertility had considerable social implications apart from affecting their psychological health. Some felt stigmatised, ridiculed and abused by their in-laws and neighbours, while a few others described being called derogatory names. Ahamefule and Onwe (2015) state that the greatest stigmatisation to childless women in Nigerian is often from the mothers-in-law. This is because they believe the infertile woman would terminate their lineage, as she is unable to bear a successor to continue the family name. Therefore, they place a lot

of pressure on their sons to take a second wife (Ahamefule and Onwe, 2015), and polygyny is usually the outcome. These findings were similar to those observed by Dyer et al. (2002) in which the authors depict respondents accounts of being shouted at, cursed, victimised and threatened with divorce. Additionally, Papreen et al. (2000) in a study of an urban slum population in Bangladesh, reported that infertile women experienced a loss of purpose in life, stigmatisation, abuse and marital insecurity. The authors further reported that the levels of abuse experienced by these women were deemed high enough to push them to suicide (Papreen et al., 2000). The Nigerian culture places a high premium on having children, and when such premiums are fulfilled, the couple is usually celebrated. However, when it is not, a study among the Ekiti's of South-Western Nigeria reports that infertile women are treated as outcasts, and when they die, their bodies are buried in the outskirts of the community (Ademola, 1982). The role of socio-cultural influences among the various ethnic groups in Nigeria affects the stress experienced by sub-fertile couples and most especially sub-fertile women. As earlier research has suggested, the desire to have a child is considered to be one of the strongest emotions experienced, it is therefore not surprising that infertile couples consider infertility to be life's worst experience (Freeman et al., 1985, Downey and McKinney, 1992a, Greil, 1997, Dyer et al., 2002b).

The study revealed that most sub-fertile women in the Nigeria cohort experienced psychosocial problems, and often adopted passive and active avoidance coping strategies. Some women reported attempting to ignore the snide comments made by their in-laws, others gave in to their emotions and cried only at home, while some mentioned distracting themselves with social media and friends. Another emotion-based coping strategy observed was turning to the word of God for solace. This was similar to findings in Donkor and Sandall (2007) in which the authors reported that 88% of the women in the sample used their religious faith as a means of coping with their infertility problems.

Strikingly, some women expressed feelings of guilt and regret over past indiscretions. A few women in both cohorts expressed their regrets in delaying childbearing, while predominantly Nigerian women expressed their regrets over abortions they had earlier in life. This finding is in keeping with results from Okonfua

(1994), in a study of 675 Nigerian women to determine if induced and unsafe abortions were predictive of infertility. The author reported that a quarter of the infertile women in the study population reported having had an induced abortion, and additionally states that these women had reported doing so before they got married.

#### ***7.1.2.1: Level of Knowledge, beliefs and understanding of ART***

On the first theme of treatment-seeking behaviour, participants described the *alternative* and *complementary* remedies they sought. Within the UK cohort, some women described having sought different remedies such as ‘acupuncture and reflexology’ and decided to complement it with their treatment. This was unsurprising as many studies have documented the potential usefulness of acupuncture in enhancing female infertility (Balk et al., 2010, Chang et al., 2002, de Lacey and Smith, 2013, Domar, 2006, Huang et al., 2011, White, 2003). Within the Nigerian cohort, the women equally mentioned seeking alternative treatments from three main outlets. These were traditional healers, spiritual healers, and when those did not seem to provide any resolution, they sought orthodox medicine. A similar finding was observed in Bhatti et al. (1999) in which the authors reported that infertile women visited various types of health care providers. Although, the authors were unable to discern the major factors that contributed to the women’s transition from one type of health care provider to the next; they suggest that it may be due to the desperation by the women to resolve their infertility status (Bhatti et al., 1999). A study from Nigeria indicated that religion and culture appear to influence women’s perception of the aetiology of their infertility (Omoaregba et al., 2011), which is why most infertile women do not seek ART until about 12-20 months after marriage (Ahamefule and Onwe, 2015). These authors reported that in Nigeria, there exists a widespread belief in the supernatural causes of infertility, which include witchcraft and blood oaths against procreation (Omoaregba et al., 2011), which is why infertile women are often blamed for their infertility (Hollo et al., 2009, Ahamefule and Onwe, 2015). Similarly, Fido et al. (2004) reported that in Kuwait, infertile women often attributed their subfertility to evil spirits, witchcraft or Gods retribution. Likewise, in a Pakistani study by Ali et al. (2011) on myths regarding infertility, the authors reported that amongst people with lower education, evil forces, ‘black magic’ and supernatural powers were implicated as causes of infertility. Omoigbu (1990) states that in critical situations, traditional beliefs usually supersede western beliefs. These beliefs may account for women seeking traditional and

spiritual remedies before resorting to orthodox medical services and might also be the reason people do not seek treatment early enough (as seen by the durations in this cohort) for it to be optimally effective.

The inadequacy of knowledge about ART was demonstrated in this study as some Nigerian participants described having no knowledge about the treatment prior to their first consultation. A similar finding was observed in Fabamwo and Akinola (2013), in which the authors reported that, although ART services are available in Nigeria, many infertile women had no knowledge of its existence or what it entails. This lack of knowledge explains why some participants who had very little understanding about it, expressed uncertainties about the working mechanism of the treatment and therefore conveyed their scepticism and myths. Many African cultures have their traditional beliefs surrounding fertility, pregnancy and childbirth, as has been shown in some studies (Darko, 1992, Odebiyi, 1989, Sundby, 1997, Brieger et al., 1987, Lori and Boyle, 2011, Ojofeitimi and Tanimowo, 1980), which may be particularly salient for decisions involving whether or not to undergo ART. Some women expressed their fears about their sperm, egg or embryo samples getting mixed up in the lab, which may lead to the creation of babies that did not possess the same genetic material as the parents. A number of them required the doctors or nurses to alleviate their fears before they agreed to proceed with the treatment. A similar finding was observed in Inhorn's (2003) study, in which the respondents about to undergo ART expressed fears of 'accidental donation'. However, while the participants in Inhorn's study were majorly concerned with third-party donations; which is considered unacceptable by Islamic standards, the Nigerian women were mainly concerned that there was no doubt regarding the parenthood of their child. This lack of knowledge equally explains why the duration of subfertility among the Nigerian cohort was relatively high, with the majority of the women presenting after five years of trying to conceive. Additionally, it explains why alternative treatment methods such as spiritual and traditional healing were sought first. The majority of the UK participants were quite knowledgeable about the mechanism of the treatment having either read about it online, heard about it in the media or via friends and family who had previously undergone a similar experience. A similar finding was observed in a survey by Adashi et al. (2000), on the public perception on infertility and its treatment in a general

population sample in Europe and the United States (US). The authors reported that 90% of the population knew about ART, more specifically IVF (Adashi et al., 2000).

While the limited knowledge about the treatment was an important discovery, the most interesting discovery was about women's reasons for undergoing the treatment. Here participants described how the decision to undergo treatment was made, with a majority of the Nigerian women stating that it was what their doctors suggested they do and others stating their friends and family informed them. In many developing countries, doctors are considered as 'demi-gods', and therefore their word is always taken as 'gospel'. However, among the UK women, the majority of them had made an informed decision to undergo the treatment, sometimes even before coming for their first consultation.

### **7.1.3: The cost burden for households accessing ART in the UK and Nigeria?**

In this study, three (3) methods were used to assess the cost-burden of ART and the findings from each method would be discussed independently in this section.

#### ***Catastrophic expenditure***

The catastrophic expenditure method compared total ART costs with estimates of non-food household expenditure, to determine the cost burden for each household, and to what level this could be catastrophic. The results showed that none of the UK respondents incurred catastrophic expenditure as a result of funding the treatment. In contrast, all the respondents in Nigeria incurred catastrophic expenditures from funding the treatment and overshot the threshold. It is recognised though that the 40% threshold used in this study as the definition for catastrophic expenditure is to an extent 'arbitrary', as those in wealthy UK households might be able to cope with spending 7-9% of their annual expenditure on ART (Dyer et al., 2013). However, other international studies have shown that higher out of pocket expenses up to and exceeding 20% of total income can lead to people suffering attributable to catastrophic expenditures (Su et al., 2006, Sun et al., 2009, Xu et al., 2003, Habbema, 2008). Therefore, if the threshold were to decrease (<40%), wealthy households within the UK cohort might be susceptible to catastrophic expenditure.



The findings ultimately suggest that the propensity to incur catastrophic expenditure from funding one ART procedure in the UK is relatively low. The findings from the study are similar to those observed in Chambers et al. (2013) for the cost of a new IVF cycle as a percentage of annual disposable income in the UK. Additionally, the findings can also be compared to those observed in Canada by Collins (2002), in which the authors reported the cost of ART to be 25% of the average annual household expenditure. Not surprising, households in the lowest socio-economic quintile faced the highest probability of incurring catastrophic expenditure from an ICSI treatment, especially if they would have to undergo a repeat cycle. This is because as Stewart et al. (2011) reports, the effectiveness of an ART procedure could be further improved if couples undergo more than two cycles. This could, however, result in treatment inequality as couples within the poorest socio-economic quintiles might be less likely to access repeat cycles, which in turn substantially reduces their chances of achieving a pregnancy.

Within the Nigerian cohort, the results suggest that out of pocket payments for ART pose a serious problem for sub-fertile couples in the country, causing financial catastrophe in all the participants whose annual expenditure is approximately 600 thousand Nigerian naira (\$6393). The findings suggest that although ART costs are prohibitive in Nigeria, the sub-fertile women could have reached a degree of desperation whereby they are willing to pay for a treatment that they might be unable to afford, thereby incurring crippling financial burdens. This result is similar to reports by Dyer et al. (2015) that some patients were willing to suffer financial hardship through debt from borrowing to access treatment. A similar observation was made in a Vietnamese study by Wiersema et al. (2009) that the cost of ART of approximately \$3000, was unaffordable, but respondents were willing to sell their houses in order to pay for the treatment. A systematic review by Dyer and Patel (2012) also concluded that infertility treatment could lead to financial ruin in those who invested their already limited resources in the treatment.

The differences between observations in both countries can be attributed to the financing of the treatment. As stated in Section 4.4.6, the ART cost in the UK encompasses all the direct costs attributed to the treatment, which include the consultations,

stimulation drugs, fertilisation, embryo transfer and pregnancy confirmation. In Nigeria, although the direct costs are included in the fee, a one-off payment is not made. The initial deposit is made, and subsequent costs are 'pay-as-you-go'. This, therefore, creates an avenue for additional unforeseen costs to be incurred. Although major differences exist between both countries, there is one similarity. In both, the lower economic quintiles would experience crippling costs if repeat cycles are required.

There is a dearth of information on out of pocket payments for ART in Nigeria, which makes comparisons within the country quite challenging. Most studies that present information on the cost of the treatment often focuses on the cost in terms of utilisation. For example, Adesiyun et al. (2011) sought to examine the perception and awareness of ART among infertile women in Northern Nigeria. The authors reported that only 3% of the surveyed population could afford a treatment cycle, although, most would opt for it if recommended (Adesiyun et al., 2011). Studies in LMIC have evaluated catastrophic health expenditure for various health conditions (Arsenijevic et al., 2013, Kavosi et al., 2012, Onwujekwe et al., 2012, Raban et al., 2013, Ranson, 2002); however, infertility treatment costs were only examined in a South African study by Dyer et al. (2013).

The traditional economic theory states that the cost an individual is willing to pay for any product or service is equivalent to its perceived benefit. However, these traditional economic tools do not lend themselves to an inexact medical intervention such as ART. Chambers et al. (2009) state that "*the cost of ART reflects the costliness of a country's health care system*". The findings show that within Nigeria, access to ART is 'prohibitive' due to a lack of financial protection or coverage for the procedure within the public sector.

### ***Subjective financial well-being***

Majority of the participants within the 'poor' socio-economic quintile in the UK cohort endorsed moderately having enough money to meet their treatment needs. This result shows that objective measures of economic status (quintiles) do not adequately capture the meaning of income adequacy. As shown in the catastrophic expenditure method, participants within this economic quintile (if the threshold was <40%) could

incur catastrophic expenditure. However, the majority of them felt that they moderately had enough money. Some others reported completely having enough money to meet the treatment needs while only a few participants within the 'rich' quintile reported completely having enough money to meet their treatment needs. As Khan and Fazio (2005) state 'income and financial strain (a form of SFW) are not the same', therefore, "*a level of income that may be sufficient to meet one individual's needs may not be sufficient for another*". This could be because perceptions of income adequacy can be influenced by comparisons with one's social group, and has been shown to vary across different local and societal contexts (Whelan et al., 2001, Whelan and Maître, 2013).

The study findings equally show that within the UK cohort, annual household income was predictive of subjective financial well-being. This finding has equally been shown in other studies (Bonke and Browning, 2009) in which the authors suggest that the relationship between income and financial satisfaction is positive but moderate in magnitude, with correlations around .20-.40 (Johnson and Krueger, 2006). A similar result was not observed within the Nigerian cohort. Majority of the women in the high economic quintile in the Nigerian cohort responded "not at all" to the question of having enough money to meet their needs.

As opposed to the predictive association observed between subjective financial well-being and income in the UK cohort, in which higher income results in more money to meet one's needs, there was no correlation between both variables in the Nigerian cohort. This could be because financial satisfaction (used here as a measure of financial well-being) in many LMIC is a concept that may not be wholly described by income, as some households get income in kind, e.g. children remitting to parents, in-laws contributions, monetary gifts and so on. This could be the reason that a few participants classified within the *poor* quintile endorsed 'mostly' having enough money to meet their treatment needs. Additionally, as it is a subjective assessment, it could also be posited that the social pressure to conceive might be unusually high within this group, and therefore they were willing to pursue the treatment despite significant resource limitations.

Furthermore, annual income or expenditure may not determine financial well-being by women in most LMIC as the definition of the household that has to be supported from that specific income is difficult to operationalise (Kakwani and Silber, 2008), and wasn't assessed in this study. Therefore, even if the women/household could have a relatively high annual income, they may not be financially satisfied as was evident in the results. These findings suggest that within both cohorts, particularly in Nigeria, some financial insecurities and vulnerabilities remain. Meaning that it was not only 'poor' women who were concerned about their financial situation. In summary, it may be pragmatic to state that those who felt insecure about their financial situation probably have the most accurate view of reality. This is because even the most careful financial planning may not be adequate to cope with the monetary loss associated with ART, especially if repeat cycles are to be considered.

This method of affordability assessment presented descriptive information of the respondent's answers to a question on financial well-being. It focused on women's personal feelings towards their income adequacy to meet treatment needs with no relation towards actual household income. A good number of researchers have demonstrated the relationship between socio-economic status and health in the UK (Benzeval and Judge, 2001, Benzeval et al., 2001, Ettner, 1996, Wilkinson, 1996, Arber et al., 2014), and have observed a reasonably linear relationship between income and health or income and ART discontinuation (Scambler, 2012, Kunst et al., 2004, Gameiro et al., 2012, Eisenberg et al., 2010). However, the relationship between subjective financial well-being and ART has relatively been ignored. Given the importance to infertility researchers, health care providers and policymakers in differentiating whether it is the patient's income or perception of their financial situation (SFW) that impacts their physical, psychological and social health, and the numerous studies indicating that psychological stressors can affect ART outcomes gauging women's economic security seems a plausible avenue for exploration.

### ***WHO/HAI Method***

The results of this study using this method, demonstrates significant inequalities in the affordability of ART in both countries, but predominantly in Nigeria. The lowest paid unskilled government worker in the UK requires approximately two months and

four days wages to purchase a standard IVF treatment cycle. In contrast, in Nigeria, this equated to about three years and three months wages. A similar finding by Adesiyun et al. (2011) showed that the cost of an ART cycle was \$4000, despite a minimum monthly wage of a public-sector worker of approximately \$100. To my knowledge, this is the first study in Nigeria and the UK estimating the affordability of ART using this method. Therefore, literature to compare with the findings of this study is scarce.

This method of assessing affordability does not take into account the income distribution of the population. Instead it presents a relatively simplified approach to assessing affordability by allowing the individual place themselves in the position of the lowest paid government worker. Many studies have examined the affordability of various drugs for ailments such as tuberculosis, asthma, HIV amongst others using the WHO/HAI method (Rajeswari et al., 1999, Fletcher et al., 2015, Cameron et al., 2009, Cameron et al., 2011, Mendis et al., 2007, Sado and Sufa, 2016, van Mourik et al., 2010). However, available evidence of this method with infertility medicines or ART is limited. A detailed review of the literature in this area is beyond the scope of this research; however, a few observations are pertinent to this discussion.

According to Huyser and Boyd (2013), the major cost-drivers of any IVF cycle are the laboratory fees (35%), the consultation fees (29%) and the medication costs (28%). Several studies have described methods and approaches to reducing the cost of fertility treatment (Ombelet et al., 1997, Pelinck et al., 2006, Ombelet and Camp, 2007, Hovatta and Cooke, 2006) to make this more affordable particularly in LMIC. Briefly, these include low-cost hormonal stimulation (Cooke and Lenton, 1994), maturation of oocytes *in vitro* (Child et al., 2001) and vaginal culturing (Ranoux et al., 1988). Of note is the reproductive justice movement known as the 'Low-Cost IVF (LCIVF)' (Inhorn and Patrizio, 2015). This movement advocates the provision of affordable treatment options to infertile couples around the world, particularly those residing in low resource countries (Hammarberg and Kirkman, 2013). However, the Low-Cost IVF technique cannot transcend the high cost of an intra-cytoplasmic sperm injection (ICSI) procedure, as there is still no published technique to offer ICSI at cheaper costs in low resource settings. Therefore, the LCIVF movement might only solve a proportion of the problem, as it can only be used in cases that require conventional IVF procedures (Inhorn and Patrizio, 2015).

Furthermore, none of these techniques have reported successful clinical trial values (Fathalla et al., 2006).

Secondly, as the stimulation drugs constitute a major part of the costs, local production of these drugs might drastically reduce the treatment costs, and the savings could be deployed back into the health budget to meet other needs. In India, the health system has developed low-cost ART strategies, enabling quality and affordable health care. This lures non-nationals to the country as a choice destination for medical tourism. The production of these drugs within a country has the potential to make the treatment more affordable and decreases the country's need to import these drugs from foreign countries. For example, in Brazil, in order to improve access to treatment for people with HIV/AIDS, local laboratories were encouraged to produce anti-retroviral medicines (ARVs), which decreased Brazil's need to import these vital drugs (Galvão, 2005). Alternatively, if local production cannot be achieved, then a reduction of taxation and tariffs should be implemented. Many countries still apply tax and tariffs for the importation of fertility medicines. Considering that this is essentially a tax of the sub-fertile woman, thereby adding to her already stressful situation, there is a strong rationale for exempting fertility drugs from taxes (Olcay and Laing, 2005). In some developing countries, certain products such as insecticides, contraceptives and vaccines are exempt from import tax duties (Goldman et al., 2008), the addition of fertility drugs to the list might help reduce the cost of the treatment and make it more accessible for everyone, not just the financially capable.

Finally, *“the way a country finances its health care system is a critical determinant for reaching universal health coverage, as it determines whether the health services available are affordable to those in need of it”* (Uzochukwu et al., 2015). As stated in chapter one of this thesis, there are various policies and plans for financing health care in Nigeria; however, none are available for ART. The implementation of an insurance scheme, some form of cost subsidisation or the provision of funding for a limited number of cycles (as in most HIC like the UK) would significantly improve the cost-burden of the treatment to the Nigerian households. While the cost-burden of the treatment to the individual household might be considered exorbitant, the total treatment cost from a national health expenditure perspective is generally less. Connolly et al. (2010) reported

that the cost of a single ART cycle as a percentage of an individual's annual expenditure was approximately 20% in the UK and Scandinavian countries, but after accounting for government subsidies fell to approximately 12%. Therefore, the provision of some form of insurance or subsidisation of the treatment would greatly benefit the sub-fertile population in Nigeria by alleviating the inequalities in access to care presently in place. With the increase in acceptance of ART procedures by individuals and the society as a source of 'hope' for maximising reproductive desires, it is essential that the treatment falls within reach of the general population. In light of this, cost reducing diagnostic and laboratory procedures for infertility treatment should work concurrently with strategies to effectively reduce OPP for ART to achieve a more holistic effect (Dyer et al., 2013).

#### **7.1.4: The perceptions and funding patterns exhibited by women in both countries?**

The findings depict that in both cohorts, women expressed their concerns over funding the treatment. Within the UK cohort, some women described the worries they had about funding the treatment. This did not differ between self-funded and NHS funded women. Some NHS funded women were concerned about not being able to afford a subsequent cycle if needed, others were stressed at the thought of having to fund the procedure themselves if their free cycle does not prove successful. Equally concerned were the self-funded women, who felt like they were essentially 'paying for a gamble', as one treatment was no more assured than the next, which could potentially wipe out their savings. Among the Nigerian cohort, similar fears were shared. Essentially women were worried about spending such huge sums on a treatment that they said only had a '50-50' chance of success. Most women were aware of the price of the treatment and felt it was costly but were not willing to forfeit it.

A Canadian study by Collins et al. (1997) has argued that the cost of infertility treatment should equally include costs of consequences and complications that arise from the treatment. The authors also stated that the majority of the treatment costs usually arise from the diagnostic categories (Collins et al., 1997). This was especially true within the Nigerian cohort, as some women expressed their displeasure at having to raise funds for one treatment, only to be told they have to fund another. These other investigations and surgeries (such as myomectomies, hysterosalpingograms (HSG)

usually arise after they had already paid the initial deposit for the treatment, and follow-up investigation such as scans reveal either fibroids or blocked tubes. Therefore, they would have to stop the treatment to resolve those issues before they can continue with the IVF or ICSI procedure. In other to pay for these surgeries, they end up 'cutting into' the money they had initially saved up and planned to spend on the treatment. Indirect costs such as these are less frequently quantified than direct costs, but the majority of studies in LMIC on medical illness expenditures that have included both categories have stated that indirect costs can be 2 to 3 times greater than the direct costs (Koopmanschap and Rutten, 1994, Asenso-Okyere and Dzator, 1997, Attanayake et al., 2000, Sauerborn et al., 1996).

A few other women did not express their fears or worries over funding the treatment but just said: "*God would provide.*" Again, religion was used as a coping strategy. A similar finding was observed in Dyer et al. (2002) in which the informants stated that 'God would provide', however, this did not stop them from actively seeking treatment. Additionally, Tabong and Adongo (2013) reported that having faith in God and hoping for a miracle was a coping mechanism employed by the infertile couples in the study. Some researchers have posited that when compared with individuals who do not attribute control to any deity or external force, individuals with a keen perception of Gods control may enjoy more favourable outcomes (Holt et al., 2003a, Holt et al., 2003b, Johnson et al., 2005).

Concerning how funds were sought, the findings suggest that cost does not prevent access to care. Within both cohorts, various sources of funds were sought, which include loans, savings, contributions, extra work/overtime and a few fortunate enough received the funds as gifts from family and relatives. This finding is similar to those observed in Dyer et al. (2013) in which the authors reported that 42% of the sample population reported having borrowed money and almost half sought extra work to generate additional income and a few received financial gifts. Within the UK cohort, while some women felt they were willing to do anything to get the funds for the treatment, some others were of the opinion that if they could not afford the costs, they would forfeit the treatment. Finally, some Nigerian women were of the opinion that it was the responsibility of their husbands to fund the treatment. This finding is in agreement with



a study by Jegede and Fayemiwo (2010), about the ethical challenges of ART among the southwestern Yoruba tribe of Nigeria. The authors reported that the female respondents were of the view that it was the husband who should pay for the treatment, and this was equally corroborated by the male respondents (Jegede and Fayemiwo, 2010).

There is a dearth of information about the funding patterns of sub-fertile women. Most studies that have conducted qualitative research in this area, usually focus on the financial disadvantages, suffering and economic deprivation sub-fertile couples, especially sub-fertile women experience. These studies present accounts of sub-fertile women who discuss their lack of access to child labour, security at old age, and more commonly (especially in Nigeria and Rwanda) the customary laws surrounding financial discrepancy between the woman and her extended family (Nieuwenhuis et al., 2009, Rouchou, 2013, Daar and Merali, 2002, Dhont et al., 2011). These studies may briefly report the financial consequences as one of the social outcomes or related to the treatment-seeking behaviours. However, no study within my scope of enquiry was identified from Nigeria or the UK that exclusively focused on the perceptions and funding patterns of the sub-fertile women or couple. Perhaps this lacuna; particularly in Nigeria, could be attributed to the ongoing debate that it is unjustifiable to use the countries limited resources to provide more children to an already overpopulated nation perturbed with high maternal and infant mortality rates (Adegbola and Akindele, 2013, Adesiyun et al., 2011).

#### **7.1.5: Socio-demographic factors that predict the quality of life of infertile women in the UK versus Nigeria**

Within both cohorts, the lowest mean value of the domain scores was reported in the physical domain. From the factors incorporated into that domain, it can be inferred that in both cohorts, there is a relatively low activity level in daily life, low capacity for work, insufficient energy and mobility, discomfort, lack of sleep and dependence on medical aids or medication. The highest mean score was reported in the environmental domain for UK cohorts, and the same was true for the Nigerian cohorts. It can also be inferred from the results that both cohorts have relatively higher levels of satisfaction regarding the safety of their physical and home environment, access to daily information, transport, leisure, access to health care and financial resources. However, this is more prominent in the UK cohort than the Nigerian as was shown by the t-test results. In this

analysis, the highest standard deviation was observed in the social relationship domain, this has also been observed in other studies (Gholami et al., 2013b, Gholami et al., 2013a, Asnani et al., 2009, Mazaheri, 2010) and could possibly be due to the small number of items in that domain, or the different interpretations people assign to those questions.

A comparison of the mean QOL domain scores obtained in Aduloju et al. (2018) in infertile Nigerian women from a clinic in Ekiti state, with that obtained from this study indicates that women from this study/clinic have a relatively lower quality of life in all the domains. Although both clinics are located within the southern part of Nigeria, are both tertiary healthcare institutions located approximately 93miles (150km) from each other and are tertiary referral centres with catchment areas that include neighbouring states, the differences in WHOQOL scores of the sub-fertile women in the two studies was reasonably substantial. The low QOL scores in this study compared to Aduloju et al. (2018) could be attributed to the differences in the sample population. The sub-fertile women in this study were attending for ART, while in Aduloju et al. (2018), these were merely sub-fertile women presenting at the clinic. Additionally, this study and Aduloju et al. (2018) observed low social quality of life scores; however, those in this study were more significant. This low social quality of life scores could be attributed to the negative social consequences of infertility in Sub-Saharan Africa, particularly in Nigeria.

In Nigeria, social status is tied closely to childbearing, and infertility can greatly impact one's social standing in the community (Dyer, 2007). When a woman has no experience of pregnancy, labour, or parenting, she may be excluded from adult discussions (Mogobe, 2005). An earlier study by Pearce (1999) on the perceptions of infertility and childlessness among the Yoruba ethnic group of Nigeria, observed that infertility was characterised as both a personal and public issue. Therefore, infertile women are often met with unfavourable attitudes from relatives, social stigma and isolation (Dhont et al., 2011, Rouchou, 2013, Naab et al., 2013, Olu Pearce, 1999). These negative social consequences could, in turn, affect their social quality of life.

The explained variance in the WHOQOL-BREF scores relied on the fertility and socio-demographic variables. The coefficient of determination observed in the model was similar to those reported by previous studies (Ragni et al., 2005, Chachamovich et al., 2010, Lau et al., 2008, Fekkes et al., 2003). These variables were able to explain between 12-24% of the quality of life variance. The analysis of how the domain scores varied

according to the fertility and socio-demographic factors in both cohorts yielded some impressive results.

Firstly, within the UK cohort, an increase in quality of life scores was associated with age in the physical domain; however, this was not observed in the Nigerian cohort. It was anticipated that older women from both cohorts would have more stress-related problems due to their age, and the possibility of ART being their last attempt at motherhood, while younger women who had more time and the option for more attempts, would have higher QOL scores. However, the results showed that younger age was associated with decreased physical quality of life among UK women. Other studies have confirmed this finding. Similar results were observed in a study in the Netherlands by Fekkes et al. (2003) who evaluated health-related quality of life in 447 women, albeit using a different questionnaire. The authors reported that infertile women between the ages of 21-30 years, when compared with a population norm, showed more emotional and social problems (Fekkes et al., 2003). A similar sub-group analysis could unfortunately not be done in this study as only a few participants reported ages <30 years. Additionally, a similar finding was reported in a Nigerian study by Aduloju et al. (2018) using the WHOQOL-BREF questionnaire, in which the authors reported a positive association between older age and quality of life. Likewise, Chachamovich et al. (2007) observed an association between age and general and mental health, of which the authors opined might be due to older women having had more life experiences with the diagnosis, and therefore had adopted better coping strategies. However, contrary findings have been observed by other studies. For example, Khayata et al. (2003) in a study investigating the factors influencing QOL of infertile women in the United Arab Emirates reported that increased age was associated with decreased quality of life, and higher quality of life was observed in younger infertile women. These inconsistencies in the findings may be due to methodological differences between the studies, such as age distribution, population characteristics and the effects specific confounders may have in studies without the right statistical expertise.

Secondly, the results showed that within the UK cohort, educational level was positively associated with psychological quality of life. A similar finding was reported in a systematic review by Chachamovich et al. (2010) which showed that educational level was predictive of lower quality of life in physical health, social, mental and environmental

domains. There are a few descriptions in the literature explaining the association between these two variables. However, as Rashidi et al. (2008) states, it is possible that highly educated women feel less stigmatised as compared to those less educated. Additionally, Fardiazar et al. (2012) suggest that higher education provides higher overall insight and greater life independence, which could positively affect mental health and improve psychological quality of life. This association was however not observed in the Nigerian cohort, possibly because as Aduloju et al. (2015) states, among Nigerian women, infertility affects their emotional, social and overall well-being, and this influence is not compensated for by a higher educational status.

Thirdly, the results showed that among the UK cohort, the duration of subfertility was a significant negative predictor of psychological quality of life, with durations <5 years associated with lower psychological quality of life. This effect was not observed in the Nigerian cohort. This finding could be explained by the pressures young couples place on themselves to start a family. If indeed for these young women, bearing children is the single most crucial role in their life, then, not being able to fulfil that desire might be more stressful for them than for women with durations >5 years who might have found various effective coping mechanisms. The findings for this study were neither similar to those reported by Aduloju et al. (2015) in which the authors observed that prolonged duration of infertility was associated with lower scores in all the domains but more significantly in the psychological QOL domain. Nor can they be compared with findings by Khayata et al. (2003), Ragni et al. (2005), Chachamovich et al. (2007) and Maroufizadeh et al. (2017) in which the authors reported no evidence of the effect of duration of infertility on psychological quality of life.

Fourthly, within the Nigerian cohort, the cause of infertility was significantly associated with the physical QOL domain; however, this was not observed in the UK cohort. With the way in which this variable was scored, the findings suggest that lower quality of life scores was reported when the aetiology was female-related, and better physical QOL domain scores were reported when the aetiology was male-factor or idiopathic/unexplained. This finding is similar to those observed by Khayata et al. (2003), in which the authors equally reported lower quality of life scores among those with female-factor infertility. They suggested that this could be due to the cultural

consequences of infertility among Arabs, in which a man must remarry if the woman cannot bear children in order to ensure continuation of the lineage. They further opined that when the aetiology is a combination of a male and female factor or idiopathic, quality of life is increased (Khayata et al., 2003). Similarly, Rashidi et al. (2008) in a univariate analysis observed that health-related quality of life was better in couples reporting male infertility and a combination of male and female infertility. Conversely, Lau et al. (2008) reported that infertile women who attributed their subfertility to the male-factor reported lower quality of life scores in the mental health domain. Similarly, Maroufizadeh et al. (2017) in an Iranian study to determine the factors associated with reduced quality of life among infertile women observed that quality of life was worse in women reporting male and female-factor as well as idiopathic infertility. The authors opined that this might be because when the cause is from both the man and women, then options such as gamete donations are almost impractical (Maroufizadeh et al., 2017). Additionally, when the aetiology is idiopathic, neither couple can play a supportive role to the other, thereby reducing their quality of life (Maroufizadeh et al., 2017). Other authors such as Fekkes et al. (2003) and Amanati et al. (2006) reported no associations between the aetiology/cause of infertility and quality of life.

Finally, annual income in the UK cohort was positively associated with physical and environmental QOL, while in the Nigerian cohort this variable was equally associated with the environmental and social QOL domains. This is not surprising as Chachamovich et al. (2008) have stated that this domain (environmental QOL) is closely related to substantive issues and is, therefore, more likely to be affected by financial aspects of the respondent's life. Accordingly, the quality of life scores decreased with income values in the sample population of both cohorts, which is unsurprising as the impact of medical expenses on quality of life is universal (Shen and Wang, 2014). As ART in most LMIC is only accessible to the more financially affluent in the society, it is expected that couples seeking ART in the Nigerian cohort are relatively wealthier than the general population, which can be inferred from the rather high number of respondents reported in the 'richest' socio-economic quintile of this study. Therefore, they may be more satisfied with the environmental proponents included in this domain. Given the strong positive correlation between annual income and monthly expenditure, it can also be inferred from

the findings that the pressure to those with reduced expenditure rates has a significant effect on their quality of life.

#### **7.1.5: The effect funding the treatment has on quality of life?**

Insights from this study suggest that the quality of life experienced by women in both cohorts after funding the treatment was affected in three ways.

Firstly, for some participants, there was no effect of the treatment costs to their quality of life. Meaning the people within this group could afford to pay for the treatment without it interfering in their day to day lives or future endeavours. This could either be as a result of being financially stable enough to pay for the treatment or as a result of having saved enough to cover the treatment costs.

Secondly, for some other participants, the cost of the treatment was not the primary focus but rather the strain it put on the relationship. Within the Nigerian cohort, the emphasis was on the unpredictable nature of their husbands and the effects an unsuccessful treatment outcome would have especially after spending such vast sums of money. Within the UK cohorts, the emphasis was more on the effects the overall process (from seeking the funds to an unsuccessful treatment outcome) would have on their relationship dynamics as a couple.

Thirdly, for some participants, their quality of life was affected by the necessary changes in habits and opportunity cost persona they had to adopt to save up for the treatment. The inability to go on holidays seemed to be the most repeated 'investment' within the UK cohorts regarding the opportunities forgone for the sake of the treatment. Within the Nigerian cohort, some participants reported that major projects and life goals had to be forgone for the sake of the treatment.

Additionally, one effect which was exclusive to the Nigerian cohorts was concerning coping with the considerable costs of the treatment. Unlike a few of the UK cohorts who had established that they would rather forfeit the treatment than incur debt or excessive expenditures, a few of the Nigerian participants were unperturbed about incurring catastrophic expenditures due to their desperation to have a child.

### **7.1.6: Relationship between social support, perceived stress and quality of life: Findings from both cohorts**

Over the past few decades, researchers have focused their attention on the role social support plays in the experience of infertility or the lived experiences of infertile couples. A plethora of psychological and social issues led to the identification of social support as a critical component of how infertile couples adjust to their diagnosis. This study went beyond the traditional perspective of determining associations between psychological distress (stress & anxiety) and social support perceptions, to investigating the role of social support in the relationship between sub-fertile women's stress or anxiety and their perceived quality of life.

Although previous research supports the association between these variables, the results of this study did not support a moderating/buffering effect of social support, but only demonstrated a main effect of social support on anxiety in the environmental quality of life of the UK cohort. The findings from that evaluation although not statistically significant; possibly due to small sample size, are noteworthy and make a valuable contribution to the body of knowledge. It increases our understanding of the potentially protective role of satisfaction with social support and not just the number of people available for support in preventing high-stress levels in sub-fertile UK women.

Against the expectations, the results show that in the Nigerian cohort, social support did not moderate the relationship between stress and quality of life. Such findings, although quite difficult to defend, can be explained by a number of factors. The first possible explanation for the lack of a moderating effect of social support is based on the theoretical framework of social support as a coping strategy stated in the literature review (section 2.). Lazarus and Folkman (1984) in describing the 'coping' process state that it is "*sensitive to both the characteristics of the individual that appraises the stressor, available coping resources and the environment; its demands and framework.*" Therefore, it is possible that the relationship between social support and quality of life may have been influenced by the woman's personal characteristics such as her beliefs, motivations, and culture, her surrounding environment (which is related to the nature of the stressor e.g. cause of infertility, duration) and the quality of available support she had.

Additional explanation of the results of this study was found from various studies of infertility-related stress. Based on the psychosocial implications of infertility reported in the literature and the fact that a number of studies have implicated “avoidance-coping” as the main coping strategy adopted by most infertile women (Peterson et al., 2006a, Peterson et al., 2008, Schmidt et al., 2005b, Schmidt, 2010), it is plausible then that women who experience significantly more stressful events tend to utilise social support less. Therefore, it may be reasonable to assume that the majority of women who participated in the study experienced either psychosocial or financial stressors which prevented them from effectively utilising the available social support and enhancing their quality of life.

Another essential aspect to consider especially in regards to social support and quality of life is that sometimes social relationships can be a source of conflict, stress and tension (Helgeson, 2003). There are adverse effects of social relationships on quality of life, because sometimes the people in one’s social environment may not be support resources but support burdens. Most times negative interactions are often more significantly predictive of quality of life, and when a diagnosis of infertility is included, an avoidant attachment style is usually adopted. Therefore, although the stress is persistent, negative interactions from one’s social resources might hinder access, and in turn, reduce the quality of life.

The results of this study offer a valuable contribution to the literature in improving our understanding of the role of social support in two culturally diverse populations and its consequences on perceived stress levels. The hypothesis that an increased number of people available for support would improve quality of life was not supported within this sample in either country, suggesting that the quality (satisfaction with available support) rather than the quantity (the number of people) was a better determinant of QOL scores, especially within the UK infertile population.

#### **7.1.7: The social support behaviours exhibited by the women in both countries and how it contributes to how women cope with the stress of ART**

There are salient differences between the experiences of social support of sub-fertile women in the UK versus Nigeria. However, there were similarities between social



support behaviours exhibited by the women in both cohorts predominantly regarding disclosing information about their treatment.

Within this study, decisions to reveal or conceal information about their infertility diagnosis and treatment were often shaped by issues related to protection and risk. Steuber and Solomon (2011) state that the vulnerability people feel about disclosing personal information falls into three categories: risk to self, risk to the relationship and risk to other people. Within this study, a few of the UK women expressed the importance of keeping their treatment a secret because they did not want to be asked about it, while some others felt that they did not see the need to inform anyone about, mainly because if they were trying to conceive naturally, no one would be the wiser. Similarly, a sense of privacy was observed within the Nigerian cohort, with several women not wanting to speak to anyone about it stating, "*it's between me and my husband alone*". Some other times it was based on fear, due to a lack of discretion from friends. Green (2009) states that when personal information is perceived as stigmatised, then the risk is heightened. Meaning that in a situation such as infertility which most sub-fertile and fertile Nigerian women perceive is stigmatised, there is a fear of negative consequences should others know that personal quality. Therefore, many women choose not to disclose information about their treatment or diagnosis to anyone perhaps to shield themselves and their partners from ridicule (Steuber and High, 2015).

Emotional support was the major reason most UK participants disclosed information about their treatment. Emotional support also referred to as 'esteem support' is the communication to persons that they are valued, despite any difficulties or faults (Cohen and Wills, 1985). This type of support is usually seen in family relationships and fosters closeness. As it has been well documented that closeness predicts disclosure in family relationships (Vangelisti and Caughlin, 1997, Golish and Caughlin, 2002), it is unsurprising then that some UK women were willing to reveal information about their treatment to their mothers or sisters without any perceptions of risk. However, some participants in both cohorts reported a *dearth of understanding* by their family, who could not adequately empathise with their predicament. The issue most UK women raised was about the responses they got, which include "don't worry about it" or "it will happen". Helgeson (2003) suggests that this could be the family members way of portraying

reassurance/emotional support. However, it can also be perceived as minimising the couple's problems, which in most cases negates the experience of telling them about it. Mindes et al. (2003) observed that not only are unsupportive responses associated with poor adjustment, but they equally are predictive of depressive symptoms and psychological distress in most infertile couples.

Financial support was the second reason participants gave for informing their family about the treatment. A few participants in both cohorts reported receiving financial support from their family, however, both equally reported a lack of financial support, but with different circumstances. In the UK cohort, this was attributed to the fact that family members did not have the means to assist them financially, however, in Nigeria, family members who could afford to assist, chose not to.

The next theme to emerge was support from partners or significant other. Most women in both cohorts described receiving *emotional support* from their partners and most felt their partner was their primary source of support. A similar finding was reported in a study in South Africa, in which the women described their husbands as supportive and understanding (Dyer et al., 2002b). Boivin et al. (1999) equally reported that talking to one's spouse served as a source of support, and Agostini et al. (2011) observed that married women reported the highest support from their husbands. This study's finding was also in keeping with other studies that have shown a positive effect of infertility on marital harmony (Schmidt et al., 2005a, Eren, 2008). Partnership dynamics within a couple has been documented to act as a buffer against or contribute to the stress associated with infertility in couples (Ying et al., 2015).

A few studies on partner support in infertility have shown that when the couple are supportive of each other, it positively affects their psychological well-being and marital relationship (Martins et al., 2014, Peterson et al., 2006a, Peterson et al., 2008, Ying et al., 2015). However, a lack of partner support was also reported by some UK as well as Nigerian women. A few UK women described feeling frustrated with their partners because they were solely responsible for the initiation of most of the treatment decisions and felt that their partners were uncooperative. A similar finding was reported in Bhatti et al. (1999), in which the authors reported female respondents complaining about their husbands being lazy and not taking the initiative to get treatment. Within the

Nigerian cohort, some women reported having conflicts with their partners, while some others reported a complete lack of financial support from their partners most notably due to the aetiology of infertility. A similar finding was observed in Hollos (2003), in which some informants report that their husbands refused to pay for their infertility treatment. Some studies have shown that a lack of spousal support leaves sub-fertile women vulnerable to a plethora of stressful situations and can lead to domestic violence (Omoaregba et al., 2011, Upkong and Orji, 2006) as was evident in this study.

Support from friends was also mentioned. Here participants described some reasons they informed their friends about the treatment which was primarily for guidance and acceptance. A few women from both cohorts reported talking about their treatment with friends, which were essentially other women who had gone through the treatment process before, as these women would be most empathetic of their situation and provide adequate guidance through their own experiences. These friendships helped alleviate their preconceived fears about the treatment, and in some cases, the women reported learning about the financial aspect of the treatment and how to approach it. Some studies have shown that the availability of friends can contribute to both marital and personal well-being of the couple, and provide increased means of support as they navigate their reproductive difficulties (Felmlee and Sprecher, 2000, Sprecher and Felmlee, 2000, Birditt and Antonucci, 2007). A few other women in both cohorts equally reported informing friends for spiritual support in the form of prayers. A similar finding was observed in a study in South Africa in which all the women expressed religious beliefs as an essential source of support (Dyer et al., 2002b). However, most Nigerian women reported not having any friends, again for fear of their lack of discretion and in a few cases a lack of quality support in the form of unwanted advice.

Some Nigerian women did not see their partners, families, or friends as a source of support and instead stated that 'God' was their principal source of support. Hall (2006) states that in painful and challenging situations, individuals usually seek meaning to their situation by turning to God and religion, and it has been shown to reduce despair. This finding is similar to those observed in Donkor and Sandall (2007), Dyer et al. (2002) Farzadi et al. (2007) and Karaca and Unsal (2015) in which the authors report respondents turning to their religious beliefs for support. The positive effects of religion

have been found in research involving all ages, genders, religious groups and health conditions (Levin and Vanderpool, 1989, Levin and Vanderpool, 1991, Levin, 1993, Levin et al., 1997, Levin and Chatters, 1998). These studies have unanimously shown that the positive effect of religion on health is based on "*the assumption that the experience itself is positive and healthy*" (Seybold and Hill, 2001).

Respondents mentioned support from work colleagues in both cohorts. A few women reported informing their colleagues about their treatment in case they needed them to cover for them at work. There is limited research on the impact of workplace support on infertility treatment, and therefore there is insufficient information from the to draw definitive conclusions about this. However, because the stress of infertility has been considered to be as traumatising as those of patients diagnosed with grave medical conditions (Domar et al., 1993), inferences can be made from the study findings. The decision to disclose treatment details to someone at the workplace could depend on the either the prevailing organisational attitudes towards infertility and infertile women seeking treatment, the extent to which the psychological stress of the treatment or diagnosis affects the woman's work, or the availability of workplace support (Swanberg et al., 2007).

Within both cohorts, some women felt it was unnecessary to inform work colleagues but somewhat more important to inform people in higher authority within the work environment like managers and bosses, primarily for job security. Again, there is insufficient evidence to make definitive conclusions about co-worker and employer response to infertility-related stress and job retention. However, studies on workplace support have shown that workplace support can be in two ways, informal (supervisor providing emotional support) or formal (the organisation providing a support policy). In this study, very few women reported informing work colleagues for emotional support.

Finally, emotional and informational support from healthcare providers was reported by a few women in both cohorts. As the findings in this study showed, most women preferred to keep their diagnosis and treatment a secret from their friends and social networks, either because they did not want to be asked about it or a lack of trust and discretion by their friends. However, they inevitably have to share their situation

with their doctors and other health care providers. Therefore, emotional and tangible support by health care providers is welcomed and could decrease treatment stress. For example, where one woman mentions a nurse whom she says, “*gives me hope*”. As studies have shown that hope is positively associated with happiness and psychological-adjustment and negatively associated with social withdrawal and self-criticism (Chang, 1998, Peterson, 2000, Snyder et al., 1991), words and actions that communicate hope likely have implications towards alleviating the stress of infertility experienced by the women. A lack of empathy, patience and cultural understanding by health care providers can affect the ability of the woman to deal with not just her subfertility diagnosis but also the treatment. Health care providers should equally not overlook the fact that women displaying ‘social withdrawal’ are at an increased risk of anxiety, stress or depression (Karaca and Unsal, 2015). Emotional support by health care providers comes at no cost to the patient, and as Willer (2014) suggests, the relational and emotional rewards are significant.

## **7.2. KEY CONTRIBUTIONS TO CURRENT KNOWLEDGE**

The principal contribution is that this study adds to the growing and diverse literature on the use of mixed methods research in providing conceptual clarity about the epistemological properties of quantitative and qualitative approaches to research. As this study analysed similar concepts such as funding of ART, stress, social support and quality of life; using different data sources, it was possible to compare the contributions, strengths and weaknesses of both methods.

The research covers a number of innovations and makes some significant contributions to the knowledge of the stress and affordability of ART as well as the role of social support in the two countries (UK and Nigeria). Each input is discussed below and situated within the literature where possible.

### **7.2.1. The Cost Burden of ART**

This aspect of the study covers a number of innovations. Firstly, this thesis reports the first use of the WHO/HAI methodology to examine the cost-burden of ART. The WHO/HAI method has been used in various developing countries as a standardised methodology to investigate medicine prices, availability and affordability, especially

when comparing costs in the private versus public sector. Additionally, the SFW measure has not been used in studies examining the cost-burden of ART to the patients. To my knowledge, this is the first study to use these methods in establishing the affordability of an ART procedure. It is therefore quite challenging to situate these findings within the literature, as more research is required.

Secondly, although there are many studies on the economic impact of ART in various countries, this is the first to examine the affordability of ART in two countries using a combination of three methods; namely, the catastrophic payment method, WHO/HAI method, and subjective financial wellbeing evaluation. Furthermore, no studies have used these methods in combination with a qualitative assessment.

The data collection process in this study was quite extensive. It provided information on the annual income and expenditure of each household, using the woman as the household reference person. Additionally, the perceptions of the infertile women were obtained regarding their subjective financial well-being and the source of funds was explored, to better understand these findings.

The findings indicate that in the Nigerian setting, out of pocket payments for ART pose a severe problem for patients even in a public hospital. Conversely, in the UK, households did not incur catastrophic expenditure from funding one cycle of the treatment. However, as the literature and my results show, the impact of the threshold used is significant on the outcome, especially in the UK cohort. Empirical research regarding 'affordability' has usually depicted the difficulty of univocally grasping the concept (affordability), especially in establishing the threshold to use (Niëns and Brouwer, 2013). Using the wrong threshold, (example, 40% instead of 20%) can negatively influence the sense of urgency in policymakers to act on financial matters regarding access to the treatment. To circumvent these, the suggestions of Niens et al. (2013) was employed. These include using a combination of methods and setting a threshold in relation to the good or service under study. The results obtained, and the use of a standard measure, facilitates assessment, interpretation and comparison of findings across various settings.

Affordability is an important issue especially with the growing rate of infertility worldwide. Although an acceptable cost of ART cannot simply be solicited from the infertile couple themselves or a country's national healthcare service, the desire for children is universal, and people are willing to go to great lengths to achieve this, as was shown in this study. Therefore, the current levels of unaffordability of ART in Nigeria can have detrimental health effects to these already vulnerable group of people.

It has been established that in Nigeria, the desperation to have a child motivates these households to incur catastrophic expenditures on ART. However, there is still a number of unanswered questions on this topic, which are beyond the scope of this thesis. These include: how households cope with the costs when accessing ART in private hospitals/clinics across the different nations, at what point do the Nigerian women/households give-up, and how do these households recover from the financial setbacks.

### **7.2.2. Significant predictors of stress & anxiety among infertile women**

This study's findings showed that women in LMIC are relatively more stressed and anxious than women in HIC. The elevated stress levels among the Nigerian cohort as opposed to the UK cohort could be attributed to a number of factors. Factors such as the stigma they experienced, the duration, and aetiology of their infertility, is supported by research in other countries that reported that all these factors significantly contribute to the stress, anxiety and low quality of life of infertile women (Chachamovich et al., 2010, Fekkes et al., 2003, Monga et al., 2004, Rashidi et al., 2008). The current research extends these previous findings to incorporate other factors that can contribute to the stress experienced by these women. These include, their fears at the uncertainty of the treatment; especially after paying such large sums, fears about the continuation of their marriage and the lack of financial or emotional support from their partners and family.

### **7.2.3. Social support does not buffer stress in Nigerian women**

Although the bulk of the literature promotes social support as a protective factor against stress, anxiety or depression in various settings, this study provides some evidence to the contrary. The current research shows that the quality rather than the quantity of social support is essential in HIC settings. However, in LMIC, social support can be more of a burden than an aid, especially when dealing with infertility. The dissociation between

social support, stress and quality of life in the Nigerian cohort was found to be a result of different coping mechanisms. Culture and religion plays a significant part in the lives and decisions of the Nigerian people, and infertility is considered an 'abnormality'. Therefore, infertile women are usually shunned. Following a subfertility diagnosis, some women may choose to keep their situation private as a way to cope with this life change, while others may avoid people and conversations that might involve such discussions.

In this study, some women reported a complete lack of emotional and financial support from their partners, while others reported feeling stigmatised. For example, one woman reported that her neighbours called her a '*witch*'. Infertility signifies a significant change in the life of any women, and in a pro-natalist country like Nigeria, it is a condition that does not generally encourage support. Therefore, it is possible that this life event (infertility) might be operationally identical to social support change (Thoits, 2011). Where in the UK, this diagnosis might cause friends and family to rally to the aid of the woman, in Nigeria, these people may quickly drift away.

However, an important caveat should be offered at this point. This research does not suggest that Nigerian women should not seek support in dealing with their infertility. These findings agree with reports in Thoits (1982) which emphasise the fact that social support is not a '*one size fits all*' phenomenon. There are risks and benefits to social support when dealing with infertility; however, it is important to understand individual situations and life events before trying to impose social support as a stress buffer, especially in LMIC.



# **CHAPTER 8: INTEGRATION**

## CHAPTER 8: INTEGRATION OF THE QUANTITATIVE AND QUALITATIVE FINDINGS

### INTRODUCTION

This study investigated the stress and affordability of ART using two contrasting settings: a high-income setting (UK) and a low-middle income setting (Nigeria). The study adopted a mixed methods approach; a quantitative survey and qualitative interview method to examine the differences and similarities in stress patterns, funding capabilities, social support mechanisms and quality of life of sub-fertile women in these two countries.

This current chapter combines the quantitative results of the stress, affordability, social support and quality of life with the qualitative results on women's experiences with infertility, funding, coping strategies such as social support and their quality of life.

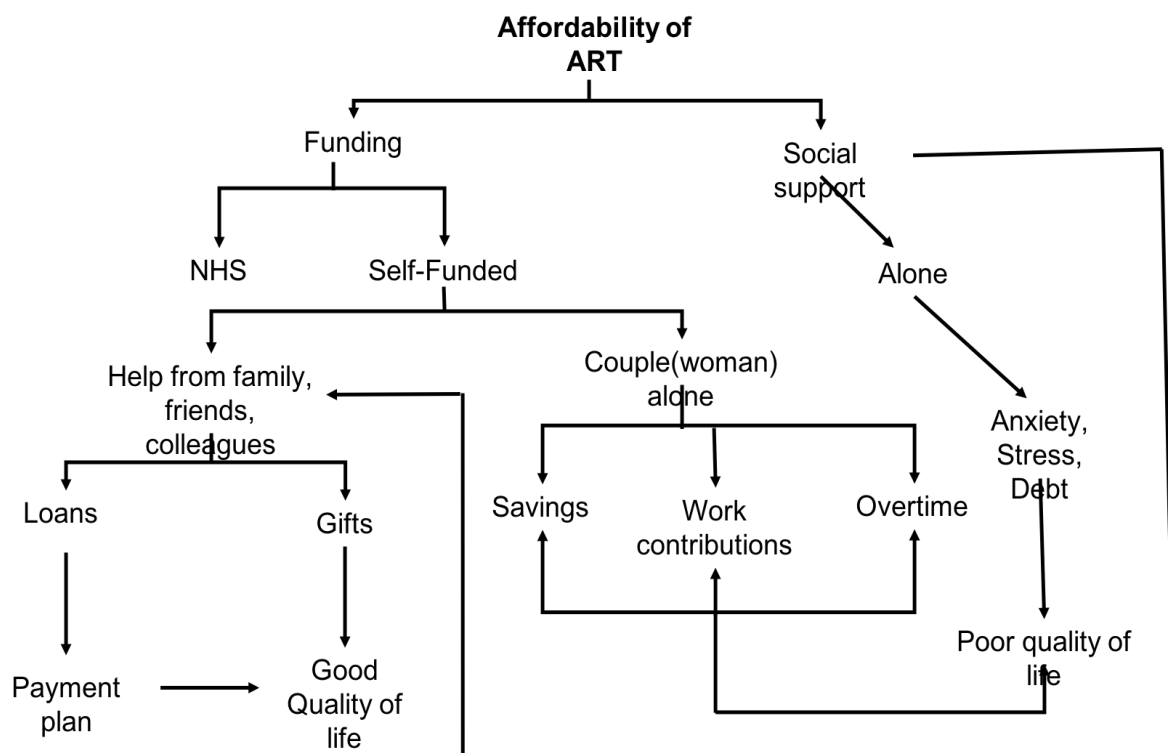


Figure 8.1: Diagrammatic representation of the relationship between stress, affordability, social support and its effect on quality of life in this study.

## 8.1. AFFORDABILITY META-INFERENCES

Three (3) meta-inferences were obtained from the combination of both studies on the affordability of ART.

The first meta-inference relates to the catastrophic overshoot observed among the Nigerian cohort. The findings from both strands on the Nigerian cohort reiterates the “willingness to pay” model, which suggests that sub-fertile couples highly value ART. However, this does not imply the ability to pay. The quantitative finding of the Nigerian cohort overshooting the catastrophic expenditure threshold from funding the treatment was explained by the qualitative results in how funds were sought. Based on the annual income and expenditure of the Nigerian households alone, it was evident that the participants were going to incur catastrophic expenditure if they had funded the treatment from their incomes. However, the qualitative findings helped put the catastrophic overshoot experienced by the majority of the Nigerian cohort into perspective. From the interview findings, we were able to understand how these expenses were financed. For example, the qualitative findings showed that one woman with a monthly income of 60 thousand Naira (~\$640) reported obtaining her treatment funds through micro-financial accumulation (‘Osusu’) from co-workers over a period before she was able to raise a sufficient amount for the treatment. Some others mentioned having used their savings, and some reported taking loans, while a few borrowed the money. As the findings in both strands (quantitative & qualitative) suggest, it is important not to ignore the financial coping strategies adopted by households especially in LMIC, as this can result in a seriously biased estimate of the relative out of pocket payments on the household expenditure (Flores et al., 2008). Relying solely on the catastrophic expenditure or overshoot results obtained in the quantitative strand ignores the various ways households draw on savings, credits and financial assistance from friends and family to meet the payment needs for the treatment. Therefore, for a short-term, they protect themselves from abject poverty or economic ‘shock’. The integration of both strands enriched our understanding that households in LMIC generally rely on different mechanisms to pay for large medical expenses such as ART, and do not solely rely on their incomes or have to sacrifice their basic needs. This is unsurprising given the magnitude of the treatment costs relative to the income distribution of the Nigerian cohorts or the subsistence living standards of many LMIC. A similar finding was observed in a study in Burkina Faso on 566 rural households by Sauerborn et al. (1996). The

authors reported that medical care was paid for by selling livestock's, from savings, by borrowing and by labour substitution (Sauerborn et al., 1996). Another study executed in a small rural village in China by Wilkes et al. (1998) reported that episodes of severe illness and subsequent expenditures were generally financed by households, without having to cut down on their consumption levels.

In the context of low-middle income populations, without any financial assistance for ART payments such as Nigeria, this mixed method study argues that acknowledging the strategies households adopt to fund their treatment has significant implications for both the measurement and interpretation of how ART payment impacts the couple's financial well-being. A failure to take the financial coping strategies adopted by these households into account leads to an oversight of the long-term opportunity costs of the treatment. By the integration of both methods, this study shows how information on the source of funds can be used to uncover the reasons behind catastrophic overshoots of households, especially in LMIC, because ART costs were financed from coping strategies.

The second meta-inference is related to the subjective financial well-being findings and how it can be equally attributed to how women sought funds. It also further explains why certain findings were observed in the analysis; such as 'rich' households not having enough money for their treatment needs. It is plausible that households/women classified within the 'rich' economic quintile who endorsed not having enough money, could have obtained the funds from their savings, and some studies have shown that this method of financial coping is usually adopted by the relatively wealthy members of society, who can better mobilize and draw on savings in time of need (Sauerborn et al., 1996, Kabir et al., 2000). However, this method also increases a household's vulnerability to future economic 'shock'. Therefore, it is possible that the women reported not having enough money to meet their treatment needs, either because they had not saved up enough money or they had to use up all their savings, which was equally reported by a few respondents.

A second method reported by participants involves engaging in additional work (overtime) to diversify their income. This coping mechanism has also been reported in Sauerborn et al. (1996) to be more stressful on the couple. A third method mentioned by the respondents involves obtaining loans. A few studies have reported that loans can be

formal or informal, but the effects of loans on the household can be severe and are usually dependent on the terms of the loan or the character of the person providing the loan (Wilkes et al., 1997, Mock et al., 2003). Findings from Flores et al. (2008) show that adopting coping strategies such as borrowing or taking loans are not the best response to meeting medical expenditure needs. These loans can lead to long term indebtedness by the couple especially when interest rates continually rise. Earlier studies have reported that indebtedness due to health expenditure is one of the major pathways to poverty and is a significant cause of its persistence (Krishna, 2006, Krishna, 2007, Kristjanson et al., 2004, Damme et al., 2004).

It is noteworthy here that although these financial coping mechanisms may protect the households from poverty and economic shock, they are 'short-term' solutions to a potentially long-term problem. Indeed, these women might be able to pay the cost of the procedure at the moment. However, the long-term implications of indebtedness and depletion of savings could be substantial. A South African study on the financial recovery of households four years after funding one ART cycle reported a less than 50% financial recovery rate among the participants (Dyer et al., 2017). Additionally, the authors reported that two-thirds of the respondents reported the financial impact on them to be quite moderate to severe.

The third avenue of complementarity between both strands in this study relates to the subjective financial well-being assessment of the UK cohort in which some households in the 'poor' economic quintile reported having enough money to meet their needs. Again, this can be explained by how funds were sought; with some women reporting receiving their treatment funds as gifts from friends and family. This highlights the importance of social networks. An example is one respondent who reported that her mother had agreed to fund her treatment. Previous research suggests that parents remain a significant source of financial support for their children, especially during times of crisis (Sarkisian and Gerstel, 2008, Fingerman and Birditt, 2011, Fingerman et al., 2011). However, this form of financial support was not observed among the Nigerian cohort. This may be attributed to the findings in earlier studies which have reported that the exchange of financial and social support between parents and adult children is more frequent among whites than ethnic minorities such as African Americans and Latinos (Cox and Rank, 1992, McGarry and Schoeni, 1995, Swartz et al., 2011). Although, the later

place greater emphasis on close family relationships for coping and survival (Diaz et al., 2007). However, these findings on the ethnic differences in financial support from parents to children are as yet inconclusive. It was evident though, from the qualitative findings, that among the UK cohort, financial support was available for some households from their families and relatives if the need arose.

## **8.2. STRESS META-INFERENCES**

The first meta-inference relates to the quantitative observation that there were no significant differences in stress patterns between self-funded and NHS-funded women. It was initially predicted that self-funded UK women would demonstrate more stressed than NHS-funded women, mainly due to their funding category (NHS/Self). The results of the quantitative study found no differences in psychological distress (stress & anxiety) between the two sub-groups, which could not have been explained without the aid of the qualitative study. Within the qualitative study, both the NHS and self-funded UK women reported similar concerns over funding the treatment and their desire for motherhood.

Within the qualitative study, both groups of women reported their desperation to have a child. Infertility is devastating and has been ranked one of the most significant sources of stress in the life of a woman, comparable only to cancer (Baram et al., 1988), ranked second when compared to the death of a loved one and divorce (Domar et al., 1993). Earlier studies by Imeson and McMurry (1996) have stated that infertility can be characterised by feelings of hopelessness, lifestyle changes by having to cope with the altered vision of motherhood, cycles of hopes and disappointment from unsuccessful treatments and feelings of isolation from the fertile female world. Anxiety, in particular, is reported to be one of the most common reactions among IVF patients followed by depression. Their anxiety levels are often elevated from the start of the treatment, during the treatment up until the point of embryo transfer (Laflont and Edelmann, 1994). It is also important to note that for some of these women, IVF or ICSI represents their last chance at childbearing. It is therefore unsurprising that there were no significant differences in stress or anxiety levels between both groups of women, as they must both be experiencing the same amount of psychological distress. Additionally, they both reported feeling pressured, stressed and worried about different aspects about funding the treatment. An example is where one NHS-funded respondent

states feeling most pressured and stressed about the fact that even her free cycle by the NHS is no more guaranteed to be successful than if she had to fund it herself. Similarly, a self-funded woman stated that she felt like they were paying for a 'gamble'. Also, both (NHS & self-funded women) reported that they were concerned about not having any savings left if they were required to fund the treatment multiple times. Additionally, some NHS-funded women stated that they often felt worried about being able to afford the treatment especially if their free cycle was unsuccessful. All these findings from the qualitative strand better explain the lack of a difference between the NHS and Self-funded women in the quantitative strand, which would have been difficult to explain without.

The second meta-inference relates to the quantitative observation in UK women of marital status being a significant predictor of stress, with unmarried/cohabiting status associated with increased stress levels. Again, it was initially assumed that married infertile women would experience more stress and anxiety than their cohabiting or unmarried counterparts. The qualitative findings also helped explain the findings. An example that explains this finding was the unmarried respondent who mentioned that although she was planning a wedding, she felt stressed and pressured because they (she and her partner) could not justify getting married without having children. The therapeutic benefit of marriage has been relatively minimised especially when compared to the accelerating divorce rates in many HIC (Bengtson, 2018). Earlier studies on self-reported levels of happiness reported that married people, in general, were happier than the unmarried ones (Bradburn, 1969, Gove, 1972a, Gove, 1972b, Coombs, 1991). Additionally, some of these authors report that single women were often happier than single men because they are more likely to develop social relationships which in turn promotes emotional support for them. However, these unmarried women were not happier than married women, which prompted these authors to conclude that marital status was a significant predictor of mental health (Gove et al., 1983, Gove et al., 1990, Coombs, 1991). This study's findings support those reported previously that depict the 'protection/support' hypothesis, which argues that emotional support provided by marital partners prevents mental illness such as anxiety.

The third avenue of corroboration between both strands relates to the duration of subfertility being a significant predictor of perceived stress among Nigerian women. In

the qualitative results, some Nigerian women stated that they ‘embodied’ stress, which most of them attributed to the length of their infertility. This finding has been quantitatively corroborated by a number of other studies and has been well discussed in section 7.1.1. However, to my knowledge, this study provides the first qualitative substantiation of this finding.

The fourth meta-inference relates to the Nigerian cohort reporting higher perceived stress levels than the UK cohort. This quantitative finding was corroborated by the qualitative findings on the experiences of subfertility reported by the Nigerian women. It is unsurprising that the Nigerian cohort reported significantly higher perceived stress levels than the UK cohort, notably because most of the Nigerian women reported feeling stigmatised in various ways, which was one theme that was not reported by any woman in the UK cohort. None of the UK informants felt isolated, verbally abused or reported being treated differently because they did not have children. However, this was a recurring theme among the Nigerian informants as was presented in the results. The potential impact of stigmatisation of infertile couples, particularly the women, has been an ongoing concern to those involved in psychosocial infertility research and has been documented extensively. The experience of infertility is stressful for any woman and coupled with stigmatisation from those who should provide emotional support such as relatives and in-laws, can be an unbearable burden for these women. With the verbal, emotional and in some cases physical abuse the Nigerian women reported in the qualitative interview, it is little wonder their perceived stress levels are significantly higher than their UK counterparts.

### **8.3. SOCIAL SUPPORT META-INFERENCES**

The first meta-inference relates to the qualitative finding of Nigerian women not having any friends. Informants that reported having some friends, stated that they did not disclose/discuss their infertility or treatment status to them. This was either due to a fear of the negative repercussions, lack of trust or as many stated, a lack of discretion. This qualitative finding helped enhance our understanding of two of the social support-related findings for the Nigerian cohort in the quantitative strand, which was the low social quality of life score as well as the low number of available support.



Firstly, the social quality of life scores among the Nigerian cohort was observed to be significantly lower than those of the UK cohort. Additionally, following statistical analysis of the data, it was observed that there was a significant difference in the availability of social support between UK and Nigerian women, with UK women having more people available to support them than the Nigerian women. This finding was equally supported by the fact that in the inter-item analysis of the SSQ scale, 25% of the women reported having 'no one' to count on for help. Possibly what was most interesting about this analysis was that, regarding their satisfaction with available support, there was no difference between the Nigerian and UK women. This finding further buttresses the theme of secrecy/privacy of the treatment by the Nigerian women identified in the qualitative research. Therefore, it can be inferred that, although these women do not have a good number of people available for support, they are quite satisfied with what they have, primarily because they want to keep their infertility and treatment status private due to the stigma associated with it. However, within the UK cohort, the women had a good number of people available to support them, they could talk to friends and family about their situation, without fear or risk of being stigmatised and they were equally satisfied with the support they received. The findings in both strands were complementary, with the qualitative findings enhancing our understanding of the quantitative results.

A second avenue of complementarity between both strands (second meta-inference) involves the findings that the majority of the women in both countries reported their husbands/partners as their principal source of support. The importance of partner support has been well discussed in chapter 7 (section 7.1.7) and so would not be further discussed here.

A third meta-inference relates to the quantitative finding of 30% of the Nigerian women reporting 'God' as their major source of support. The qualitative study provided additional insight and a more nuanced understanding of the patients' experiences with social support and how they used religion and spirituality to cope with their diagnosis. This theme of spirituality was one that emerged during the data analysis process of both strands in this study, especially within the Nigerian cohort. A discussion of this theme has already been carried out in chapter 7 (section 7.1.7); however, a summary would be provided. Elkins and Cavendish (2004) state that when faced with a life-changing phenomenon, people often turn to spirituality for comfort, relief and hope. As numerous

studies have depicted, infertility is an unanticipated and, in some cases, prolonged life crisis, with sometimes no resolution. It is therefore unsurprising that these women may use their faiths and beliefs as their primary coping mechanism during their confrontation with infertility. In establishing a holistic approach to care for infertile women, their psychological, cultural, social and spiritual needs have to be addressed in order to help them effectively cope with their diagnosis (Ledger, 2005).

The final meta-inference relates to the fact that in the quantitative study, it was observed that social support among the UK women plays an important role in cushioning the effect of stress on quality of life. Some studies have corroborated this finding by showing that higher perceived support is associated with greater quality of life and lower emotional distress in sub-fertile women (Abbey et al., 1994, Nachtigall et al., 1992, Connolly et al., 1992). The perception that others may provide tangible support may redefine the potential for sub-fertile women to appraise their situation as highly stressful. However, this finding was not observed among the Nigerian cohort. Two possibilities have been suggested as explanations by the qualitative research. Firstly, we could see that a barrier to the access of support was the secrecy with which women handled their condition. Due to the stigma associated with infertility, Nigerian women go to great lengths to conceal their condition and keep their friends and relatives from learning about it. In this situation, receiving help comes at a cost to self-esteem to not just the woman, but also her husband. In Nigeria like many other African countries, the individual does not exist in a vacuum but is integrated within the collective values, social and cultural relationships (Jegade and Fayemiwo, 2010). Therefore, living within this community, growing up as a young girl (the infertile woman), she would have seen how infertile women were treated or stigmatised within her community, by neighbours, in-laws and others and as a sub-fertile woman herself, would have experienced it in some way. This usually determines how decisions are made by the individual to keep their situation as private as possible. Secondly, it was also observed (in the qualitative study) that a few women who shared their situation with friends reported a lack of quality advice from them. It is, therefore, possible that even the received support could be ineffective in reducing stress because the persons' well-intentioned efforts to give support may fail to be helpful and can even make matters worse (Bolger et al., 2000) as was shown in the informant's statements.

**CHAPTER 9:  
LIMITATIONS  
AND  
CONCLUSIONS**

## **CHAPTER 9: LIMITATIONS & CONCLUSION**

### **9.1. METHODOLOGICAL ISSUES**

The methodological issues within this study are outlined in this section. Issues relating to designing and running a mixed methods research, the strengths and limitations of each aspect of this study, recommendations and suggestions for future work are presented.

#### **9.1.1. MIXED METHOD ISSUES**

The mixed method design of this study was intended to capture a more comprehensive understanding of the cost burden of ART to the sub-fertile population of the two different countries (UK and Nigeria), their coping strategies and social support patterns, than could have been achieved by solely using either a quantitative or qualitative method. The key strength of this study lies in the combination of both the qualitative and quantitative strands, which was a pragmatic decision to bring together the differing strengths and non-overlapping weaknesses of one method with those of the other, to answer the different research questions. The quantitative analysis was used to determine the cost-burden of the treatment to households, while the qualitative was used to explore how the households financed the treatment and also to examine how funding the treatment affected their quality of life.

The secondary objective of this study was to determine the impact of social support on stress and quality of life of the women. The original assumption about this aspect of the analysis was that, number of people available for support as well as the satisfaction with social support buffers the relationship between stress and quality of life. However, the quantitative results showed this assumption to be fallacious especially among Nigerian women. Instead, the finding was that in UK women, satisfaction with available support and not the number of people was pertinent in buffering the relationship between stress and quality of life. However, in Nigeria, neither the number of people nor the satisfaction with social support appeared to buffer the relationship between stress and quality of life. This finding would have been quite puzzling without the qualitative results on how the psychosocial, cultural and societal stigma of infertility promotes the secrecy of an infertility diagnosis and therefore prevents these women from seeking support. Therefore, both strands enrich and expand the comprehensiveness of the research topic and its contribution to current knowledge (Gell, 2013).

Previous mixed method infertility research has used a variety of approaches, which include: surveys, focus group discussions, interviews and ethnography. For example, Dhont et al. 2011, Hollos et al. 2009, Wiersema et al. 2009, Sundby, 1997. To my knowledge, the use of data sets from a developing and developed country for cross-country comparisons, alongside semi-structured interviews is scarce in infertility research. This study demonstrates the potential benefit of a mixed method design to cross-country comparisons.

Finally, the primary concern in conducting mixed methods research is usually ensuring that each strand, as well as the integration phase, is performed at a high standard. A literature review on performing mixed methods research identified quality enhancing strategies to adopt (See Table 3.3). Various aspects of the study were steered by using the quality criteria. For example, a reputable mixed methods study should outline when integration would take place. Consequently, in presenting the general methodology (in Section 3.5), this was clearly stated. Overall, this research was strengthened by a continuous reflection on these quality criteria.

### **9.1.2. STRENGTHS AND LIMITATIONS OF THE QUANTITATIVE RESEARCH**

#### ***Quantitative Study Design***

Some limitations of the *study design* include its cross-sectional nature, which does not allow for inferences of causality. Associations were explored; however, causality could not be determined. Follow-up studies would be required to address this issue. Additionally, the relatively small sample size in each cohort and the inherent constraints of self-report measures of stress and anxiety are also limitations. A future study should include a larger sample size. It is equally possible that selection bias was introduced, with women experiencing more anxiety and stress refusing to participate in the study, whereas some others may have used this as an exercise in stress reduction. Furthermore, no information was provided on the previous psychological history of the participants, regarding past mental health issues such as anxiety disorders or depression. These can be rectified by including a question in the pro-forma asking if participants have any previous history of mental health issues. This can also be verified by checking in the patient's records.

### ***Participants***

A strength of this study was a high response rate in both cohorts. I found that sending and receiving questionnaires through the mail, along with sending phone and email reminders to the participants was effective. Some socio-demographic limitations of the present study are highlighted.

Firstly, the average educational level, particularly within the Nigerian cohort, is higher than that of the overall population. This is partly because the investigation was not community-based, and the participants were recruited from clinics in major cities. Secondly, the relatively high socioeconomic groups present in the study could equally be attributed to this factor, which therefore acts as an economical filter. This can be Thirdly, although intentional, the sample population was entirely female. The study focused on women because their experiences with infertility, the treatment, financial situations, stress and anxiety, social support patterns and quality of life have been documented to be significantly different from men. Therefore, future research needs to examine how these processes work within male cohorts.

Fourthly, this is a point-in-time sampling study, and the data was collected from only two public fertility clinics. Although both clinics were located in major cities, thereby minimising geographical barriers, the results are less generalizable than if multiple sites were sampled within both countries. Furthermore, this was a cross-country ART cost-burden survey, and the way in which ART is accessed and priced, and the context surrounding the importation of the drugs (which constitute a significant proportion of the costs in Nigeria) in the different health systems in both countries was not part of this study's methodology.

Response and compliance remain major issues in studies such as this which require participants to complete multiple questionnaires. However, the strength of this study lies in the relatively high response rate, equally due to the use of pre-paid envelopes, reminder text messages as well as the use of face-to-face interviews in administering the questionnaires to a majority of the Nigerian cohort.

### ***Catastrophic expenditure method***

The strength of this method of analysis lies in the provision of a basis for assessing the financial burden to households for using an assisted reproductive procedure relative to that particular household's resources (Dyer et al., 2013). However, the interpretation of the findings from this method needs to be moderated by the limitations of the methodology employed.

Firstly, although this study tried to capture information from the low-income members of society in both countries, it is expected that the estimates generated by this analysis might underestimate the actual effect of ART expenditure on poverty. This is because ART expenditure can only be incurred by sub-fertile women/couples who actively seek treatment. However, a number of sub-fertile women do not seek treatment due to various barriers. Thereby creating an impression of a higher degree of financial protection than actually exists especially within the UK cohorts.

Secondly, this study is only measuring the cost burden of the treatment for households, based on participants reports on their current household annual expenditure and treatment costs. Out of pocket payments for the treatment might have been financed from other sources not captured by the survey instruments, such as savings, borrowing, or financial gifts. These other sources may protect the households from catastrophic expenditure (in the UK) and impoverishment (in Nigeria), and result in estimates that suggest adequate financial protection (as in the UK). However, repayment of such loans and replenishment of savings might impose financial hardship subsequently, which should be examined in future research.

Thirdly, the highest annual expenditure reported for the Nigerian cohort was approximately 600 thousand Nigerian naira (equivalent to £4462.8). This poses a threshold in itself, as some participants may spend more than that and could afford the treatment but were classified as equally incurring catastrophic expenditure. This could have increased the validity of the findings. Future research should either allow all participants to provide their income and expenditure values as an open variable or expand the range of values used for income and expenditure capture among the Nigerian cohort.

Fourthly, the cost of a single IVF or ICSI cycle was used to calculate affordability, even though women who had undergone repeat cycles were included. This could pose an

issue in the generalisability of the findings. This is particularly true in the UK cohort which reports no catastrophic expenditure, as the number of treatments undertaken can have an effect on catastrophic expenditure calculations for this cohort. However, it could also be considered that patients who have access to multiple cycles might be more financially secure.

Furthermore, due to the various differences in the price and economic structures of the UK and Nigeria, and the methods used to calculate purchasing power parity (PPP), comparisons between HIC and LMIC might be less precise than comparisons of similar economies or economies in the same region. Additionally, although PPP provides information on the overall price level of a nation's economy, it does not capture price differences within an economy or nation.

### ***Subjective Financial Well-being (SFW) method***

The findings from this method make a unique contribution to the literature by addressing some questions not previously assessed by infertility researchers. It examined the financial well-being of UK and Nigerian women sub-fertile women accessing ART. It also examined the relationship between financial well-being and an objective measure of financial wellness (economic quintile/income) to determine whether women's perceptions of their finances were consistent with the reality of their financial situation.

This study was restricted to the UK as a high-income country, which has been shown to be in an 'intermediate' position by Whelen et al. (2001) regarding income inequality and subjective financial well-being. This intermediate position enhances the generalisability of these findings to other European nations. However, further longitudinal research is required on this method in relation to ART costs.

The comparative nature of the study also provides a new avenue in comparing racial and cross-country differences in financial well-being assessment of sub-fertile women. A limitation to the method is that literature to compare with the findings of this study is scarce, and no control groups were recruited to make comparisons with: this limits generalisability of these observations.

### ***WHO/HAI method***



The strength of this method lies in the standardised WHO/HAI methodology which has been validated through several studies. The study used the national minimum wage as the benchmark for establishing the wages of the lowest paid unskilled government worker as this metric is universally available, reliable and can be used for international comparisons (Rani et al., 2013). However, some limitations do exist.

Firstly, calculating affordability based on the wage of an unskilled government worker may lead to an over-optimistic result as can be inferred from the socio-demographic characteristics of the study, in which majority of the participants had higher educational levels and full-time employment. Therefore, a significant proportion of the population may earn more or less than the minimum wage.

Another limitation of this method stems from its simplistic nature. This is because, although this method provides valuable information to local policymakers who can better position the wage in relation to the average income or income distribution of the people, it does not give clear information on what this means to the population as a whole.

Thirdly, estimation of affordability with this method did not include additions to the wages if individuals worked over-time and are rewarded for it at a premium rate, bonus payments or holiday payments, which might cause an increase in the basic hourly rate. Future research should include this as an open variable in the pro-forma, for participants to include any additional sources of income.

### ***Stress and Anxiety Questionnaires***

The overall pattern of results provides additional support for the reliability of the BAI and PSS as instruments for measuring the severity of stress and anxiety in sub-fertile patients. Some limitations include that when examining the psychometric properties of the BAI, some authors have stated that the BAI tends to over-identify anxiety in females and under-identify it in males. Additionally, employing self-report measures of assessment with the PSS and BAI, which ask participants about how they have felt in the last 4-weeks, is likely to result in recall bias. Furthermore, a control group was not used in this study, and so a comparison of the data with the general population was not possible. To rectify this, future studies should include a control group of fertile women.

### ***Social support Questionnaires***

Regarding the social support accounts presented by the respondents, this study has relied on the recipient's account of social support transactions, and there was no way of knowing the accuracy of those accounts or whether recipients were more or less accurate than providers. Additionally, although the study used a social support questionnaire that could provide information on the social support network size and satisfaction with received support, it did not access perceived support from other contexts. This could be infertility-specific support, such as, who was informed about the diagnosis, who provides emotional support, frequency of contact etc. Furthermore, future research is required to examine how these support patterns vary long term.

### ***Quality of life Questionnaires***

The strength of the WHOQOL-BREF survey includes the fact that it is the first study to examine and compare the quality of life between UK and Nigerian infertile women. Additionally, it involved the use of a previously validated questionnaire. The WHOQOL-BREF is not restricted in the determination of health conditions and therefore creates an opportunity to test if the impact of infertility is as broad and intense as other clinical conditions such as cancer or HIV. However, there exist some limitations.

While the WHOQOL-BREF represents one of the most validated instruments used in cross-country comparisons of subjective quality of life, in its breadth lies its primary weakness. It might be argued that this instrument does not collect information on all aspects related to the infertility experience of these women.

Secondly, this study recruited patients from the clinic, rather than from the community. Therefore, the findings cannot be generalised, as community-based research might reveal contradictory results on the QOL of women who do not have access to ART or choose not to undergo treatment. Thirdly, there were no control groups to determine population norm for the quality of life scores drawn. Therefore, it would be quite difficult to generalise these results, and so classifications made in this study might differ from other studies using the same instrument.

Furthermore, the role that some characteristics such as race, culture, ethnicity and religion play in the quality of life of these women in both cohorts, although slightly

mentioned in the qualitative discussion remains to be explored locally and cross-culturally.

### **9.1.3. STRENGTHS AND LIMITATIONS OF THE QUALITATIVE RESEARCH**

The principal strength of this study is that it was not limited in diversity. It presents the singularity of infertility, its treatment-seeking behaviours and funding concerns as a psychosocial issue in women from both sides of the world. In its inclusivity, it also portrays women with various durations of infertility, from those who have been coping with it for less than five years and those who have been dealing with it for 20 years and more. It also includes aspects on how infertility impacts marriages and women's perception of support.

A second strength of the qualitative study involves the flexibility of the topic guide. Using a flexible topic guide allowed the respondents to discuss the important issues to them rather than restricting the discussion to the listed topics. To expedite this process, open-ended questions were asked, and the order in which the questions were posed was adaptable so that the flow of the interview was undisturbed. The use of these open-ended questioning and a flexible topic guide allowed new themes to emerge that were not initially considered, such as lack of financial support from the partners of the Nigerian women and the use of alternative remedies by UK women.

The provision of a conducive environment in which participants felt comfortable to speak freely about their infertility issues, marital relationships and funding capabilities was a third strength of the qualitative research. This created a good rapport between the interviewer and the interviewee and promoted a feeling of trust. Reflecting on my role in the interview process, being responsive and showing a level of empathy for these women encouraged them to be more open during the interview. These strategies have been documented by Ritchie and Lewis (2009) to be necessary in conducting a successful qualitative interview.

Probably the only limitation of the qualitative study was its deliberate exclusion of the spouses of these women as it provides only one side of the story. However, reflecting on the level of interaction I had with these women and the depth of the

information they provided, I do not consider the omission of the spouse a significant limitation. This is because, the presence of a spouse during the interview might have limited the depth of our discussions and could potentially provoke some form of hostility, disagreements or abuse after the interviews and once the couple departs the venue.

## **9.2. REFLECTION ON THE INFLUENCE OF THE RESEARCHER ON THE CURRENT STUDY**

My decision to use a mixed method design was determined by my beliefs that both research methods have inherent strengths and weaknesses and it is important to integrate both methods in order to better explore women's experiences with infertility. However, a different researcher might decide to use a single research method (either quantitatively or qualitatively) to explore women's experiences with the stress and affordability of ART and might have designed a very different PhD.

In addition to exploring the strengths and limitations of the quantitative and qualitative components of the current research, it was important to reflect on how the background, experiences and beliefs of the researcher may have influenced the design, conduct and interpretation of the findings. For example, the decision to explore the study variables such as stress and affordability of infertility treatment was driven by both my experience in a fertility clinic and my background in embryology. A different researcher might have chosen different variables for analysis.

In addition to my influence on the research design, during the interviews in Nigeria, I realised I had a methodological problem. The protocol said to interview couples but where its only one person available, it had to be the woman because she is the household representative. In most cases, in Nigeria, when it was a couple to be interviewed, the men did most of the talking and especially if it was male related infertility, the woman felt she did not have anything to contribute to the conversation. I soon realised that I was missing a huge chunk of my data. There was this one major interview where the man was a military officer and he pretty much did all the talking. Then I asked about sources of support, and he said "no one, this is a closely guarded secret between me and my wife". And I said "*so, who does your wife talk to when she needs consolation?*" and he said "*Nobody, but if you want she can talk to you*". He said, "*give her your number, she will call you*". And so, I did.

That night by about 11pm, the woman called me. We ended up having a telephone interview, but it was one of the most horrific telephone calls I'd ever gotten. She was in tears throughout the conversation as she narrated her experience, and I felt equally bad because all I could say was "*it's going to be alright*". At the end of the call, I could not sleep. I kept replaying the interview in my head, and how I was literally helpless in her time of need. But that night, I knew that my data collection protocol for the Nigerian participants had to change. I could not understand why I did not have as much data from the women until after that call. I realised that these women experience heinous emotional abuse and even domestic abuse which they could not talk about in the presence of their partners. The data collection method had to change because if I had probed and they eventually open up about it, I cannot control what happens after they leave the interviews or the hospital. At this point, the choice to interview women only in Nigeria was conceived. A different researcher might have chosen not to change the protocol or have chosen different variables/issues for analysis than the one used in this research.

During subsequent interviews, most women were moved to tears when discussing their experiences. Some were quite frightening due to the graphic nature of the occurrences, while others were more disheartening. Additionally, having to listen to them over again during the transcription process was probably even more traumatic for me. Although these stories provided great depth to my research, listening to them every day took its toll on me, and in a lot of instances, I had my beliefs and convictions questioned. Most importantly, it was quite difficult to provide hope in a potentially hopeless situation for these women and I found the lines between being a researcher; trying to obtain my data, a counsellor; therapist (trying to talk some women down the suicidal ledge), and a woman, who might potentially experience this same condition (infertility), rather blurred.

As the field work progressed and I had more contact with these women, every interview became more revealing. I met women who just needed to hear a kind word, who wanted to hear that everything would be alright, who needed me to have faith and provide hope for them. But as stated earlier, it was incredibly difficult to provide hope in a potentially hopeless situation. I mean, how do I tell a woman who has just spent her life savings on a treatment to have a baby, that she has got a less than 20% chance of success, when they ask? Tell a 45year old woman who has just parted with almost 3 years' worth of savings that the odds are not in her favour, when it's all she wants to know? These

questions became more and more difficult to answer, and whenever I could, I tried to refer them to their healthcare professional within the unit, but because I introduced myself as a researcher, and had access to their records, they expected me to be knowledgeable about their situation.

Additionally, my beliefs around contraception and abortion may have influenced the interpretation of findings regarding women's experiences with infertility. For example, my belief that contraceptive use does not lead to infertility, as some of the women felt, or that it is ridiculous to deny women information and access to birth control and then also deny them the right to terminate an unintended pregnancy. This might have meant that I more easily identified instances where women described their 'guilt and regrets' over previous experiences such as abortions, than a researcher who shares a different view. Consequently, it was important to examine the data thoroughly for findings that explored, supported or contradicted my beliefs, and to discuss these findings with my supervisors to ensure a holistic interpretation of the data.

## **9.2. IMPLICATIONS FOR POLICY AND PRACTISE & RECOMMENDATIONS**

Considered within the limitations of this research, the findings suggest that the 'poorest' household in the UK cohort did not experience catastrophic expenditure from funding a cycle of IVF or ICSI. However, in the Nigerian group, even the wealthiest home overshot the catastrophic expenditure threshold by 4-7% depending on the treatment costs. The findings highlight the importance of financial risk protection of infertility treatment in LMIC. This financial protection can only be effective if ART is incorporated into the national health financing systems in the country (Uzochukwu et al., 2015). The government or other funding bodies should place a higher priority on infertility care by replacing out-of-pocket payments with more equitable ways of financing the treatment. The development of funding agencies to cover infertility costs in Nigeria might require considerable time and resources. Until such programs have been developed, the state can fund part of the treatment with strict eligibility criteria's as well as preclusions, which would provide relief to poor households. An opportunity for future research is in utilising these findings to develop and test a study to identify and explore the effects of the indirect costs associated with ART. Additionally, equity of the treatment can help alleviate the psychological stigma associated with infertility. As observed in the UK cohort, all

households have access to treatment, and none of the participants reported feeling stigmatised. Equity dramatically reduces the stigma and social suffering associated with infertility and impacts positively on social relations and gender norms (Dyer et al., 2017).

Secondly, in 2004, the National Institute for Health and Clinical Excellence (NICE) published a guideline for NHS assisted fertility services. One of its recommendations was the provision of up to three IVF cycles for infertile patients based on the age and weight of the patients (NICE, 2004). However, a 2006 survey by the British Fertility Society on IVF providers reported that there are areas in England in which no NHS-funding for IVF exist, and some with only one treatment cycle funded (Kennedy et al., 2006). Almost ten years later, these numbers still had not changed. In 2017, the NHS Sheffield Clinical Commissioning Group (CCG) published a report which stated that “the number of full IVF cycles funded by the Sheffield CCG for patients who meet the access criteria is one” (p.2). In both reports, no recommendations were made for the use of ‘non-medical’ or ‘social’ criteria for the provision of NHS-funding to these patients. The current research has provided evidence to suggest that although funding one treatment cycle might not be a cost-burden to most UK households, subsequent treatment cycles might. Additionally, it might be worthwhile to establish a mechanism for calculating the affordability of the treatment for these couples during their consultations, to prevent them from incurring catastrophic expenditures due to their desperation for a child. The findings suggest that using either method or in combination, would be effective as a ‘non-clinical’ criteria for establishing the cost burden of the treatment to potential patients. This would ensure that large proportions of their income are not spent or required for the treatment. It would also ensure that patients who insist on purchasing the treatment are not pushed into poverty when subsequent cycles are required; as this can affect their quality of life and that of the unborn child.

Thirdly, the findings of this study have an important implication for policymakers in the procurement of fertility medicines in LMIC. For example, in Nigeria, as the cost of the drugs constitute a significant proportion of the treatment costs, lowering the procurement prices could help bring patient costs down (Olcay and Laing, 2005). As most of these drugs are imported into the country, strategies to improve procurement efficiency which includes national pooled purchasing and purchasing by generic name

should be implemented (Organization, 2008). Secondly, promoting differential pricing based on the wealth of a country could benefit lower-income countries and could equally lower the cost of the drugs (Lopert et al., 2002, Organization, 2001). Additionally, policies should be put in place to address the excessive price mark-up that occurs between the time the drugs are procured to the time it gets to the patient. This can equally help reduce the cost of the drugs, and in turn the overall treatment cost. Furthermore, as already stated in chapter 4 (discussion of research question 1), exempting fertility medication from tariffs and value-added tax (VAT) might lower the prices of the drugs and the profits can then be used to finance other aspects of the health care system.

Fourthly, the findings of this study have significant implications for healthcare professionals working with infertile couples. Physicians, nurses and mental health professionals in various settings can use the findings to learn that sub-fertile patients have different stress and anxiety patterns that vary by demographic characteristics. Anxiety, in particular, has been documented to be one of the most common emotional reactions among patients about to undergo ART (Chan et al., 2006, Edelmann et al., 1994, Laflont and Edelmann, 1994). Over 50% of the participants reported stress and anxiety levels above the minimal range. It is therefore vital that clinical environments are fostered in which sub-fertile women can freely and non-judgementally discuss their feelings and seek assistance where necessary. The delivery of brief advice to these women, particularly in LMIC can be efficacious in reducing their anxiety either over the treatment or other personal treatment-related concerns. Additionally, sub-fertile women should be counselled in a way that promotes growth. They should be educated and counselled on ways that would expand their identity from solely an 'infertile woman' to being a more positive individual. This might help them achieve a better overall sense of well-being, help them relinquish unrealistic expectations about the treatment and encourage them to enjoy other aspects of their lives.

A fifth important implication of the study for clinical practice concerns the questionnaires used. The data indicate that the BAI-21, PSS-10 and SSQ-12, may be used as a way to identify sub-fertile women in need of support. Mainly pertaining to the items that were most commonly endorsed by the women in the BAI such as 'fear of the worst happening' and 'nervous', which are salient items in the context of sub-fertile women



about to undergo ART. Creating environments in which the treatment fears including financial risks are discussed with the couples prior to the treatment is essential especially when dealing with 'desperate' sub-fertile women in LMIC. This can be linked to recommendations made elsewhere that healthcare professionals working with infertile couples should address the psychological (mood swings, time off work etc.) and financial risks associated with the treatment (Dyer et al., 2013, Dyer et al., 2017). A yet unanswered question is whether high scores on the BAI and PSS could accurately predict cases for generalised stress or anxiety disorders in sub-fertile women, as determined by instruments such as the Fertility Problem inventory. Future studies need to investigate the sensitivity of these scales in comparison with other infertility specific instruments among women, especially in LMIC.

Additionally, using the SSQ-12, mental health professionals can adequately gauge the patients' perception of available support and their satisfaction with said support. Although the quantitative study did not show social support to protect against stress among Nigerian women (notably due to the stigma associated with infertility), in the qualitative study, a few women reported confiding in friends that had similar experiences. These people can adequately empathise with them, which can reduce isolation, provide encouragement, guidance and hope. This finding is consistent with Cutrona and Russell's theory of 'optimal matching', which suggests that "certain types of support are most beneficial when matched to a particular type of stress" (Cutrona and Russell, 1990). It would be important for health care providers to establish volunteer peer-mentor support groups within their various clinics, as this might be a more beneficial and cost-effective way of fulfilling support needs. This may be especially beneficial in a health care context such as Nigeria, where public funding for ART is not available, and yet patients are not deterred from seeking treatment. Such support groups would allow these women to learn from each other about funding sources and funding options available. This form of peer mentoring and support has been shown to have numerous benefits in areas such as breastfeeding, cancer care and management of postpartum depression (Ingram et al., 2005, Dennis et al., 2009, Pistrang et al., 2012). For other women who would rather not engage in the peer support programme, they can be encouraged to join online support groups (High and Steuber, 2014).

### 9.3. CONCLUSION

In reporting barriers to the access of ART, a number of studies in both HIC and LMIC have reported the unaffordable and exorbitant cost of the treatment as a major cause for concern (Giwa-Osagie, 2007, Fabamwo and Akinola, 2013, Adesiyun et al., 2011, Chambers et al., 2009, Chambers et al., 2013, Connolly et al., 2010, Dyer and Patel, 2012, Huyser and Boyd, 2013). Most studies provide information on the cost of care, with no information on the annual household income or expenditure. Likewise, very few studies have sought the perception of the sub-fertile couples on their ability to afford the treatment or explored how they obtained the funds for the treatment. Additionally, to the best of my knowledge, no study has compared this in HIC versus LMIC.

This study contributes to both the research on the cost-burden of ART in LMIC and HIC, and the mixed methods literature on the psychosocial implications of infertility, social support and perceived quality of life of infertile women. The contribution to mixed method research, is highlighted by the combined use of survey as well as interview data. A combination of both data sets in exploring the cost-burden of ART, is not widely employed. Applying both approaches in this study, provided a more comprehensive understanding of the affordability of ART to the sub-fertile woman's household, especially in Nigeria.

The Nigerian cohort experienced catastrophic expenditures for the treatment by their annual household incomes alone. However, we were able to understand that they did not solely rely on their salaries to cover the treatment costs. By obtaining contributions from co-workers, using their savings, taking loans and in some cases borrowing, they were able to meet their treatment needs. There was a lack of financial support from some partners, family and friends within the Nigerian cohort. However, this was contrary to the experiences of the UK women.

For some of the UK women, funding the treatment would have little to no effect on their livelihood because either they obtained the funds as financial gifts or used their savings. For some others, it wasn't the financial implications to their household that was their main concern, but the thought of how an unsuccessful treatment might affect their marital dynamics as a couple. Similarly, Nigerian women were more desperate for the

treatment to be successful, than their ability to pay back the loans. Results from these findings highlight the importance of financial risk protection, especially in LMIC. Additionally, the current research highlighted the socio-demographic factors that contribute to the stress patterns and perceived quality of life of the sub-fertile woman. It is essential that healthcare providers and professionals are sensitive to the socio-demographic factors that predict stress-patterns and quality of life in their sub-fertile patients. As this can vary based on ethnicity, religious and cultural backgrounds, a knowledge of how specific factors, e.g. the duration and aetiology of infertility can impact the psychological quality of life of the patients is vital to provide the best possible medical support for these women.

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## APPENDICES

### APPENDIX 1: ETHICAL APPROVAL LETTER FOR THE UK



**Health Research Authority**  
**Yorkshire & The Humber - South Yorkshire Research Ethics Committee**

North East REC Office  
Room 001  
Jarrow Business Centre  
Rolling Mill Road  
Jarrow  
Tyne & Wear  
NE32 3DT

Tel: 0207 104 8118

25 April 2016

Professor DOC Anumba  
Jessop Wing  
Sheffield  
S10 2SF

Dear Professor Anumba

**Study title:** **Stress and affordability of assisted reproductive treatments: a comparative study of the United Kingdom and Nigeria.**  
**REC reference:** **15/YH/0569**  
**Protocol number:** **STH 19129**  
**IRAS project ID:** **197700**

Thank you for your letter of 22 April 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Assistant, Miss Kerry Dunbar, [nrescommittee.yorkandhumber-southyorks@nhs.net](mailto:nrescommittee.yorkandhumber-southyorks@nhs.net)

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

A Research Ethics Committee established by the Health Research Authority



## Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

## Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

## Ethical review of research sites

### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter and response to Ethics]	NA	20 April 2016
IRAS Checklist XML [Checklist_22042016]		22 April 2016
Letters of invitation to participant [Letter of invite]	v1	12 November 2015
Non-validated questionnaire [Proforma Appendix 2]	1	12 November 2015
Other [Appendix 1 to protocol Literature review]		12 November 2015
Participant consent form [Consent qualitative]	2	12 April 2016
Participant consent form [Consent questionnaire study]	2	12 April 2016
Participant consent form [Consent saliva study]	2	12 April 2016
Participant information sheet (PIS) [PIS qualitative]	2	12 April 2016
Participant information sheet (PIS) [PIS questionnaire woman]	2	12 April 2016
Participant information sheet (PIS) [PIS Qualitative female]	2	12 April 2016
Participant information sheet (PIS) [PIS Salivary amylase]	2	12 April 2016
REC Application Form [REC_Form_22042016]		22 April 2016
Referee's report or other scientific critique report [ISR summary]		
Research protocol or project proposal [Protocol v2]	2	12 April 2016
Summary CV for Chief Investigator (CI) [CI CV]		
Summary CV for student [CV Ms Achinanya]		
Summary CV for supervisor (student research) [Robert CV]		
Validated questionnaire [Combined validated questionnaires 3]		

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

### Reporting requirements

A Research Ethics Committee established by the Health Research Authority

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

<b>15/YH/0569</b>	<b>Please quote this number on all correspondence</b>
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With the Committee’s best wishes for the success of this project.

Yours sincerely

pp



**Dr Ian Woollands**  
**Chair**

Email: [nrescommittee.yorkandhumber-southyorks@nhs.net](mailto:nrescommittee.yorkandhumber-southyorks@nhs.net)

*Enclosures:* “After ethical review – guidance for researchers”

*Copy to:* Ms Angela Pinder, Sheffield Teaching Hospitals NHS Foundation Trust

**APPENDIX 2: ETHICAL APPROVAL FOR NIGERIA**



**UNIVERSITY OF BENIN TEACHING HOSPITAL  
P.M.B. 1111 BENIN CITY NIGERIA**

**Telephone: 052-600418  
Telegram: UNITECHOS, BENIN  
Telex: 41120 NG  
Website: ubth.org**

**CHAIRMAN:** GEN. A.B. MAMMAN (RTD)  
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ADMINISTRATION:** A.P. OMOREGIE (MRS)  
B.Sc, MSc, MHPH  
E-mail: officeoftheda@ubth.org

**ETHICS AND RESEARCH COMMITTEE  
CLEARANCE CERTIFICATE**

**PROTOCOL NUMBER: ADM/E 22/A/VOL. VII/1450**

**PROJECT TITLE:** "STRESS AND AFFORDABILITY OF ASSISTED REPRODUCTIVE TREATMENTS: A  
COMPARATIVE STUDY OF THE UNITED KINGDOM AND NIGERIA"

**PRINCIPAL INVESTIGATOR(S):** PROF. DILLY ANUMBA, MS. ADA U. ACHINANYA, DR. ROBERT  
AKPARIBO, MR. MOSTAFA METWALLY, MR. JONATHAN SKULL, PROF.  
M.E. AZIKEN

**DEPARTMENT/INSTITUTION:**

**DATE CONSIDERED FEBRUARY 13<sup>TH</sup>, 2017**

**DECISION OF THE COMMITTEE: APPROVED  
REMARK:**

**CHAIRMAN: PROF. A.N. ONUNU**

**SIGNATURE & DATE**

**SUPERVISOR(S):**

**DECLARATION BY INVESTIGATOR(S):**

**PROTOCOL NUMBER** (please quote in all enquiries)

To be completed in four and three copies returned to the secretary, Ethics and Research committee, Clinical services and Training  
Division, University of Benin Teaching Hospital Benin City.

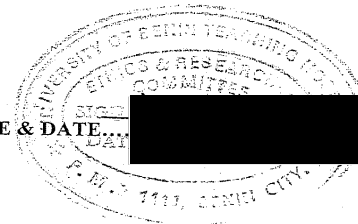
I/We fully understand the conditions under which I am/we are authorized to conduct the above mentioned research and I/We  
undertake to resubmit the protocol to the Ethics and Research Committee.

Signature...

*Prof M. E. Aziken*

Date

*13/2/17*



APPENDIX 3: CONSENT FORM

# Sheffield Teaching Hospitals

NHS Trust

Study Number: STH 19129  
Patient Identification Number for this study:

## CONSENT FORM

### Stress And the Affordability of Assisted Reproductive Technology – Questionnaire Study

**Researchers:**

Professor Dilly OC Anumba  
Mr Mostafa Metwally

Consultant in Obstetrics and Gynaecology  
Consultant Subspecialist in Reproductive  
Medicine and Surgery  
PhD student

Miss Adannaya Achinanya

Please initial box

1. I confirm that I have read and understand the information sheet Version 1 dated 12 11 2015 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the above study
4. I understand that all the information that is collected will be kept strictly confidential.
5. I understand that relevant sections of data collected during the study may be looked at by individuals from Sheffield University, from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

STH: 19129 Version 2 dated 12/04/2016

**Participant Information Sheet**

**Stress And the Affordability of Assisted Reproductive Technology –  
Questionnaire Study WOMAN**

Chief Investigator: Professor Dilly Anumba. Honorary Consultant in Obstetrics & Gynaecology/Subspecialist in Fetomaternal Medicine

*You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. You can also seek further advice from the Patient Services Team (PST), Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF, Tel: 0114 2712400, Email: pst@sth.nhs.uk.*

**1. What is the purpose of the study?**

You are about to undergo/have recently undergone an assisted reproduction technique (ART) to help you achieve a pregnancy. The purpose of this questionnaire survey is to find out how stressful this experience is for you, and whether being able to afford this procedure yourself affects your levels of stress and anxiety. Our findings may inform government policy regarding whether making ART more affordable across repeated cycles, when required, could improve the experience of couples as well as reduce the stress and anxiety associated with ART.

**2. Why have I been chosen?**

We will survey women (and their partners where possible) undergoing ART to find out whether the level of funding and emotional support which they have whilst undergoing ART treatment influences stress and anxiety levels associated with the procedure.

**3. Do I have to take part?**

No. It is up to you to decide whether to take part or not. You are free to withdraw from the study at any time and without giving a reason. Whether you join the study or not will not affect your care at the hospital in any way.

**4. What will happen to me if I take part?**

We would ask you to consent to fill in a questionnaire. If you take part you would be required to fill the questionnaire whilst attending the hospital on a clinic visit, or alternatively fill it in at home and post it back to us in a self-addressed envelope. We will ask you to fill in the questionnaire 3 months after your first interview, to assess whether you feel any different from how you did before your treatment. You will not need to attend clinic more often than usual. You would not need to have any extra physical examinations or investigations. You would not need to take any additional medicines.

**5. What are the benefits of taking part?**

You will not derive any benefits from taking part in the study. However the findings of this study may enable better care of other women who are trying to conceive through ART in the future.

**6. Will this study harm me in any way?**

There should be no risks from taking part in this study.

**7. What if I am harmed?**

If you are harmed by your participation in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action.

**8. What will happen with the results of this study?**

We will analyse the data to see if the results can be used to care for patients in the future. We may also publish our results in medical journals and share our findings at relevant conferences. You will not be identified in any report/publication. If you would like a copy of the research report we will send this to you.

**9. Will my taking part in the study be kept confidential?**

Yes. All information that is collected about you will be kept strictly confidential. The data that we obtain from you in relation to this study is kept anonymised so that no one can trace the information to any individual study participant. When the results are published, no names will be used, and it will not be possible to identify anyone who has taken part

**10. Will anyone else be told about my participation in the study?**

No. However, if you wish us to, we will inform your GP that you are helping with this study.

**11. What will happen if I do not want to carry on with the study?**

You will receive the same quality of clinical care even if you withdraw from the study.

**12. Who has reviewed the study?**

This study was given a favourable ethical opinion for conduct in the NHS by the Yorkshire Research Ethics Committee.

**13. Who is organizing and funding the research?**

Professor Dilly Anumba (Consultant Obstetrician and Gynaecologist) is organizing the research within the Obstetric, Gynaecology & Neonatology Directorate at Sheffield Teaching Hospitals NHS Foundation Trust. The study is funded from the Medical Research Council.

**14. What if I wish to complain about the way in which this study has been conducted?**

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you.

If you have any complaints, queries or concerns you may contact either:

Chief Investigator: Professor Dilly Anumba Consultant Obstetrician and Gynaecologist, Jessop Wing, Tree Root Walk, Sheffield S10 2SF on 0114 226 1075

OR

**APPENDIX 5: TOPIC GUIDE**

**INTERVIEW GUIDE**

**General Research Area:** Stress and affordability of ART, the impact of social support on and their perceived quality of life

**Specific research question:** To explore from the perspective of the couple/ patient undergoing the procedure, the extent to which affordability of ART contributes to the stress experienced and the impact of social support mechanisms on these stress patterns.

**Interview topic:** Icebreaking questions, experience with infertility & treatment experiences with funding the treatment, feelings towards social support and opinion about quality of life.

**INTERVIEW GUIDE PROTOCOL**

<p><b>INTRODUCTION/KEY COMPONENTS</b></p>	<p>I want to thank you for taking the time to meet with me today. My name is Ada Achinanya, I'm a research student, and I would like to talk to you about your experiences before the treatment particularly how it has been for you (stressful or otherwise), and whether being able to afford this procedure affects your stress &amp; anxiety levels.</p> <p>There are seven (7) questions in total, and each should take about 2-3 minutes to answer. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we are on tape, please be sure to speak up so I don't miss your comments.</p> <p>All responses would be kept confidential. This means that your interview responses will only be shared with the research team members and we will ensure that any information I include in my final write-up does not identify you as the respondent. Remember you don't have to talk about anything you don't want to and you may end the interview at any time. Are there any questions about what I have just explained? Are you willing to participate in this interview? If so, please read and sign this consent form...Thank you.</p>
<p><b>QUESTIONS</b></p> <ul style="list-style-type: none"> <li>• No more than 7 open-ended questions</li> <li>• Ask factual before opinion</li> <li>• Use probes as needed</li> </ul>	<ol style="list-style-type: none"> <li>1. Can you tell me a little bit about yourself?</li> <li>2. Can you tell me about the decision-making process of undergoing ART, and what was going on through your mind?</li> <li>3. Please tell me about your experiences (as a couple) with funding your treatment, and how it's been.</li> <li>4. How has funding this treatment affected your household/lifestyle?</li> <li>5. Can you tell me how you feel funding this treatment might affect your quality of life in the next couple of months?</li> <li>6. Has considerations of funding affected your worries regarding IVF treatment?</li> <li>7. Please tell me about any kinds or sources of social support you or your partner has received before or after deciding to undergo this treatment.</li> </ol>
<p><b>KEY CLOSING COMPONENTS</b></p> <ul style="list-style-type: none"> <li>• Additional comments</li> <li>• Next steps</li> <li>• Thank you</li> </ul>	<p>Is there anything more you would like to share? I'll be analysing the information you and others given me over the next couple of months. Would you be happy for me to contact you if I've got additional questions or for the follow-up interview? Thank you for your time and good luck with your treatment.</p>



## APPENDIX 6: CONTACT SUMMARY

### 6. APPENDICES

#### 6.1 Appendix A: Contact Summary Sheet

Contact type: \_\_\_\_\_

Visit: \_\_\_\_\_

Phone: \_\_\_\_\_  
(with whom)

Site: \_\_\_\_\_

Contact Date: \_\_\_\_\_

Today's Date: \_\_\_\_\_

Written by: \_\_\_\_\_

1. Impressions from the contact:

2. The main issues or themes that struck you in this contact:

3. New or remaining target questions for the next contact with this (person, family)

4. Concerns: