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Assisted Reproductive Technology: Perceptions and Behaviours in Guatemala before and during the Covid-19 Pandemic

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“Today, encouraged by the rapid advances in the field of assisted reproduction that took place in the past decades, we dare to predict that the field will continue to evolve, and evolve rapidly”

(Emre Seli, 2019).

Abstract

Infertility is a challenge many people presently face and will continue to face in the future around the world. Conceiving can present several psychosocial challenges and obstacles in Western and non-Western countries. Two ethnic groups in Guatemala (a non- Western country), namely The Maya[1] and Ladino (Maya n = 35, 11 males 14 females, mean age = 27.3, Sd = 7, and Ladino n = 146, 58 males and 88 females, mean age = 29.2, Sd = 10.3) were investigated on the perceptions and behaviour towards Assisted Reproductive Technology (ART) (study 1). The study was conducted a few months before the outbreak of the Covid-19 pandemic. A 13-statement questionnaire e.g., "children born by ART may be socially withdrawn" was presented to the participants to rate on a Likert scale, ranging from 1 = Strongly Agree to 5 = Strongly Disagree. Furthermore, participants were instructed to justify their response by making written comments and rating their level of knowledge about ART on a scale 1 = not at all to 10 = a considerable amount. Half of the participants rated their level of knowledge before reading the questionnaire items, the other half after reading the questionnaire items. Demographic information and factors namely, age, gender, religion, education and knowing someone undergoing ART were also recorded. Data collection took six months to complete (April to September of 2019). Data was subjected to Principal Components Analysis followed by Stepwise Regression, Factorial Anova and Correlational analyses. Written responses (219 from The Maya and 931 from Ladinos) were subjected to Thematic Analysis (TA). The results generally showed that religion, social acceptance, trust in modern medicine, gender,

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[1] Throughout the text The Maya will be referred to using proper nouns and common nouns depending on the context.

and ethnicity play an important role in Guatemalan populations' perceptions and behaviour towards ART.

The results of study 1 was supported by findings of key medical fertility practitioners in Guatemala (study 2) and in the UK (study 3), two single case studies. The two single case studies also extended to investigate if Covid-19 will, or has already, had an impact on study 1 findings and patients' perception and behaviour towards ART. Findings from studies 2 and 3 via the application of Interpretative Phenomenological Analysis (IPA), mirrored study 1 findings to a large extent on secrecy, racial integration issues, religion, and risk factors. Both practitioners in Guatemala and the UK indicated that since Covid-19 there are new concerns about risks involved regarding ART treatment.

Study 4 was a Scope literature review (between the period of 2020-2021) of the impact of Covid-19 and possible changes in behaviour of patients involved in ART treatment. The results indicated an overall distress caused by the Covid-19 pandemic and the worries triggered when undergoing infertility treatments during this very difficult time. The importance of continuing infertility treatment during the Covid-19 pandemic was also a factor in the findings. These findings also illuminate that if treatments were to stop, it would be detrimental to patients and the scientific community.

In general, these findings have significant implications for the scientific community as the data was collected before and during the outbreak of the Covid-19 pandemic. Whether such perceptions and behaviours towards ART in Guatemala may be different post Covid-19, is a study worthy of follow-up investigation. What is significant about the present findings is, the data collected before and during the outbreak of the Covid-19 pandemic. A unique opportunity that can only be replicated retrospectively i.e., what people can recall about their perceptions and behaviour about ART before the period of the Covid-19 outbreak?

More specifically, there are significant implications from the four studies reported for practitioners and those involved in infertility treatments, in giving the best advice to their patients and to the Guatemalan public.

Acknowledgements

Firstly, I'd like to show my gratitude to my two supervisors. I'd like to thank Dr Deborah Bailey-Rodriguez who was understanding, compassionate, relatable, and most importantly uplifting. Her words of encouragement and comfort never went unnoticed. She shared her insight and experiences with me, in particular her expertise in qualitative methods. She continuously ensured I had full understanding of the task at hand and remained completely inviting, in what can at times, be an intimidating academic environment. For that I am endlessly grateful.

I am forever thankful to my supervisor Professor Bahman Baluch who time and time again pointed me in the right direction. His patience, kindness and guidance allowed me to persevere, and his wisdom and expertise kept me immersed and motivated during this timely process. I would like to express my deepest gratitude to him for his constant support and supervision of my PhD studies and research. With his help, encouragement, and extensive insight, I was able to find my voice and confidence through my doctorate studies.

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sure I had an outlet to decompress with. Their display of true friendship during this lengthy process did not go unnoticed.

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For my Abuelita Elia and the people of Guatemala

Preface

On being infertile

A well-known motto by the World Health Organization[2] (WHO) "Mother or nothing, the agony of infertility" (World Health Organization, 2010) depicts the suffering and challenges that millions of people around the world have faced, and will face in the future, for being infertile. This is especially true for people in developing countries such as Guatemala whereby the pressure of conceiving presents several additional challenges due to the cultural make up and deeply rooted traditions of its people. Numerous studies, as reviewed in Chapter 1, are aimed at examining the perceptions and impact of infertility and infertility treatments mainly from the perspective of Western cultures (e.g., Edelmann, 1990; Miranda et al., 1995) with much fewer focused on non-Western cultures (e.g., Baluch et al., 1993; Inhorn, 1994; Pir Jalian 2020).

The 'miracle cure'

The birth of the first test tube baby in 1978, the advent of In Vitro Fertilisation (IVF), and its variants have provided a greater chance for women to conceive as opposed to what was previously thought impossible using traditional methods. Chapter 1 provides an account of IVF and its variants, generally referred to as Assisted Reproductive Technology (ART). However, as also documented, any early enthusiasm regarding ART was marred by the realisation that a host of factors should be considered before the

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[2] References will be kept in their original organisation spelling as per APA guidelines, and therefore may fluctuate in spelling throughout.

breakthrough in fertility treatment could achieve its goal. As with many new innovations in medical sciences, the initial reaction often faces a reluctance by the public. This is especially the case with those who have deeply rooted traditions and religious views, many hesitate to accept any changes to the traditional norms. Unsurprisingly, as reported in Chapter 1, there were negative remarks from religious leaders in the West regarding the 'morality' of producing test-tube babies. For example, comments from the Vatican warning that doctors (scientists) might find themselves struggling to contain the consequences of their actions and not all scientific advances are for the good of humanity (Sommerlad, 2018).

The challenges of Assisted Reproductive Technology (ART)

As with most new innovations, ART inevitably provoked many factors to consider. For example, are there any medical consequences for a child conceived via ART, such as a higher risk of developing autism? Are there any psychological and/or social consequences for a child born by ART, particularly with regards to public perception and acceptance of such procedures? Will ART children be accepted by society? What if there is a third party involved such as conception by egg or sperm donation?

In addition to the aforementioned factors there is also the issue of morality and medical ethics in relation to advising infertile couples that undergo ART, particularly in relation to the uncertainties around conception along with the medical, psychological, social, and ethnical consequences that may arise.

About this thesis

Chapter 1 provides in-depth coverage of the topics mentioned above. The conclusion being that whilst numerous research has been aimed at examining applications and consequences of ART in Western (and to some extent on non-Western cultures), there is a dearth of scientific research reported employing a Guatemalan population. Guatemala is a country with two distinct populations, namely The Maya and Ladinos. These populations are divided by race, traditions, religion, social class, and access to and trust in modern medicine. In some ways a divide that could fit into the category of the 'non-Western' (Maya) and the 'Western' (Ladino). Such distinguished divisions of populations living together in one country provides a stronger and a more valid scientific ground to directly examine applications and consequences of ART from a 'Western and non-Western' perspective. To date, many studies on this line of research had to either focus on one population e.g., Western, or to compare people in two different countries representing Western and non-Western populations. The possible methodological problems with the former and latter lines of research are obvious. For example, when looking at one specific population (e.g., Western) the study may be one-sided and when comparing populations in different countries (e.g., non-Western vs Western), there is the inevitable inclusion of many extraneous variables that can affect research findings such as accessibility to participants, demographic variables and environment setting.

Chapter 2 is thus a comprehensive review of the two culturally distinct populations in Guatemala, The Maya and Ladinos. It provides the key thinking and rationale behind Study 1, reported in Chapter 3, in which the perceptions and behaviour of the Maya and Ladino populations with regards to ART and its consequences are examined for the first time (and just a few months before the outbreak of the worldwide Covid-19 pandemic).

Study 1

Study 1, reported in Chapter 3, employs mixed quantitative and qualitative methodologies to ensure that it captures the perceptions and behaviours from the perspective of statistical evidence and in-depth described experiences. The results as discussed in chapter 3 generally highlighted that divisions alongside the Maya and Ladino have a significant impact on perceptions and behaviour of people undergoing ART in Guatemala.

Covid-19 and the impact on research

Whilst the results of study 1 were being analysed, The Covid-19 Pandemic occurred. As detailed in Chapter 3, a survey conducted in March 2021 stated that 58% of academics reported how Covid-19 made it impossible to continue their research as planned (UK Research and Innovation, 2021).

For example, many disruptions were due to limited in person contact and had greater reliance on virtual instead of in-person interactions. Doctoral research was equally affected by many restrictions determined by the Covid-19 pandemic. Several blogs by PhD students indicated how their planned research had to be changed in view of Covid-19, see e.g., Taman, A. (2022), Dhungana, N. (2020).

The use of blogs in scientific publications

It is important to make a note here about the use of blogs and grey literature as sources in scientific materials. As debated recently in a document by the University of

Cambridge (University of Cambridge, 2022). There are pros and cons about use of blogs in scientific publications, the key cons are listed as:

- Not peer reviewed
- It may not be possible to confidently establish the authorship of blogs or verify their content.
- Blog text may not be fixed (i.e., the author may change the content of a particular blog page without warning).
- Blogs may not be permanently accessible and could be removed.

The key pros are:

- Blogs offer a significant and readily available corpus of information, ideas and opinions that could be of value to academic research.
- Contain original research or ideas that are not published in an alternative form.

It is also important to note as cited in chapter 2 and chapter 6, that in view of little scientific research of ART in Guatemala, the author has to make reference to blogs and grey literature as providing additional materials for the study. In addition to this is the fact that Covid-19 gave rise to timely blogs on this topic that made a significant difference on how a researcher felt and conducted research in general during this period. Thus, there are several sections of this thesis that blog citations are utilised. The author has applied considerable attention in choosing the blogs for citation and ensured that the contents and its implications for the reported thesis were evaluated with great care and scientific rigour. This was done by screening blogs to ensure they were appropriate for research by assuring relevance.

Study 2 and Study 3

As a result of such unexpected events by late December 2019, it was inevitable that Covid-19 and its impact on ART had to be incorporated into this research. Originally the plan was to cross validate the findings of study 1 from the point of view of medical practitioner involved in treatment of fertility patients. In view of Covid-19 it was decided to extent the possible impact of the pandemic on patients' perception and behaviour.

However, to find such expertise to participate in the research at the time of a worldwide pandemic was a big challenge. It was indeed fortunate to have overcome this challenge by finding a key medical expert and fertility practitioner in Guatemala willing to engage in an in-depth semi-structured interview by video call. This interview was subjected to Interpretative Phenomenological Analysis (IPA) and is reported in Chapter 4. Furthermore, to cross reference the findings from interview with Guatemalan practitioner, a key medical expert in the UK was also interviewed using the same semi-structured questions and subjected to IPA analysis. This would enable one to have additional materials for better understanding of the extent to which findings from a Guatemalan expert are culture specific or can be generalised to a wider Western population. This was the objective of Study 3 reported in Chapter 5.

Furthermore, there was a need to engage in a new literature review, one that examined the impact of Covid-19 on ART from various perspectives. Indeed, there appeared to be a massive increase in publications on various aspects and consequences of Covid-19 since 2020 (396,000 papers listed in Google scholar 2020 to 2021). An article in Nature (December 2020) highlights how a torrent of Covid-19 science changed research, publishing “A flood of coronavirus research swept websites and journals this year. It changed how and what scientist study” (Else, 2020, p.553).

The Scope Review (Study 4)

Returning to the present thesis it was thus necessary that there should be an up-to-date literature review to identify the specific impact of Covid-19 on ART patients and what the future holds for both patients and practitioners. This new line of literature search would provide some informative findings to verify against the findings from IPA analysis in Studies 2 and 3.

This came in the format of a Scope review. A Scope review is often defined as a hybrid between a traditional literature review and systematic review. Dating back to the 1990’s (in healthcare studies) this method takes into account broader topics and designs. Scoping review is more rapid by comparison to the above reviews. Most notably the scope review is aimed at drawing conclusions from existing literature in a specific time period, reflecting the overall state of research activity and findings producing guidelines for practitioners, researchers and policy makers. As reported in Chapter 6 the current Scope review provided an up-to-date, current version of the state of affairs regarding ART, Covid -19, patients and what lies ahead.

Implications and conclusions from the present thesis

As documented in Chapter 7 the present thesis has the novelty of not only being the first systematic research on perceptions and behaviour of the Guatemalan population towards ART, but also one that was conducted just before the outbreak of Covid-19 (study 1) and during the peak of the pandemic (studies 2 & 3). Any future studies aiming to investigate perceptions and behaviour of public or patients towards ART before or at the peak of the Covid-19 pandemic would be retrospective and at best based on evidence of peoples’ recollection of the events. For this reason, this research should provide a baseline for future researchers. This would enable researchers to improve research when embarking on follow–up, and much needed exploration on perceptions and behaviours of the Guatemalan (and universal) population, in relation to ART.

Publications and Presentations From This Thesis to Date

Urrutia, C. I, Baluch, B., van den Akker, O & Bailey-Rodriguez. D (2019). Assisted Reproductive Technologies (ARTs) in the eyes of the Maya and Ladinos *Society for Reproductive and Infant Psychology,* 39th Annual Conference 2019. London.

Urrutia, C. I. (2019). *Assisted Reproductive Technologies in the Eyes of Ladinos and Mayans.* Psychreg. https://www.psychreg.org/assisted-reproductive-technologies/

Urrutia, C. I. (2020). *Covid 19 and Assisted Reproductive Technologies: A Doctoral Research Reflection During Lockdown*. Psychreg. https://www.psychreg.org/covid-assisted-reproductive-technologies/

Urrutia, C. I. (2022). *No Right to Abortion: What Could This Mean for Assisted Reproductive Technologies?* PsychReg. https://www.psychreg.org/no-right-to-abortion-what-could-this-mean-assisted-reproductive-technologies/

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Abbreviations

ART Assisted Reproductive Technology

AI Artificial Insemination

DI Donor Insemination

DIT Disruptive Innovation Theory

GIFT Gamete Intra- Fallopian Transfer

HFEA Human Fertilisation and Embryology Authority

ICSI Intra-Cytoplasmic Sperm Injection

IVF In Vitro Fertilisation

WHO World Health Organization

ZIFT Zygote Intra-Fallopian Transfer

CHAPTER 1 Infertility, Assisted Reproductive Technology (ART) and Public Perception

1.1 Introduction

This chapter is a detailed account of the definitions and statistics regarding infertility as a worldwide problem. The turning point of infertility treatment was the birth of Louise Brown ‘the first test-tube baby’, which led to the highly popular In Vitro Fertilisation (IVF) treatment. Follow up medical advances resulted in a host of treatments generally known as Assisted Reproductive Technology (ART) which will be explained in this chapter. Whilst the statistics of a successful treatment are still relatively low and the treatments are costly, the desire to have a family is much greater. This is particularly the case in developing countries, where there is an ever-growing population of patients undergoing ART (Adamson, 2009).

As mentioned, infertility is acknowledged as a major health problem worldwide. The latest statistics on the prevalence of infertility in women of reproductive age have been estimated to be one in every seven couples in the Western world and one in every four couples in the developing countries (Bosdou et al., 2016).

Greil (1991) stated that the experience of infertility is dependent on the sociocultural context, age, gender, occupation, social class, and ethnicity. One of the most important parts of human life is to have children, and all societies value the birth of children and upbringing. However, the meaning and the importance of having children vary for different people and in different times (van Balen & Bos, 2009).

According to van Balen and Bos (2009) there exist different theories to explain the reasons why people choose to have children, for instance, theories about internal motives and rational choices. The motives for having children in Western societies are for individual reasons such as happiness, well-being, and life fulfilment (see also Mokoena et al., 2007; Eriksson et al., 2012). However, in most non-Western societies, it is in part to fulfil the general populations expectation i.e., people who do not have children are regarded as ‘failures’. Furthermore, having children is also seen as providing support for parents when they are in their older age (Bos & van Rooij, 2007).

In this respect, factors such as religious beliefs also play a significant role affecting reasons and motives for fertility. Religious encouragements such as “Multiply and replenish the earth” (Holy Bible: Genesis, 1:28), reminds childless couples of society's expectations that they must have children. The stigma attached to infertility is thus countless.

In view of the above there will be a review of different cultural, socio-economic divisions (Western vs Non-Western) and religious perspectives on infertility and its consequences for the couples and in particular for the women. Public perception of infertility treatment particularly via ART is thus of great significance. Understanding what people of different ethnic, religious, cultural orientations regard as consequences of undergoing ART treatment is a subject that has been under investigated and is the rationale behind study 1. Thus, the present chapter will conclude with a review of public perceptions on infertility and infertility treatment worldwide, and particularly in Western and non-Western societies, with a view to providing a background of the aims of study 1. This study will examine, for the first-time, perceptions of Guatemalan population consisting of two distinct ethnic groups namely The Maya and Ladino.

1.2 Infertility definitions

According to the WHO (2012) a couple is deemed to be infertile if they fail to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse. This is known as primary infertility; secondary infertility indicates the failure to conceive after a previous successful pregnancy (Inhorn & Patrizio, 2015).

However as noted, the previous definitions are not biased to a particular gender. Looking back in time and how people defined infertility leads to the emergence of an interesting picture. Historically, in all ancient civilizations, women were blamed as the primary source for why a couple is infertile. Hippocrates, the famous Greek physician who founded the Hippocratic Oath, blamed all kinds of things in a woman’s body for preventing her from conceiving, one of them being hysteria and referring to the womb as Pandora’s box, the jar that releases all evil (Hecker & Thorpe, 2015).

It took medical science many centuries of development and convincing evidence to change the view of an exclusively female cause to more balanced figures in which both male cause and female cause could be the reason for infertility (Johnson & Everitt, 2000). Indeed, there are now well-established statistics on reasons for male and female infertility with still a reasonable proportion considered as ‘unexplained’.

1.3 Causes of infertility

As explained, causes of infertility may be related to the male, the female or both. In some cases, no explanatory cause can be recognised, and the infertility is then named unexplained or functional or unknown. The main causes of infertility are known as ovulatory problems, blocked or damaged fallopian tubes, and poor quality or low quantity of sperm. These causes identified account for 75-80% of all explainable cases of infertility (Johnson & Everitt, 2000). Consequently, treatment choices and success differ with the cause of infertility (Quaas & Dokras, 2008).

The main causes of infertility in the UK comprise of unexplained infertility (25%), ovulatory disorders (25%), tubal damage (20%), factors in the male causing infertility (30%), uterine or peritoneal disorders (10%). Approximately, in 40% of cases, disorders are found in both the man and the woman. Uterine or endometrial factors, gamete or embryo defects, and pelvic conditions such as endometriosis might play a role (Excellence, 2015).

1.3.1 Female infertility

Fertility declines with age, particularly in women. Female fertility is at its highest between the ages of 18 and 24 years whereas, it begins to decline after the age of 27 and declines at a greater rate after the age of 35 (Sudha & Reddy, 2013).

The most common reason of female infertility is ovulatory difficulties with differing severity. Some women ovulate irregularly or not at all. Fertilisation occurs naturally in the fallopian tube. The second most common reason of female infertility is a tubal disease where one or both fallopian tubes have been damaged as a consequence of an infection or abdominal surgery. Other reasons of female infertility comprise endometriosis where the tissue that lines the uterus (endometrium) grows inappropriately elsewhere in the pelvic area causing damage and the formation of grips, which can impair the function of the fallopian tubes (Johnson & Everitt, 2000).

1.3.2 Male infertility

Male infertility remains a ‘hidden’ reproductive health condition, even though it contributes to more than half of cases of childlessness worldwide (World Health Organization, 2014). Inhorn (2012) argues that due to the genetic aetiology of many cases, male infertility is often impossible to prevent and difficult to treat, lasting over the course of a man's lifetime, even if he attempts to have children by changing partners. In other words, male infertility is a chronic reproductive health condition for millions of men worldwide, even though it is hardly acknowledged as such (see also Inhorn & Patrizio, 2015). Some statistics reported of male infertility to 50% of cases overall (Agarwal et al., 2015).

1.3.3 Unexplained infertility

According to the Practice Committee of the American Society for Reproductive Medicine (2006) unexplained infertility is declared once the results of a standard infertility assessment for both partners are normal (Quaas & Dokras, 2008). According to Human Fertilisation and Embryology Authority (HFEA), approximately, 32% of couples will be diagnosed with unexplained infertility after their diagnostic workup (Human Fertilisation & Embryology Authority, 2020).

1.3.4 Age-related infertility

Sharma et al. (2013) stated that the proportion of couples with no detectable organic cause of infertility increases with rising female age. This higher rate of unexplained infertility reflects the decreasing chance of conception with increasing female age. Many couples in developed countries, specifically those privileged with a good education, wish to delay reproduction until achieving their primary goals of their life (Penzias et al., 2021).

The tendency to plan childbearing later in life may in part be influenced by insufficient understanding about the negative effect of how increasing female age may affect fertility. Lampic et al. (2006) surveyed a randomly selected sample of 222 female and 179 male Swedish academics and reported that both women and men had an excessively optimistic view of women’s chance of conceiving after the age of 35. Similarly, in an Australian study of 152 women over the age of 37 who were looking for assisted reproduction techniques for their first pregnancy, nearly one in five stated being not completely aware of the adverse relationship between age and fertility (Hammarberg & Clarke, 2005).

1.4 The ‘miracle cure’

Well over a century after the early attempts to achieve pregnancy via Artificial Insemination (AI), Louise Brown, was born in July 1978 in Oldham and District Hospital in Greater Manchester (Davis & Loughran, 2017). The procedure of IVF raised the hopes of millions of previously untreatable couples to achieve conception by traditional means (Edwards et al., 1980). However, by passage of time it was evident that the success of IVF was very low (around 6% in its early days) and had relatively high costs for treatment (see e.g., Wang & Sauer, 2006). However, subsequent years have seen a rise (around 25%) in the success rate of IVF treatment that resulted in a successful birth (still far from high success rates), all depending on many factors, in particular the woman’s age and the cause of infertility (Human Fertilisation & Embryology Authority, 2020).

1.4.1 In Vitro Fertilisation (IVF) and its variants

The vast majority of ART involves in vitro fertilisation, a process that includes removal of eggs from a woman’s body (following a couple of weeks of prior medication), combining sperm and egg in the laboratory or outside the body (in vitro), and returning the fertilised egg, called the embryo, to the woman’s womb. This process could be with the woman’s own eggs and her male partner’s sperm or with eggs, sperm or an embryo from a donor (see e.g., Baluch et al., 1992, 1993).

Other variations of IVF include Intra-Cytoplasmic Sperm Injection (ICSI), first described in 1992 by Palermo and associates in Belgium (Palermo et al., 1992). This is a treatment variation within IVF in which each egg is fertilised directly by injecting a single sperm using a microscopic needle and seen as the treatment of male infertility. For example, men with sperm motility problems or very low sperm counts can now conceive a child with a partner when previously donor sperm would have been required for conception.

Further advancement and varieties of ART include Gamete Intra-Fallopian Transfer (GIFT) in which eggs and sperm (gametes) are isolated and transferred directly into the fallopian tubes by laparoscopy, and Zygote Intra-Fallopian Transfer (ZIFT) fusion of IVF in which embryos are transferred into fallopian tubes by laparoscopy (Squires & Kaplan, 2007).

1.4.2 Reproductive donation: A controversial issue in ART

Conception by egg(s) donated from a fertile woman to an infertile woman is a new chapter in the battle of infertility. However, the fact that a third party is involved (the same for sperm and embryo donation) has its own controversies ranging from religion, cultural norms, social constructs, medical consequences, and psychological consequences. However, before engaging in the reasons for such complications it is important to briefly outline how the process works.

Since 1984, with the introduction of egg donation, it has been possible for a woman to become pregnant and give birth to a child to whom she is genetically unrelated. Conception by egg donation (Oocyte donation) is now the answer to the problems of women suffering from diseases such as premature ovarian failure, impaired quality of eggs, loss of ovaries, ovarian dysgenesis or old age and demand for postmenopausal pregnancy (Inhorn, 2007). Moreover, the demand for egg donors has been on the rise globally (Bracewell-Milnes et al., 2016).

However, as explained before with regard to the egg donation process, the donor of the egg will undergo the same procedure as IVF with the difference that when the eggs are ready and retrieved, the donor's task is completed. The eggs from the donor and the sperm from the recipient's partner are then transferred to the lab for fertilisation. The resulting embryos are then implanted in the recipient's uterus (Lutjen et al., 1984). The child is therefore genetically related to the father/male partner but not to the mother. As the process of donating eggs undergoes the same process as if the person is undergoing IVF (e.g., involving self-administered injections to stimulate the ovaries, blood tests, ultrasound scans and surgery to remove the eggs from the ovaries), it is not something that all people agree to volunteer to. Also, there is the risk that the donor may herself become infertile as a result of donating their eggs (Woodriff et al., 2014); this is significant as it could contribute to one of the reasons women hesitate to volunteer to donate eggs. It is important to note that because egg quality declines with age, egg donation clinics generally do not accept donors over 30 and in particular should have no family history of hereditary diseases (Almeling, 2006).

The success rate of conception by egg donation therefore would in large part depend on the age and medical background of both recipient and donor. The success rate thus is an estimated value and differs between clinics and countries and with growing scientific advancements, it is bound to improve. Egg donation is particularly widely used in Western countries, for example, in the United States, with over 3000 live births resulting from fresh donor egg cycles started in 2015, of which 27% were twin births (Imrie et al., 2019).

In the latest version of the Latin American Network of Assisted Reproduction (REDLARA) registry, it stated that 15 out of 20 countries in Latin America who offer ART, and who reported their egg donor cycles to the registry, had a collective successful birth rate of 33.4-33.9% (Zegers-Hochschild et al., 2020). Guatemala reported to have conducted 38 egg donor cycles in total for 2017, the second lowest cycles reported in Latin America.

1.5 The controversial aspects of ART

It is true that with the advent of IVF and its variants generally known as ART the hopes of millions of infertile couples was raised, but as with each new innovation, there are many challenges to be overcome as the key factors detail below.

Artificial insemination, although invented in the eighteenth century, was rarely used until the 1930s and only legalised in the 1960s. Its application to surrogacy and its use by unmarried women extends the controversy into the twenty-first century (Bernstein, 2002). Moving to more recent times, the public reaction was mixed. The Tabloid Press called it the advent of ‘Frankenstein babies’, the Vatican warned that doctors (scientists) might find themselves struggling to contain the consequences of their actions, and that not all scientific advances are for the good of humanity.

Indeed, the growth of interest in new innovations and reproductive technologies stretches to recent times and Cohen et al. (2017) have outlined disruptive aspects of reproductive technologies. Werner-Felmayer (2018) discussed how the new technologies and innovative procedures might have an effect on “the disruption of social and cultural norms” (p.18). Such considerations also require exploring the extent to which the public are knowledgeable and have opinions about the new innovations in human reproduction (Werner-Felmayer, 2018). The importance of identifying ‘lay’ perceptions and misperceptions of scientific and technological developments, including those that relate to ART, has been discussed in several new lines of research (e.g., Goldfarb, 2019).

1.5.1 Ethical concerns

Assisted reproductive technologies have also raised a number of ethical and moral concerns. Ethical issues, especially medical ethics i.e., the extent that professionals consider the benefits to the patients, as opposed to the desire to conceive by whatever means, is also an important factor in any ART treatment. As Pir Jalian (2020), argued the question that medical professionals may have to consider is the extent to which new medical innovations (in particular, conception by egg donation) may cross paths with cultural norms, traditions, and religious beliefs. This is particularly true in developing countries with deeply rooted religious beliefs, significance of genetic links, and living in a collectivist society in which people belong to ‘in-groups’ that take care of themselves in exchange for loyalty, particularly as a community, family, or nation more than as an individual. Thus, the actions people take will be of concern to others (Pir Jalian, 2020).

To name a few of such concerns includes the risks of multiple pregnancies and the use of selective abortions, lack of biological relatedness or genetic link in sperm and egg donation and surrogate mothering (Greenhalgh & Stacey, 1998; Macklin, 1991; Rebar & DeCherney, 2004). One set of ethical issues concerns the impact on offspring, on participants, and on the family of rearing arrangements that separate female genetic and gestational parentage. Another set of issues includes obtaining consent, risk, and commercialisation in gaining donor eggs (Jacoby, 2006). The right to privacy of the recipients and the donors might be in conflict with the right of the child to know his/her origin. Confidentiality, disclosure to the child and protection of privacy are key ethical issues accompanied by profound legal, religious, social and cultural questions (Larijani & Zahedi, 2007).

1.5.2 Medical consequences of ART

Since the early reports in 1985, several cohort and case-control studies have reported increased risks of pregnancy complications, such as miscarriage, ectopic pregnancy, congenital anomalies, premature birth, low birth weight, gestational diabetes and pre-eclampsia (having high blood pressure and protein levels during the second half of pregnancy) in ART pregnancies compared to naturally conceived pregnancies (see e.g., Bradbury & Sutcliffe, 2014; Dupont & Sifer, 2012; Isaksson et al., 2002; Zhu et al., 2016).

Perhaps one reason why conception by ART may end up with medical complications is the many facets and procedures that have to be fulfilled before, during and after any ART treatment. For example, Baluch et al. (1992) reported how infertile women in their clinic undergoing IVF treatment were concerned about daily injections of hormones and the use of nasal spray followed by the pain of egg collection, embryo transfer and finally waiting for the results of pregnancy. In similar fashion, when one examines each procedure in more detail e.g., IVF, IVF/ICSI or GIFT, there are reasons to believe that many factors are involved at different stages of the treatment that may have medical or even psychological impact on the mother and on her conceived infant. Thus, the past few decades have seen a growing body of research on the health outcomes of children born through ART (see e.g., Golombok et al., 2017; Helmerhorst et al., 2004; Ilioi & Golombok, 2014; Ludwig et al., 2006; Zhan et al., 2013; Zhu et al., 2016).

There are questions that remain outstanding regarding the use of IVF. Conflicting data exists about the risks of IVF on the developing embryos. Multiple studies have failed to find a clinically relevant association between IVF or embryo cryopreservation and adverse maternal or fatal effects. Other studies have suggested that infants of IVF pregnancies may be at a small but statistically significant increased risk for rare epigenetic, other abnormalities and antenatal complications (Brezina & Zhao, 2012; Zhu et al., 2016).

The use of hormonal drugs during pregnancy and embryo manipulation may also affect the long-term health of children conceived through ART (Dupont & Sifer, 2012; Klimanskaya et al., 2006; Zhu et al., 2016). Others have argued that the various artificial procedures (e.g., cultured embryos in the lab or freezing and thawing) during ART may have the impact that children born by ART might be exposed to greater health risks than naturally conceived children (Zhu et al., 2016); See also Alexander et al., (2005), Liu & Blair (2002), Pinborg, (2019).

There are other concerns apart from what happens in the lab or the procedural aspects of ART that call for concern. The American College of Obstetrics and Gynaecology (2004) list the following: Firstly, couples who require ART often are older (mean age of 33 years for women undergoing ART versus 27 years for women who conceive naturally) increasing the chances of genetic problems in offspring as well as pregnancy complications. Secondly, most couples turn to IVF because of infertility, which may itself increase chances of developmental problems in children because of pre-existing medical and genetic problems in the parent(s). Thirdly, mothers who undergo IVF take a combination of fertility drugs before and immediately after the procedures, which may have effects on growing embryos, and finally, more than 50% of IVF births are from multiple gestations, resulting in a large negative impact on developmental outcomes (see Wenstrom et al., 2004). Sazonova et al. (2011) argued that singletons conceived by ART are still at a higher risk of lower birth weight, younger gestational age, premature delivery, prenatal mobility, and hospital admission compared with naturally born singletons. Miles et al. (2007) found that ART born children around the age of 5-6 are on average taller than naturally born controls (also controlling for parental height). Generally, a child born from premature delivery is reported to be taller than controls. Thus, as most IVF born children are subject to premature delivery, they are expected to be taller than those naturally conceived. Whilst height may not be an issue of immediate concern, Ceelen et al. (2009) examined whether this increased height would lead to health risks in the future because evidence has already shown that the rapid weight gain (as a result of getting taller) during early childhood (1-3 years) in IVF children could be related to higher blood pressure levels.

Zhan et al. (2013) went further and attributed the higher rating of premature and lower birth weight in the ART group as a factor for the lower educational performance. However, Zhan et al. (2013) also argued that decent home environment might be a contributing factor to the better educational achievement. In addition to ART itself, the history of infertility or the infertile state of the parents (mother) at the time of treatment may contribute to the high risk of obstetric outcomes and birth defects (Hayashi et al., 2012; Romundstad et al., 2008; Shen et al., 2013).

Finally, there is also concern about the drugs used before, during and after ART treatment. According to Maheshwari (2012) it is still not clear whether the drugs used for ovarian stimulation, the manipulation of gametes, the artificial environment for fertilisation and the early embryo’s intrauterine exposure to hormones, produce longer-term health risks for children.

In short, there are many reasons to be concerned about medical consequences of children born by ART. What is not clear, is how much the public, as well as women with children conceived by ART, agree with such consequences, especially in developing countries.

1.5.3 Psychological consequences

Often linked in with medical consequences, there have been concerns that psychological disorders may be more prevalent in children conceived from IVF treatment (Beydoun et al., 2010). A study by Wagenaar et al. (2009) of parental and teacher observations, reported that more IVF children 9 to 18 year olds (mean age 13.6 years), scored in the borderline/clinical range, as well as on the syndrome scale of withdrawn/depressed behaviour compared with their naturally conceived counterparts. Hart and Norman (2013) in a systematic review of the longer-term mental health and development consequences of birth resulting from IVF treatment suggested that there is an increase in the prevalence in early adulthood of clinical depression, attention-deficit disorder and binge drinking in IVF born children.

Zhan et al. (2013) argued that ART children are at greater risk of autism due to parents' age, which are on average higher than naturally conceived children. Golombok et al. (2009) in research on parent-child relationships and the psychological well-being of 18-year-old adolescents conceived by in vitro fertilisation, concluded that adolescents born through IVF have lower self-esteem than the naturally conceived group.

Sutcliffe et al. (2014) found significant differences between ART born children and control in the rate of hospital admissions before the children were 9 months old, with the ART group showing higher rates of hospital admission. However, children born after ART had comparable health and development beyond 9 months of age to their naturally conceived peers. These results suggest that artificially conceived children have as good prognosis as other children with respect to the health and well-being related outcomes. This is in line with a previously published study in which older ART born children seem to show no differences in psychological problems compared to naturally conceived children.

Golombok, et al., (2013) examined parenting and children's adjustment in 30 surrogacy families, 31 egg donation families, 35 donor insemination families, and 53 natural conception families. Children's adjustment was assessed at ages 3, 7 and 10 using the Strengths and Difficulties Questionnaire (SDQ) and the results indicated that children born through reproductive donation obtained SDQ scores within the normal range. The follow-up study at age 14 showed there were no differences between adolescents themselves in terms of adjustment problems, psychological well-being, and self-esteem (Golombok et al., 2017).

Zhan et al. (2013) stated that one possible reason for studies reporting no difference or a significant difference between ART and naturally conceived in psychological factors might be due to evaluation measurements and the sample size. Furthermore, it could be due to cultural differences (e.g., Pir Jalian 2017). There is of course a possibility that the child's difficulties might have been under-reported, especially by reproductive donation mothers who may have wished to present their children in a positive light (Golombok et al., 2013).

1.5.4 Social consequences

A study conducted in Israel has found a higher incidence of emotional problems among IVF children. In a comparison between IVF and naturally conceived children of middle-school age on measures of school adjustment, hyperactivity, trait anxiety, depression, aggression and behavioural problems, the IVF children, particularly the boys, were found to show poorer adjustment to school as rated by teachers and reported themselves to be more aggressive, more anxious and more depressed (Levy-Shiff et al., 1998). Other researchers have indicated that children born as a result of IVF may be more hyperactive (Beydoun et al., 2010) and are more likely to be expelled from school (Shen et al., 2013).

Ponjaert-Kristoffersen et al. (2004) argued that children conceived via ART might be liable to a reduced IQ. In line with the latter claim an age-matched study by Knoester et al. (2008) observed a slightly but significantly reduced IQ in 5- 8-year-old children born after ART which could be a factor in the child’s social skills. Evidence on lower IQ scores in ART born children is also reported by other researchers (see also Bowen et al., 1998; Ponjaert-Kristoffersen et al., 2004; Zhan et al., 2013).

Furthermore, the social recognition and acceptance of these families, their social context and the processes through which social environment affects family relationships are issues of concern (Colpin et al., 1995). It is important to emphasise that negative attitudes may exist towards reproductive technologies, with procedures such as IVF and donor insemination sometimes considered being immoral or unnatural. As a result, families with a child conceived by assisted reproduction may experience overt prejudice not only from the wider community but also from relatives and friends (Fasouliotis & Schenker, 1999; Golombok et al., 1995). Gibson et al. (1998) indicated that children conceived through IVF techniques might suffer potential psychosocial risks, as well as being more at risk through psychological maladjustment. Also, the study of Gibson et al. (1998) reported lower scores on receptive language skills in IVF infants. These studies suggest that social acceptance may be at risk when families chose to embark on ART.

In short, research on medical, psychological, and social consequences of ART born children is flourishing with some mixed results. However, the main focus of the present thesis is not to dispute or support the findings on psychological, medical and social consequences of children born by ART. The main aim is to examine the perception of the public (men and women) representing two contrasting cultures living in Guatemala on infertility treatment.

1.6 Summary of this part of the chapter so far

In short, the worldwide problem of infertility has made significant advances both in terms of definitions and treatment options. Not long ago, most people would regard women as the main cause of infertility, whilst the more recent statistics revealed a different picture with men as well as the yet unknown factor, which is considered as another possible contributor.

It is the rise of ART that led to significant advances in treatment options for various forms of infertility. Whilst the statistic of a successful treatment is still not ideal, it also continues to be too costly to undergo ART. However, the desire to have a baby overcomes any concerns of success rate or costs, in 2020 the European Society of Human Reproduction and Embryology (ESHRE) estimated that around 9 million babies have been born via ART since 1978 worldwide. As explained in this chapter, ART is controversial, and it adds to the general concerns that the public may have about undergoing new medical innovations. In what follows, there will be a review of the position of different religions, cultures, and ethnic groups about ART. This is followed by public perception of ART from a worldwide perspective, a factor that may have significant implication for practitioners and anyone involved in infertility treatment and ART.

1.7 A few notes of clarification on some of the key terms used in the following part of Chapter 1

1.7.1 Culture and Religion

It is important to highlight the distinction between a couple of terminologies in this part of chapter 1 as they are often used interchangeably in the relevant literature. The first relates to culture and religion. By definition two persons might have the same culture and yet follow different religions. Culture places an emphasis on human beings and social inheritance, whereas religion is related to the creator of the whole universe or God. In this respect, culture is concerned with the evolution of human beings and their beliefs and practices (see e.g., Bonney, 2004). When examining how ART cross pathways with culture and religion, it is often the case that the two inevitably enter into the investigation. For example, Pir Jalian (2020) when studying British and Iranian cultures on ART, acknowledged that it is also a contrast of Islam (Iran) vs mainly Christian (UK) and thus it was hard to tell that any perceptions are due to deeply rooted religious beliefs or cultural constructs. In the present thesis it will be argued that religion, ethnicity, trust in medicine and governmental concerns are key factors distinguishing the two ethnic groups in Guatemala. Equally significant is the fact that each ethnic group, particularly The Maya follow their own deeply rooted cultural heritage.

1.7.2 Collectivism vs Individualism

Collectivist vs individualist is another noticeable contrast. The collectivist and individualist societies (countries), is a distinction that one could also make in line with the Western and Eastern, developing and developed countries. In collectivist societies, people belong to ‘in-groups’ that take care of themselves in exchange for loyalty, particularly as a community, family, or nation more than as an individual. Most developing countries follow a collectivist society. In individualistic societies, on the other hand, people are supposed to look after themselves and their direct family only. Particularly, people are encouraged to do things on their own. Britain tops the list as an individualistic society (European Commission, 2017).

Hofstede's theory of culture, also known as Hofstede's Cultural Dimensions Theory, is a framework developed by Dutch social psychologist Geert Hofstede in the late 20th century to understand and describe cultural differences between nations. The theory is based on his extensive research involving surveys of IBM employees from various countries (Hofstede, 2011).

Hofstede's theory proposes six cultural dimensions that help to distinguish different cultures and their values, beliefs, and behaviours. These dimensions are as follows: Power Distance (PDI), Collectivism vs. Individualism (IDV), Masculinity vs. Femininity (MAS), Uncertainty Avoidance (UAI), Long-Term Orientation vs. Short-Term Orientation (LTO), and Indulgence vs. Restraint (IND).

The Collectivism vs. Individualism (IDV) dimension represents the extent to which individuals prioritize their own interests and independence over group cohesion. Individualistic cultures value personal achievements, autonomy, and individual rights, while collectivist cultures emphasize group harmony, loyalty, and shared responsibilities. For example Guatemala is considered a Collectivist society and England is considered Individualistic.

Such definitions may be seen as yet another reason for why people’s attitudes, perceptions and behaviours about fertility and fertility treatment may be influenced by community members and family dictates (collectivist), compared to what people do because they are personally interested and not dictated to by ‘others’ (individualist), see Greif (1994) for a review. However, there has not been any direct attempt to examine issues related to ART in line with the latter definition. In the present thesis it will be argued that although the two distinct ethnic groups in Guatemala live in the same country, their behaviour may be divided along the definitions of collectivist vs individualistic societies.

1.7.3 Western vs non-Western

Western vs non-Western is yet another noticeable point of contrast when studying ART. Researchers when studying cultural differences, also make the distinction between Western and Eastern on various aspects of infertility such as views on family, religion, access to health etc. (see e.g., Baluch et al., 1993; Bosdou et al., 2016; Greil et al., 2010). Another line of comparison is with developed and developing countries, which inevitably ties with Western vs. Eastern classification. For instance, it has been reported that the main reason for having children in most ancient societies, and even up to modern day in developing nations, is that children are seen as a source of financial support and future breadwinners of the family (Touba, 1980). In the present thesis it will be argued that The Maya represent more non-Western aspects of life whilst Ladinos are geared towards the Western lifestyles. This is an ideal research scenario in which the two contrasting lifestyles and its relationship to ART perception and behaviour could be studied amongst people living in the same country.

1.7.4 Assisted Reproductive Technology and Religion

There is one common factor that ties in most countries major religions, and it is that being fertile is seen as a must and being infertile is seen as an unforgivable act. Extracts from some of the major religion’s commandments are listed below to highlight the joys of fertility and the agonies of being infertile.

- The Jewish faith: The first commandment from God to Adam was “Be fruitful and multiply and replenish the earth and subdue it” (Holy Bible: Genesis, 1:28).
- Judeo-Christian religious faiths: “Infertility is seen as punishment for wrongdoing” (Sewpaul, 1999).
- Christian faith: Rachel’s agony of not being able to conceive is highlighted by her crying out to Jacob “Give me children or I shall die” (Holy Bible: Genesis, 30:1).
- Islamic faith: Infertility is a God-given impairment with the inability to conceive, a ‘punishment’ from God (Inhorn, 2018).

As explained previously, the birth of the first test tube baby in the Western world was not received favourable by the Vatican and much of the public. However, with the passage of time today, assisted reproduction is accepted in almost all major religions. However, not all aspects of ART are accepted by all faiths. For example, there is more acceptance of ART when the egg and sperm originate from the wife and husband/partner respectively (Schenker, 2005). Even with the latter procedure there are some exceptions, for example ART in all its forms is unacceptable to Roman Catholicism.

It is the involvement of a third party in the format of egg (gamete) or sperm donation that is when it unites different religions in questioning the morality of such actions.

“Research must continue into the causes of infertility, but the morality of these should be carefully considered” (Paul, 1968, p. 11). Most Orthodox Jews reject any third party involvement whilst other religious groups such as Shia and Sunni Muslims, Protestants and

Anglicans have provided rules and regulations with regards to gamete or embryo donations but sperm donation is strongly forbidden (for a review see Serour , 2006; Sallam & Sallam, 2016).

Interesting to note is that with the passage of time there has been some changes to how religion interacts with ART. For example, in contrast to Sunni Islam, Shia Islam now accepts gamete donation and validates it by Fatwa from religious leaders. Fatwa allowed third party involvement including egg donation, embryo donation and surrogacy and even sperm donation (Serour, 2005). According to Fatwa, in egg donation the new-born would be the child of the person who collected the sperm (i.e., the husband) and the egg donor, as well as the surrogate (i.e., infertile) mother (Inhorn, 2006). The justification for bending the ‘rules’ and accepting different forms of ART at least in some religious groups is based on the importance of family structure and maintaining a healthy lifestyle. As will be explained in the next chapter, the two ethnic groups in Guatemala represent a diversity of religious beliefs and traditions. It is thus expected that the acceptance of ART should vary significantly according to ethnicity and religious beliefs. In the Buddhist faith, the Dhammapada a canonical work of Buddha, places an importance on the right of human beings to ‘exist and to procreate peacefully’, placing a great honour on large families with an expectation to have as many children as possible (Srinivas, 1993). In Hinduism, having children is the path to take for parents that want to be saved; according to the scriptures (Brihadaranyaka Upanishad 1.5.17) a couple can only live a fulfilling life on earth by having children (Agarwal & Sridhar, 2016).

Guatemalan culture, religion and ethnic divide is documented in more detail in chapter 2. However, it is important to make reference to religion in Guatemala as this complements the arguments put forward in this chapter.

In Guatemala, the majority of the population follow Christianity, most Ladinos follow Christianity and identify under one of its branches like Catholicism and Evangelic-Protestants. The Maya tend to follow their own Mayan Spirituality which can also have Christian influences. It is important to note that The Maya believe they follow a spirituality more than a religion (however the term can be used interchangeably) as during the colonisation in the 15th century, many of their religious scriptures were destroyed by the Spanish, and therefore they now mostly communicate their beliefs orally (Collective, 2021). Maya religion and Catholicism have many similarities, both have written and oral traditions, several of which are parallel in plot and content, The Maya have the Popol Vuh, Catholics have the Holy Bible, both scriptures contained sacrifice as a ceremonial component, both religions believe in an afterlife, and both maintain rules and convictions to guide one's life by (Ballou, 2008; Hill & Moore, 1939).

In Maya religious tradition, a great importance is put upon new life and bearing children. Traditional birth attendants receive their calling by dreams. They will dream of the fertility symbol, for example a snake, which means they have been chosen to be a Comadrona, a traditional birth attendant. This is a great honour to the woman's family and community; it is believed if this is ignored, it will lead to death. Comadronas follow their own fertility practices and rituals which have been passed down through generations. This is a custom and tradition The Maya have followed for more than 2,500 years and continue to do so today (Collective, 2021).

The majority of Ladinos follow Catholicism and Evangelism. The official Roman Catholic doctrine states that human life begins at the moment of conception and certain moral judgements are born from these claims such as: a foetus or an embryo must be respected and treated as a human person with dignity and rights, including the right to life. The Vatican states that the experimental use of embryos such as implantation is condemned because it violates human dignity, reducing embryos to objects and instruments of scientific knowledge (Cook, 2015). In Evangelic-Protestant teaching, IVF is accepted with the spouse's gametes and no embryo wastage, however, gamete donation and surrogacy are forbidden. In contrast to the Roman Catholic Church, the Protestant Church does not condone IVF due to the use of medication and surgical techniques and leaves the final decision to the individual couples. Moreover, artificial insemination using the husband's sperm is acceptable (Sallam, 2016).

In short, religion plays a major role in people's perceptions towards assisted reproduction and various religions have reacted to this treatment in different ways. These range from total acceptance to total rejection of all techniques of assisted reproduction, with many shades in between. Acceptance of ART in all its forms is not universal and is affected/dictated by factors such as religious beliefs and commandments, social and cultural constructs, and economic status as defined by developed and developing or Western and non-Western societies. In the next part of this chapter, there is insight of what the public perceives to be the realities of ART, and the do's and don'ts when taking advantage of the medical innovations of infertility treatments.

1.8 Children born by Assisted Reproductive Technology public perception and behaviour

As discussed in the above sections of this chapter, the birth of the first test tube as it is with most new innovations provoked the media, the public and even the Vatican to focus on controversial aspects of the new innovations, but little effort was put into providing balanced and complete information to the general population on the subject of infertility and its treatment. As a result, the public had either to rely on what scientific studies report on the medical, social, psychological and ethical consequences of ART, or to rely on myths and claims made by advocates who are not so scientifically minded.

1.8.1 Why public perception and behaviour towards ART matter

In previous section of this chapter there was a review on the psychological, social, medical, as well as ethical sides of children born by conception via assisted reproduction and egg donation. For example, Bonduelle et al. (2005) reported that children born as a result of ART have more childhood illnesses than those naturally born. Wagenaar et al. (2009) reported that children born by ART are more socially withdrawn and unhappier than those naturally conceived. Zhan et al. (2013) reported that ART conceived children have lower IQ scores than naturally conceived.

Whilst such findings are of interest, there is still the question of what the public think about the new innovations in human reproduction and their consequences. This is because what scientists report may not be in harmony with what the public thinks. For example, reviewing several grey literature and blogs indicates that indeed there are a number of myths growing independently from scientific findings. For example, in a recent blog there is a discussion about whether the public myth that ‘the babies conceived through ART will have problems such as birth defects, low birth weight and developmental delays’ is true. The author expresses an opinion that “if there is an increase in problems such as birth defects, low birth weight, and developmental delays in babies conceived through ART, it is very small” (Gutmann, 2022). Indeed, a Google search does indicate that the debates on the myths of the conceptions and misconceptions of ART are considerable (see e.g., IVI Fertility, 2022).

The important issue here is a) to have a better understanding of breakdown of the public's points of views and ideas in relation to their perceptions and behaviour towards ART, and the extent to which public perception had an influence in their behaviour towards ART treatment. For example, are gender differences a factor in accepting the view that children born by ART or by egg donation have more childhood illness? Or is it true that people in non-Western countries believe that children born by ART are more socially withdrawn than people in Western societies? To what extent do cultural differences, ethnicity and religion play a role in public perception of the consequences of ART? (Rationale behind study1). And b) apart from the public, would the actual medical practitioners that deal with patients, agree that public perception has played a role to play when dealing with their treatment (rationale behind studies 2 and 3)?

A review will thus, be made of the very few reported studies on the subject of public perception in the remaining part of this chapter. One thing to note here is that the terms perception and attitude have been used interchangeably by the researchers and this is a noticeable issue when the reviews are made. Is there a difference between perception and attitude? Some argue that there is a difference between the term's 'perception' and 'attitude' (Refrence.com, 2020). In the author's opinion, the main distinction is on the wording and aims of the study and what will be achieved from studies on 'perception' or 'attitude' about ART.

1.8.2 Public perception in the Western societies

In a survey on the public perception (n = 8194) of infertility and its treatment conducted in six European countries and in the USA and Australia, it was found that only 38% of people surveyed considered that infertility is a disease and not accepting of the medical opinion and definition of infertility. The results also showed that there is little awareness of definition and incidence of infertility despite the fact that half of the people surveyed claimed to know someone affected by infertility. Over 90% of participants surveyed had knowledge of IVF but very few knew the chances of success. There was also very little knowledge about the costs of IVF cycle treatments (Adashi et al., 2000).

As mentioned above, Adashi et al. (2000) reported that the public are not very knowledgeable about ART. However, on the subject of attitudes towards IVF and gamete donation, a survey in 2019 (n = 6,000) conducted online, with participants living in France, Germany, Italy, Spain, Sweden and the UK, found a positive attitude among respondents toward IVF, gamete donation, and support for public funding for fertility treatment (Fauser, 2019). The problem with this type of attitude survey study is that it consists of items such as: Would you/have you ever considered using IVF treatment? How much would you pay to have a child through IVF? Do you believe that IVF treatment should be available to single women without a partner? The answers provided by participants were simply to say ‘Yes’ or ‘No’ with little or no chance given for comments. Such costly surveys do not seem to answer some fundamental questions. In particular, the extent to which the participants surveyed have perceptions about possible psychological, social, and medical consequences of children born by ART when responding to each item. Did any such ‘perception’ affect their ‘attitude’ when responding ‘Yes’ or ‘No’ to the survey? Thus, with such a method of assessing public attitude not much could be achieved. The statistics of what percentage agreed or disagreed with each item can be of little use to practitioners. This is because when the respondents surveyed gave their ‘Yes’ or ‘No’ answers, were they aware of, or had any perceptions of, scientific claims that a child born by ART may have an unhealthier life compared to a naturally born? Were the public surveyed aware of, or had any perception, that a child born by ART may be unhappier than naturally born? These are questions that cannot be answered even with such large-scale surveys of 6,000 participants in six European countries. What is required is to confront the public with statements regarding what scientists have been investigating for decades and see what their perception is about such claims and to give their reasons for their answers. The benefit of this method of research is that a) it identifies the conceptions and misconceptions that the public (and those involved in ART treatment) may have about ART and try to minimise the gap between public and scientific research and b) it provides practitioners with valuable information to provide the best advice to those planning for ART and for educational programmes for the general public.

In Canada, a qualitative study of Ottawa university students' awareness, knowledge and perceptions of infertility, infertility risk factors and assisted reproductive technologies indicated that participants were generally familiar with infertility as a biomedical health problem, could identify sex-specific risk factors but overestimated fertility of women in their thirties and ART success rates (Sabarre et al., 2013). Reproductive health knowledge gaps and confusion of the physiological life-stage of menopause with infertility were apparent. Most participants would pursue in vitro fertilisation or international adoption in the event of personal infertility. Some participants wished to use a 'natural' approach and were concerned with the potential side effects of ART-related medications (Sabarre et al., 2013). Daniluk and Koert (2012) indicated that both Canadian men and women, if confronted with infertility in the future were open to using IVF. Men were significantly more willing to consider using donated eggs and embryos, gestational surrogacy and fertility preservation. Women were significantly more willing to consider using IVF, ICSI and donor sperm. This could suggest, the childless respondents were not positively inclined to third party options

Similar results were reported about Swedish participants, indicating that men seemed to have more favourable perceptions of egg donation than women (Isikoglu et al., 2006). In contrast, Skoog-Svanberg et al. (2003) in a research in Sweden found that women were more positive than men towards egg donation. Interesting that an earlier study in 2000 in Sweden on only women aged 30-39 years on attitude towards use of egg donation in ART showed, 94% were positive towards oocyte (egg) cryopreservation for medical reasons. 70% considered that this treatment was also indicated for social reasons. 76% found it acceptable to offer ART to single women. Uterus transplantation was found to be more acceptable than surrogacy (80% vs. 47%) (Wennberg et al., 2016).

In the UK a survey by Kazem et al., (1995) aimed to find out the attitudes of both fertile and infertile men and women, as well as egg donors and recipients towards egg donation for treatment, diagnosis and research. They found that both sexes, irrespective of whether they were fertile or not, were more open to egg than sperm donation. Fertile participants were significantly less aware of egg donation. Education had little influence on attitudes, although more educated people were unlikely to use gamete donation for treatment themselves. As mentioned above, people seemed to generally favour egg donation as a way of treating infertility.

A more recent study, again in Sweden (2013), was conducted to assess the attitudes towards aspects of embryo donation in a randomised sample of 1,000 Swedish women and men of reproductive age. A majority of the respondents (73%) were positive towards embryo donation. 75% agreed that it should be possible to donate embryos to infertile couples. Around half of the participants (49%) supported embryo donation to single women. A majority of the participants emphasised that demands should be imposed on the recipient's age (63%), alcohol addiction (79%), drug addiction (85%), and criminal record (67%); 47% of the respondents agreed that the recipient should be anonymous to the donor, and 38% thought that the donor should remain anonymous to the child (Wånggren et al., 2013). In Lithuania, research on fertile and infertile women found that fertile respondents were statistically more likely to believe that the IVF procedure should be applied only to married couples or women who had a regular partner, the age limit should be defined and the psychological assessment of the couple's relationship and their readiness for the IVF procedure was necessary (Blaževičiene et al., 2014). In contrast, infertile couples were statistically more likely than fertile respondents to maintain that the IVF procedure should be fully reimbursed by the State. Fertile respondents were statistically more likely to be categorical with respect to the number of embryos and the freezing of embryos. There was also a statistically significant difference in opinions of infertile respondents who were in favour of stricter regulation on the donation of reproductive cells (Blaževičiene et al., 2014). Both of these studies imply that the participants in Sweden and Lithuania believe specific regulations should be in place when undergoing infertility treatments.

An extensive study in 2021 was conducted in Hungary on knowledge and attitudes about assisted reproductive technology using an online survey (Szalma & Bitó, 2021)**.** The participants were 1370 men and women between 18 and 50 years of age. The questionnaire had 3 parts. Part 1 included questions about self-rated knowledge. This was in the format of choosing one of the four options: (1) no knowledge (2), has some knowledge (3), is fairly knowledgeable (4) or is very knowledgeable (4). Part 2 was a 27-item attitude questionnaire on subjects such as costs of ART. Participants had to make a choice on a five-point scale: oppose very 1) strongly, 2) oppose, 3) neither oppose nor support, 4) support or 5) support very strongly. Part 3 was an 8 item eight questions on knowledge about general fertility and

ART, respectively. For example ‘Most women have to go through IVF more than once to have a baby ‘ or ‘Children conceived through the use of assisted reproductive technology have more long-term health problems than children conceived without the use of these fertility treatments’. Each of the items contained a statement, and the respondents were asked to decide whether the statement was true or false, and rate their decision on a five-point scale (i.e. 1 = definitely not true, 2 = probably not true, 3 = do not know, 4 = probably true or 5 = definitely true) (Szalma & Bitó, 2021).

The results showed that approximately half of the respondents (49.3%) rated themselves as fairly knowledgeable about ART. However, 56% of the respondents answered just three of the eight knowledge questions correctly. The greatest lack of knowledge about ART was about its risks: the majority of respondents did not know that in-vitro fertilisation poses health risks for women and conceived children. Regarding attitudes, the majority of respondents had a very positive attitude towards ART. Only those respondents who were religious were less supportive of ART. These data suggest that men and women of reproductive age overestimate their ART-related knowledge as there were inconsistencies with how they rated themselves and what they actually knew. Other interesting findings about this study is that in a Western society such as Hungary, there is still religious concerns about ART, there is lack of knowledge and perhaps considerable misconceptions about what is involved in ART.

These studies that have been conducted in Western societies give an insight of the perception, and attitudes of the people living in these countries may have towards ART. One could argue the results from the studies reflect a general positive perception towards ART. The studies reflected results of willingness to consider infertility treatments, good knowledge of treatments available and the openness to ART in the participants.

1.8.3 Public Perception in non-Western societies

Very little research has been reported on non-Western public perception on ART. Iran seems to be one of the countries that has attracted some attention on this topic. Ahmady and Bamdad (2017) examined 505 Iranian public perceptions of assisted reproduction and its influence on adoption in Shiraz, the most populated city in the south of Iran. The results indicated that respondents did not support all types of assisted reproduction. Amongst modern infertility treatment methods, IVF (using husband's sperm and wife's egg) was the most widely acceptable. Gestational surrogacy and the use of donated gametes were less accepted. Fereydouni et al. (2009) investigated the attitude of males and females towards egg donation and factors affecting these variables such as gender and education. The result showed that in conditions with female infertility, female subjects were more open to accepting the procedure than men, and men were reported to be more against any kind of treatment under any circumstances. Kian et al. (2014) conducted a study to assess the attitudes of Iranian infertile couples toward surrogacy, with a sample of 150 infertile couples selected using a systematic randomised method. The researchers concluded that although there was not a significant difference between the overall positive attitudes of infertile women and men toward surrogacy, the general attitude toward using this method is not strongly positive.

A more recent study (2018) examined Nigerian women's knowledge and perception of ART (Osian et al., 2019). The women (n = 348) were selected from those attending a tertiary health facility. Participants were administered 10 questions on self-rating of knowledge of ART. For example, 'Have you heard about ART' or 'Do you know that ART can fail' 70% rated excellent knowledge, 60%–69% rated very good knowledge, 50%–59% rated good knowledge, 40%–49% rated poor knowledge, and <39 rated very poor knowledge. There were

7 questions on self-perception with responses on a Likert scale. For example, ‘Couples fear rejection by the society if they use ART’ or ‘Cost of ART should be taken care of by the government’. The results of the perception part of the study showed there is generally negative perception on ART amongst Nigerian women. The authors concluded that whilst there is a high awareness albeit negative about ART there is also a low level of knowledge about ART. They argued that appropriate policies and programs must be put in place to educate the populace on the importance and success rate of ART.

These studies that have been conducted in non-Western societies also give an understanding of the perception, and attitudes of the people living in these countries may have towards ART, however it differs in several aspects compared to Western societies. One could argue the results from the studies, which are not many, reflect a general negative perception towards ART. The studies reflected results of negative attitudes towards surrogacy, low levels of knowledge of infertility treatments, and an overall negative attitude towards ART and infertility treatments in participants.

1.8.4 Disruptive Innovation Theory and research on public perception

In short, the overall review of studies on public perception and attitudes towards ART shows inconsistencies and discrepancies in findings between self-rating of knowledge, actual knowledge and facts such as gender differences, cultural divide and religion affecting perceptions and attitudes. The final part of this chapter is an attempt to explain why ART has been subject to such controversial debates and conceptions and misconceptions. This perhaps can be explained by Christensen (1997).

Christensen (1997) maintains that any new innovation may come into conflict with public perceptions due to existing traditions and norms. Not all innovations can be categorised as ‘disruptive’, although they might be revolutionary in other ways.

Taking the basic premise of Disruptive Innovations Theory (DIT) into account, the three-century old controversy surrounding the innovation of artificial insemination resulted in disruption to socio-legal, religious values, and beliefs of the family. Artificial insemination, although invented in the eighteenth century, was rarely used until the 1930s and only legalised in the 1960s. Its application to surrogacy and its use by unmarried women extends the controversy into the twenty-first century (Bernstein, 2002). Moving to more recent times, one can see how the new innovations have crossed pathways with the existing norms, traditions and religious beliefs. As mentioned in the earlier sections of the thesis, this led to negative reactions by the press and the Vatican which was highly published in the following links but more recently has been removed. (https://www.independent.co.uk/news/health/test-tube-baby-40th-anniversary-world-first-reaction-ivf-louise-brown-a8454021.html; https://www.freethink.com/shows/wrong/season-1/beware-the-frankenbabies).

The initial public reaction to the first test-tube baby due to moral, ethical and religious concerns is perhaps not surprising, as explained by disruptive innovation theory. DIT fits nicely with the latter, which maintains that any new innovation (especially of a sensitive and debatable nature) may come into conflict with public perceptions due to existing traditions, norms and religious beliefs. This is captured in articles by Cohen, Daley and Adashi (2017) and Werner-Felmayer (2018) in which, the extent of disruptive aspects of the new technologies and innovations, in particular from a cultural and social perspective, have been discussed. An understanding of public perception of innovative technologies is thus of prime interest from a research point of view. It is therefore under the umbrella of studying 'public perception' that one can examine the extent to which any new innovation has been accepted or absorbed by the general population. The importance of identifying 'lay' perceptions and misperceptions of scientific and technological developments, including those that relate to ART, has been discussed in several new lines of research (see e.g., Goldfarb, 2019; Hudson, et al., 2009). It has been stated "Lay people can address complex social and ethical questions without a full and detailed understanding of the technical processes involved" (Kerr et al., 1998, p 58.). With regards to infertility and ART, Jensen and Jensen (1993) stated that people with strong religious beliefs tend to be more traditional in lifestyle choices, gender ideology, and marriage and family patterns. Singer et al. (1998) reported that the more religious tend to hold more conservative views and perceptions towards issues such as genetic testing and a prenatal test for themselves or their spouses. Inhorn and Birenbaum- Carmeli (2008) reviewed more than 50 anthropologists who were studying the effects of ART in many areas of social life, including the traditional anthropological domains of kinship, marriage, and the family, gender, religion, and biomedicine. Their research signifies both the destabilising and the generative impacts of ART at the interface between science and society.

In line with the present thesis, it is thus expected that the more traditional and deeply rooted religious populations are more reluctant to accept ART than those with more 'Westernised' views and lifestyles.

1.9 Summary of the chapter

The birth of the first test tube baby and the rise of different variants of ART raised the hopes of millions of infertile couples worldwide but as with most new innovations it gave rise to a number of challenges and factors. The challenges ranging from medical, psychological and social consequences to acceptance by different cultural, ethnic groups and the general public.

Whilst there had been considerable research on the psychological consequences of being infertile and undergoing infertility treatment, little has been done on public perception as well as those involved in ART on psychological, medical and social consequences of children born by ART. As discussed in this chapter, the general conclusion is that to date, there are mixed views on the medical, psychological and social consequences of ART, as well as mixed views on what the public think about ART. There has also never been an attempt to study the extent of what the public perceive as positive and negative aspects of ART which have been verified by medical practitioners involved in ART treatment.

The topic of public perception of ART has never been investigated in Guatemala, a country that will be discussed more thoroughly in the next chapter, provides an excellent research venue in which two contrasting ethnic groups divided by religion, culture, and trust in government, socio-economic status and language cohabitate for centuries. No comprehensive record exists as to how ART may cross pathways with the two ethnic groups of Guatemala and what are specific points of concern when undergoing ART from both general public and medical practitioners.

CHAPTER 2 Guatemala: The Land of The Maya and Ladinos

Preface

Guatemala is a country situated in central America with a population of 17 million, made up of mainly the ethnic groups of The Maya and Ladinos (*Guatemala Overview: Development News, Research, Data | World Bank*, 2022). The population of The Maya makes up for approximately 42% of Guatemala, largely living in rural areas. Ladinos are estimated to be 56% of the population, generally living major cities as well as rural areas (Instituto Nacional de Estatística, 2018). The main language is Spanish, spoken by 70% of people, and 30% of people speak an Indigenous Mayan dialect (The World Factbook, 2022). However, one of the key aspects of the country is the existence of two main ethnic groups living in the same country for four centuries (Instituto Nacional de Estatística Guatemala, 2007).

Each ethnic group has maintained distinct traditions and religious rituals. As will be explained in this chapter thanks to 'historical events' there is a marked difference in the level of education, trust in modern medicine as well as issues related to family, gender roles, social class and fertility between The Maya and Ladinos. The historical events (in particular the civil war) are discussed in this chapter as well as the possible impact of Covid-19 pandemic (affecting the world population in late 2019 onwards) on the daily life of The Maya and Ladinos.

It should also be emphasised that there have been relatively few scientific publications aimed at the Guatemalan population towards their perception and behaviour on health-related factors (and none on ART) and very few new studies have targeted the Maya population of Guatemala. As will be explained below, trust in modern medicine is a factor that is very much lacking amongst the Maya population as well as in the Ladinos who also show degrees of distrust in the modern medicine. For example, evidence suggests that the Maya prefer to seek help for any medical issues particularly targeting the magical (traditional), religious and social processes (Frayissinet, 1994). It is for this reason that there is a need to investigate the perceptions and behaviour of The Maya and Ladinos' population towards modern medicine and equally important to compare the perception and behaviour of the two ethnic groups towards ART as the most advanced and controversial health related treatment option. Indeed, it could be the case that whilst there is a distrust in both the Maya and Ladinos, there is different levels of distrust in the Maya. It could be argued that the Maya have higher levels of mistrust compared to Ladinos, as historically the Guatemalan government have taken advantage of the most vulnerable, many times targeting the Maya (to be discussed in this chapter).

As a result of scarcity of scientific evidence, what is reviewed here is in some parts based on government reports and grey literature, with the understanding that their scientific rigour may at times be questioned.

2.1 Religion, family values, gender roles, machismo, social class and fertility patterns

2.1.1 Religion

In Central America, the leading religion is Roman Catholic and Evangelic Protestant. Roman Catholicism is the main religion in Guatemala, among The Maya, it is often practiced with beliefs of pre-Columbian Maya traditions and spirituality. Evangelic Protestant is the second most followed religion in Guatemala (Diaz, 2012). Religion and ethnic differences are thus significant factors to take into account, should Guatemalans consider ART as an alternative to natural conception? Whilst chapter 1 provided an overall view of how different religions regard fertility, it should be noted that for Maya and Ladinos, the interpretation and acceptance of such commandments may differ significantly. For example, as reported in chapter 1, the official Roman Catholic doctrine states that human life begins at the moment of conception and certain moral judgements are born from these claims such as a foetus or an embryo must be respected and treated as a human person with dignity and rights. The Vatican states that the experimental use of embryos is condemned because it disrupts human dignity, reducing embryos to objects of scientific knowledge (Cook, 2015). In Evangelic-Protestant teaching, IVF is accepted with limitations, in contrast to the Roman Catholic Church, the Protestant Church does not condone IVF due to the use of medicine. More or less, artificial insemination using the husband's sperm is acceptable (as long as the couple are heterosexual and married) (Sallam, 2016). The issue here is that only some, or none, of what is reported above would necessarily apply, or be accepted, by The Maya or Ladinos. This is because the Ladinos may adopt a more Western approach and be flexible in either accepting the views of their religion, community members or make their own choice about how to deal with their fertility problems. The Maya on the other hand, may have to be more directed by centuries of traditions, religious rituals and ancestral lifestyles before deciding on any ART approach. At least this is the current thinking, at the present time, and in the absence of any scientific studies on the perceptions and behaviour of the Maya and Ladinos towards ART.

2.1.2 Family values, gender roles and machismo

The values and traditions of the Guatemalan population are a contributing factor to the publics' perception of ART. For example, traditionally Guatemala has a patriarchal society whereby men are usually the money earners and women are the nurturers/homemakers. Men are often expected to be the dominant figure in the household and women to be of support these roles can differ depending on how traditional the household may be (Gendell et al., 1970).

In general, women in Guatemala live under the societal model and control of machismo. Machismo is the social construct where men dominate, and women tend to suffer emulating virginal idealism (Rodman, 2006). These kinds of categories diverge with other traditional male gender role values that Latin culture holds, such as chivalry, hard work, honouring and providing for one's family (Gibbons, et al., 2006). In the model of social gender relations, adopted by Stevens in 1973, Latin women in general are thought to be spiritually tougher than men and must therefore endure men's abuse, irresponsible behaviour, and extramarital affairs in order to establish themselves as true respected women. In Machismo, men are considered to be spiritually weak, and are thus unable to refrain from abuse, irresponsible behaviour, and extramarital affairs (Stevens, 1973). In the machismo societal model, women can prove their true womanhood only by tolerating the transgressions of men over a period of many years, during which time they must produce viable heirs. Only then will a woman be considered a respected member of the community.

More recently however, machismo is viewed through two separate lenses. Arciniega et al. (2008) argue that there are the more traditional aspects of machismo, and caballerismo (translates in English to gentleman-isms). A study conducted in 2008, found that machismo was related to aggression and antisocial behaviour, greater levels of alexithymia, and more wishful thinking as a coping mechanism. Caballerismo, was positively associated with affiliation, ethnic identity, and problem-solving coping. Traditional Machismo was also associated with less education, whereas there were no differences across education level on caballerismo scores (Arciniega et al., 2008).

In many instances it may be common for Guatemalan women (Maya and Ladino) to be economically active due to the fact that for the majority of people, maintaining a family with one income can be financially challenging. Studies conducted in 1991 explain the model of Machismo by researching the economic situation of Latin American society. Their studies suggests that women endured abusive behaviour because of the sexual division of labour, women's economic contribution to the household, and the community's relation to capitalism (Ehlers, 1991). Research exploring gender roles in relation to negative cognitive-emotional factors, found that encouragement of traditional male gender role beliefs like machismo, have been associated with detrimental outcomes to women's emotional health, such as higher depression, anxiety, and anger (Fragoso, 2000).

It is believed Maya and Ladino women have different experiences with machismo. Maya women have a more of an egalitarian experience than Ladino women due to their importance to the mode of economic production. This means that Maya woman seem to be appreciated more in their relationships as their work complements that of Maya men. The work of a Maya woman is directly involved with the agricultural sector which commonly dominated by Maya men. The majority of Ladino women however, work in positions of low status and low pay, which only widens the gap between them and Ladino men (Rodman, 2006). Even though a Ladino woman’s status in Guatemalan culture is higher than that of Maya women, Ladinos can often be seen as more vulnerable in a marriage than their Maya counterparts.

2.1.3 Social class and fertility patterns

Like in many countries, often Maya and Ladino families in Guatemala have to decide whether they can afford to have as many children as they desire (Davis & Lopez-Carr, 2010).

Both Ladino and Maya families’ value tradition and the opinions of the family elders. Important life choice decisions are often based on the effect they may have on the family; this includes career choice, social circles, and choosing a partner. Decision making in Latin families is often stratified based on age and sex, and generational hierarchy is expected – grandparent, child, and grandchild. The oldest male (direct relative) holds the greatest power in most families and may make important decisions for others in the family (Carteret, 2011). The Maya and Ladino societies hold strong beliefs in having a large family. Large families are considered valuable and ultimately, the main goal. One of the key reasons for wanting a large family in an agrarian society like Guatemala, is the economic security it provides (Payton, 2015). When the parents become older and unable to support themselves through agriculture, their children support them with necessary resources.

The Maya hold strong beliefs in a big family, some Maya couples even lend their children to their childless family members not only to help with labour, but because a house without a child is considered lonely and useless, children are extremely important (Ward et al., 1992). Within the majority of Maya communities, the Catholic Church is a primary source of family planning information. It is a widely accepted notion that God decides how many children a woman will have and that she is born with all the children she will bear in her lifetime already established within her. Furthermore, having children is considered to be the sole reason for existence and the dominant reason for marriage. Therefore, Maya couples do not get married and just have children; instead, they wed in order to have children (Ward et al., 1992).

Like many other countries, Guatemala has a class system which is based on wealth and ethnicity. The upper and middle classes are few and far between, whereby the majority of people fall into the working class. The upper class consists of well-educated executives and employers, mainly under the ethnic group of Ladinos. The Guatemalan middle class is urban in character and is composed in almost equal proportions of university-educated professionals and administrative employees, mostly of a Ladino background with few from a Maya background. The working class, which can include both Ladinos and Maya, mainly consists of unskilled workers, such as farm workers and street vendors (Diaz, 2012).

The results from a census sample conducted in Guatemala City in 1964, revealed that both Maya and Ladino women who were economically active, specifically domestic servant workers (majority of Maya heritage), had lower fertility than women who were economically inactive. A study carried out in the 1960’s showed that being economically active had a depressing effect on women’s cumulative fertility in Guatemala City in 1964, furthermore, working as a live-in domestic servant had a considerably more negative association with fertility patterns than a live-out domestic servant and any other types of economic activity (Gendell et al., 1970). This historical data is relevant today, as Guatemala has entered a more modern era. Women in general have begun to enter the workforce in much higher numbers than in the 60s, however this could be one of the causes for a steady decline in fertility patterns (de Broe & Hinde, 2006).

In order to fully understand Guatemalan perceptions on infertility treatments, it is important to highlight Guatemala's fertility patterns. The results from Urban and rural fertility patterns up to 2002 are from data gathered from the Demographic and Health Surveys of 1987, 1995-96, and 1998-99, the National Maternal and Child Health Survey of 2002 and the Census of 2002 propose a continuous slow decline in fertility from 1972 until mid-1990s amongst the population as a whole. The National Maternal and Child Health Survey and the Census of 2002 also show a sharp decline in fertility since 1998. The decline in fertility for both The Maya and Ladinos in Guatemala until recently can be acknowledged by the fact that Guatemala has been lagging behind in socioeconomic development and the challenge of being a very culturally diverse and segregated population by economic class and race, makes it difficult for modern reproductive ideas and behaviour to spread (de Broe & Hinde, 2006). Guatemala has socio-economic barriers that prevent the progress of infertility transition (the historical process whereby fertility and mortality rates declined from high levels that they exhibited in past times to the low levels that they exhibit in rich countries today). For example, it has the largest proportion of Indigenous people in Latin America of whom the majority are poor and illiterate. Social interaction between Ladinos and the Maya is limited and on unequal terms due to the socioeconomic divide, therefore contemporary ideas and behaviours are difficult to disseminate (de Broe & Hinde, 2006).

2. 2 A 36-year civil war

The Guatemalan civil war began at the start of the 1960s when a segment of the military attempted a coup. This led to a violent and long conflict that affected nearly every aspect of human health and development. Violence ultimately peaked during 1978–1984, when tens of thousands of rural Indigenous people were killed by the Guatemalan government to destroy the guerrilla forces (a small independent group taking part in irregular fighting, typically against larger government forces) who used the rural areas to organise their agenda (Beckett & Pebley, 2003; Chamarbagwala & Morán, 2011).

The war and violence created general fear and mistrust of the government in Guatemala, especially among the Indigenous as many Maya villages were destroyed. Suspicion, mistrusts, and uncertainties festered around government sponsored programmes especially within the educational, economic, agricultural and family planning sectors. These effects were felt throughout Guatemala and particularly in the rural areas where it is largely populated by Indigenous people (Chamarbagwala & Morán, 2011; de Broe & Hinde, 2006). The violence was incredibly damaging, and it included torture, murder, rape, and abductions usually targeting women and children. During this time of violence and mistrust, governmental health systems and education systems were severely disrupted and often inaccessible causing the inequality gap between the Maya and Ladinos to widen even more (Chamarbagwala & Morán, 2011; de Broe & Hinde, 2006; Grace & Sweeney, 2016). Guatemala reached a peace agreement in 1996 that promoted firm and lasting peace.

Today however, this mistrust still carries weight throughout attitudes and perceptions towards the government Guatemala, particularly in Indigenous populations like The Maya. One could argue that limited research indicates The Maya show less interest in participation of government led activities or seeking professional health care instead of traditional methods.

2.3 Post-war mistrust

Even after the civil war in Guatemala, mistrust still lingers. Although a peace agreement was reached in 1996, people generally still hold mistrust towards the government. A study conducted in 2021 about people's trust in post-war societies looked into people’s perceptions of the strategies aimed at ending the violence and rebuilding the state, and how they have an enduring impact on people’s view of the state. The study found that in Guatemala having a peace treaty did not necessarily mean the people trusted their Government (Dyrstad et al., 2021). At the time of the study, the peace agreement in Guatemala was 20 years old but approval of the requirements in this agreement, which continues to be of significant political issues (for example, indigenous peoples’ rights), are still associated with political mistrust. The findings do not appear to be driven by specific groups or regions in any of the cases. In particular, the main findings are robust to the inclusion of indigenous identity or region in Guatemala (Dyrstad et al., 2021).

2.4 Medicine and mistrust

Mistrust in modern medicine is still a problem in Guatemala today. People, particularly The Maya, do not trust Western medicine and have a negative perception towards it. For example, many people do not trust the potency of drugs the government provides, others do not trust Western medicine as they practice their own traditional remedies, and many others do not trust Western medicine as Guatemala has a dark history with medical ethics which will be illuminated below.

In Guatemala, following traditional remedy methods is generally the norm for most of the Maya population. A study was conducted in 1996 in rural Guatemala, which has a majority of low-income populations. The study investigated the opinions on Western medicine and the acceptance of public services that mothers of Ladino and (mostly) Maya ethnic background. The study found that the acceptability of public services for children was poor because the

Social Security clinic did not prescribe the ‘potent’ modern drugs mothers preferred for the treatment of symptoms. This then made mothers turn to the partially informal private sector, like traditional remedies (van der Stuyft et al., 1996). Another study carried out in 2017, used semi-structured interviews with physicians and pharmacy staff in 30 pharmacies around Guatemala. The participants’ gender was not disclosed but their demographic was noted in their education level. For physicians, the level of pharmacy-specific training or certification varied. Half of the participants received no pharmacy-specific training of any kind. Among those who did report receiving such training, the quality and nature of the training varied from formal to informal. Among the pharmacy staff, the level of formal education prior to entering the pharmacy business was typically low, with only 2 of 30 respondents having received any formal higher education. The study found that the people interviewed did not trust the quality or efficacy in ‘low’ costing drugs. The researchers suggested that strengthening state capacity and transparency in the regulation and monitoring of the drug supply is the key goal of access-to-medicines advocacy in Guatemala (Flood et al., 2017).

Not only is there mistrust around the efficacy of Western drugs but Guatemala has an obscure history with medical ethics. In the 1930s and 40s harmful and highly unethical medical experiments were conducted on vulnerable Guatemalan people (Reverby, 2012). In October of 2010, The United States issued a high-level apology to Guatemala about the U.S. Public Health Service S.T.D. Inoculation Studies of 1946-1948. This study was a PHS Inoculation Sexually Transmitted Diseases (STD) study that looked into the effects penicillin had on STDs. The study aimed to see what STDs penicillin could cure. However, this study was unethical as it had lack of any real consenting processes and the study had actual purposeful transmission of potentially life-threatening STDs in Guatemala. The study extended for two years, recruited more than 1300 vulnerable men and women (sex workers, mentally ill patients, soldiers, and prisoners) and involved infecting them with syphilis, gonorrhoea and chancroid and then treating little more than half of them. However, not only did the study fail to treat everyone that got infected, the people that did get treatment did not get it for long enough to be cured. Thus, this resulted in tremendous suffering and distress. The study had horrific physical procedures like spinal punctures and the abrading of men's penises and women's cervixes to deliver the disease inoculums. Major ethical concerns were noted including lack of control over body autonomy, dangers of abuse by those with great power, terror of putting trust in physician/scientists who respond with what many see as close to medical torture, and perhaps most destructively the racism of treating people of colour as the 'other' both in the U.S. South and the Global South. The study has been analysed in the context of the racism and imperial power that made it possible for the doctors to believe they had the right to do the studies and have fuelled the suspicion of public health and medicine in Guatemala. One could argue that the lack of access to effective Western medical treatments and the horrific medical malpractice the Guatemalan people as a whole have endured, has led to mistrust in Western medicine.

2.5 Research to date on infertility and treatments in Guatemala

There has been limited research examining the factors that may influence infertility treatments via ART within the Guatemalan population particularly, with regard to the key factors of society as explained above. For many people in Guatemala, having more children can affect the quality of life, many people with infertility issues simply cannot afford average day-to-day life, sometimes even basic necessities like food and clean water can be a struggle, let alone infertility treatments. ART is perceived as a luxury for wealthy people, and not everyone who is infertile and wanting to have children can afford it. A prejudice that many countries hold, as well as Latin American countries is that poor women should not have children because they cannot afford to, and therefore should not use these techniques. Infertility is often viewed as a problem of the wealthy rather than just a problem - this reflects a gap between the poor and the rich (Luna, 2001). This poses socioeconomic issues, where on one side the small percentage of the wealthy classes have access to ART and highly refined medical treatments. However, on the other side, there is a large population of underprivileged people who cannot even provide for their basic needs, let alone have access to or validate a costly infertility treatment. The issue of ART is restricted to the wealthy classes even though the population in the most need of these technologies is the underprivileged classes. Disadvantaged people are more likely to have reproductive medical issues such as sexually transmitted diseases and reproductive tract infections and therefore have a higher chance of infertility. For example, it has been reported that Indigenous people from Guatemala, have been exposed to pollutants like certain kind of fertilisers, as they mostly work in agriculture, which have caused infertility problems (Luna, 2001).

Attitudes towards ART and infertility tend to differ amongst Guatemalan males and females, for example when it comes to adoption, Ladino men in Guatemala were reported to frequently display machismo attitudes towards the subject. Machismo traits are primarily evident in areas of Guatemala of low education and low socioeconomic status, however machismo views are often times rooted in culture regardless of economic stature (Gibbons, Wilson, & Rufener, 2006). The Latin American culture of machismo contributes to the discrimination of women and children, magnifying their essential dependency on men for economic survival. The machismo culture is still rooted in Guatemala today, some of the reasons are due to gender pay gaps, poverty and the lack of legal structures that safeguard women and children (Cone, 2018).

Gender attitudes reported by Gibbons, Wilson, & Rufener (2006) suggest that the participants who held machismo beliefs, also had negative views towards adoption. The participants in this study were the general public from a private university campus in Guatemala and consisted of 88 men and 64 women, 96% of whom described their ethnic background as Ladino. The participants were administered an adoption belief Likert-type scale (agree, disagree, neither and don't know). The study revealed that the acceptance of adopted children as part of the idealised family unit in Guatemala may depend on attitudinal differences, such as the values held by different genders (Gibbons et al., 2006). Baron (2003) conducted a study analysing the psychological aspects of the female partner in cases of male infertility. The study examined 100 couples where the female partner was under 35 years of age and presented with no pathology for infertility. The participants took part in a study of male infertility treatments; the ICSI (89/100) and donor insemination (11/100) programme. The study reported that sharing emotions with others was rare, whereby 84% of the patients did not talk to their husbands because they feared they would hurt their feelings and 81% did not talk with their families to protect their partner's image. The study also reported the women to have defensive aggressive attitudes towards their partners, the women hid the problem and blamed themselves. It also shows how 'macho' attitudes exist not only in males but reinforced by the woman's attitudes and expectations (Baron, 2003). This study strengthens the idea that women in a Latin culture would feel highly uncomfortable discussing male infertility with their partners in fear of a negative (machismo) reaction.

Infertility and infertility treatments have been a controversial topic in Latin America like in many other parts around the world. For example, in Costa Rica, IVF was banned for several years because it went against their Catholic beliefs. Religion plays a big role in ART because it shapes individual perceptions, social norms and availability to ART services

(Adamson, 2009). Access to ART around the world varies, depending on many different factors where the highest ART cycles performed is 3263 per million inhabitants in Israel, and the lowest two cycles per million inhabitants in Guatemala, in other words, of all the countries that offer ART, Guatemala is reported the country with the lowest cycles performed (Adamson, 2009).

2.6 Guatemala and Covid-19

Covid -19 has brought changes to all aspects of life. In Guatemala, many Indigenous and Ladino people have already adopted new preventative measures such as masks and regular handwashing. Many people who live in rural areas are now accessing their preventative information through radio and TV programmes, as this is the most trusted of Covid-19 information (The Population Council, Inc., 2020). It is recommended for 70-80 % of a population to be vaccinated to reach collective immunity (Cleveland Clinic, 2021). As of August 2022, nearly 39% of the Guatemalan population has been vaccinated (Mathieu et al., 2021), 1.5 million Covid-19 cases and out of those 19,082 deaths have been recorded (Mathieu et al., 2021). When Covid-19 vaccination started, comadronas (traditional birth attendants) were established as a priority group. Guatemala has one of the highest infant mortality rates with the majority of deaths happening in poor areas. This is impacting mainly Maya communities, so when the Covid-19 vaccine was rolled out, comadronas had some priority. After comadronas received their protective doses, they went out to their communities to spread the word about the efficacy and safety of Covid-19 vaccines (Pan American Health Organization, 2021).

In 2000, the maternal mortality rate for Indigenous women in Guatemala was more than three times that of Ladino women (Nieves Velásquez, et al., 2018). Covid-19 may widen the gap between Maya and Ladinos even more as a result of the current pandemic which has brought an uncertain future as well as economic hardship.

2.7 Summary of the chapter

This chapter highlighted key features of the Guatemalan society with regards to the two distinguished Maya and Ladino populations. As noted, numerous events, traditions and practices have led to an evident divide in how the Maya and Ladinos value family structure, religion, gender roles and fertility issues. There is also a noticeable lack of trust in modern medicine which is more noticeable in the Maya community and government post-civil war. There are several key features in Guatemala’s social construct that may have a significant impact on the perceptions and behaviour of Maya and Ladino towards infertility and infertility treatment, particularly via ART. These include religion, gender roles, ethnic differences, social class and socioeconomic status. Surprisingly, very little research has been aimed at the perceptions and behaviour of the two ethnic groups in particular The Maya, to this date.

Indeed, having two distinctive ethnic groups living side by side in same geographic location like Guatemala, provides a unique and scientifically strong contrast of a ‘Westernised’ vs ‘non-Westernised’ population views. These views will give some insight into issues related to perceptions and behaviour towards fertility treatments and ART. This is the topic of the next chapter.

CHAPTER 3 Study 1 Public Perception and Behaviour Towards Fertility Treatment in Guatemala

Preface

This chapter presents study 1 aimed at Guatemalans' perceptions and behaviour towards assisted reproductive technologies (ART). In the absence of any published work on public perceptions and behaviour towards ART in Guatemala, this study has elements of originality as far as the Guatemalan population is concerned. As argued in chapter 1, for a comprehensive understanding of public perception and behaviour towards ART; it is crucial to take into account the persons religious beliefs, ethnicity, level of education, gender and the selection of people representing the Westernised and/or non-Westernised way of living. Previous research on this topic have either focused entirely on a Western (e.g., Wennberg, et al., 2016) or non-Western populations (e.g., Ahmady & Bamdad, 2017). Such studies whilst having their own merit, cannot clearly demonstrate the extent to which ethnicity and cultural orientations are factors affecting ART perceptions and behaviours. This could be because the studies are conducted in different countries, in different settings, and incorporating different materials in each study.

Furthermore, different methodologies may be employed in each study that could question any comparison of the outcomes. As mentioned in chapter 1, Pir Jalian (2020) contrasted British (Western) and Iranian (non-Western) public, as well as mothers of children born by fertility treatment on their perception of ART, in particular conception by egg donation. Based on both qualitative and quantitative analysis of the data, Pir Jalian (2020) reported that Iranian mothers with a donor egg child agreed more than their British counterparts that conception via egg donation might have psychological, social and medical problems for the resulting children. Furthermore, the comments made were that this is due to a) lack of genetic link; b) being unhappier than naturally born; and c) might experience overt prejudice from the society. Pir Jalian's pioneering study further highlighted the divide between the 'Western' vs 'non-Western' perceptions of ART. One may thus expect to see more resistance to acceptance of new reproductive innovations when contrasting participants with different levels of deeply rooted traditions and religious beliefs. Pir Jalian (2020) argued that this is in line with the Disruptive Innovation Theory (DIT), developed by Christensen (1997) which maintains that any innovation may come into conflict with public perceptions due to existing traditions and norms. Pir Jalian (2020) demonstrated that the Iranian public with more traditionally and religiously rooted beliefs showed more resistance to acceptance of new reproductive technologies compared to the Western (British) population. Whilst Pir Jalian (2020) attempted to employ comparable materials such as matching age and gender of participants, there was the issue of people in a Western country, contrasted to people in a non-Western country on their perceptions of ART.

Although the findings of Pir Jalian (2020) are significant in contrasting cultural orientation on ART perceptions, it is nevertheless comparing people living in two different countries with possible extraneous factors like accessibility and knowledge of ART, affecting the conclusions. A study on the two distinct populations of Ladinos and the Maya living in the same country, presents an ideal research ground to study the extent to which cultural orientation affects perceptions and behaviour towards ART. Would the same findings as Pir Jalian (2020) be true if the perceptions of two contrasting ethnic groups in Guatemala namely, The Maya and Ladinos are investigated? Should the term ‘Attitude’ or ‘Perception’ be used in this research?

Most researchers do not distinguish between the two terms and indeed it may come across that if a researcher is studying public attitudes towards a topic, it might as well be labelled as public perception towards the topic. However, others argue that there is a difference between the term’s ‘perception’ and ‘attitude’ (see e.g., Refrence.com, 2020). According to Pir Jalian (2020) the main distinction is on the wording and aims of the study and what instructions are given to participants. By definition, attitude is a mind set or an inclination to act in a particular way due to both an individual’s experience and temperament. When referring to a person’s attitudes about a particular topic we attempt to explain his/her general thinking beliefs, values, behaviours, and motivations (Pickens, 2005). According to Lindsay and Norman, (2013) perception is also strongly associated to attitudes. It is the process by which a person interprets and organises sensation to produce a significant experience of the world. Simply put, when a person comes across a situation or stimuli, the person interprets the stimuli into something meaningful to him or her based on previous experiences.

The conclusion drawn from the above definitions is that attitude and perception are strongly related, and studies aimed at attitudes may very well be also investigating perceptions and vice versa. From the purpose of the present study, it was felt that it would be best to draw attention to the possibility that the two terms may imply different meanings in different studies. In the present study the term perception is adopted with the view that if it is explained to the participants that ‘perception’ is what is intended, they may give some more in-depth, meaningful, and personally based experience of topic under investigation.

Study one is aimed at Guatemalan’s perceptions and behaviour and level of knowledge towards assisted reproductive technologies.

3.1. Perception of scientific statements

As explained in chapter 1, there is a host of psychological and medical research on ART and its consequences. Based on the criteria explained in this chapter the task was set to select most significant findings of scientific research on ART and present it to the Guatemalan public. These statements investigated what the public’s perception is about the claims by allowing the public to respond in a Likert scale type questionnaire. The questionnaire also allowed the public to express their written reasons for their answers. The responses (numerical and written) are then subjected to inferential statistical analysis followed by thematic analysis. These analyses have the benefit of a) identifying the conceptions and misconceptions that the public (and those involved in treatment) may have about ART and try to minimise the gap between public understanding and scientific research. And b) it provides practitioners with valuable information to offer the best advice to those planning for ART and for educational programmes for the public.

3.1.1 Public perception

It is important to note the significance of targeting general public or what can be termed ‘lay perceptions’ (and misperceptions) of scientific and technological developments, including those that relate to ART. Furnham (1992) explains that lay people view science differently than researchers. Lay people's points of views on scientific issues can vary depending on different factors in their lives, such as physical, political, social and economic factors. This has been discussed in several new lines of research (see e.g., Goldfarb, 2019; Hudson et al., 2009). It has been stated 'Lay people can address complex social and ethical questions without a full and detailed understanding of the technical processes involved' (Kerr et al., 1998) meaning 'lay' people can comprehend ethical questions without needing to understand the technicalities.

With regards to infertility and ART as stated in chapter 1, there are reasons to believe that religious beliefs, Westernised or non-Westernised lifestyles, gender, level of education and self-estimation of knowledge about ART may affect public perception. Thus, there are reasons to believe that rather than expecting a universally agreed public perception of issues related to ART, one might expect divisions based on the latter factors. There are now sufficient reasons to investigate for the first time, the perceptions of two contrasting ethnic groups in Guatemala, namely The Maya and the Ladino, on ART and their level of perceived knowledge on such procedures.

3.2 Aims of Study 1

The aim of study 1 is to examine Guatemalan public, Maya and Ladino's perception and behaviour towards key issues related to infertility and infertility treatment via 13 Likert scale statements (Appendix A). In the absence of any published research on this topic, this pioneering investigation is intended to provide opportunities for understanding the extent to which ethnicity, religion, age, and level of knowledge on ART is a factor in Guatemalans' perceptions and behaviour towards ART. However as mentioned, in the absence of any published work on this topic in Guatemala, a pilot investigation was deemed necessary.

3.2.1 Pilot work prior to main study

An extensive literature review was conducted during the first six months of the investigation aimed at key research findings and controversies related to children born by ART. For example, “Donor egg conceived children may experience overt prejudice from the wider community, relatives and friends”. The statements (20 in total) were then verified by two independent reviewers knowledgeable in research on ART and then presented to 6 Spanish speaking participants with higher education, to help with the selection of the final list based on the following criteria: a) clarity of the statements for both Maya and Ladino populations (for example to avoid statements with complicated medical terminologies) and b) possible willingness to give a response. For example, to avoid items that may not be pleasant or offensive to a particular group of participants. Finally, as the original items were in English the pilot study was aimed at rooting out any items in the study questionnaire that after translation to Spanish are likely to affect accuracy of responses, for example if participants commented that the English to Spanish translation is not clear, such an item would be revised before being used in full-scale research. Participants were particularly requested to read carefully and respond to each statement. After conducting the pilot study, 13 statements were found to be clear to the 6 Spanish speaking participants and was included in the main part of the study.

3.2.2 Study 1 research questions

As explained, issues of ethnicity and religion were shown to have a significant effect on how participants perceive various aspects of ART and its consequences (see Chapter 1). Pir

Jalian (2020) referred to the Disruptive Innovation Theory (DTI) of Christensen (1997) when explaining the findings on Iranian and British perceptions of consequences of children born by egg donation. DTI maintains that any new innovation may come to conflict with existing cultures, traditions and norms. Pir Jalian (2020) argued that this conflict of existing traditions and norms when it comes to ART are more noticeable with Iranian population with more non-Western orientations than the British population. In view of the argument put forward about the ethnic divide in Guatemala, one would expect to see that ART cross pathways with how The Maya and Ladino perceive its significance and consequences. In particular one could predict to find significant differences in perceptions of ART between Maya and Ladinos. Specifically, the more traditional participants, like the Maya, are anticipated to be holding more conservative views than the more 'Western influenced' Ladinos. Furthermore, differences with regards to cultural orientations are anticipated in the thematic analysis.

3. 3 Methodology

3.3.1 Research design and materials

In a concurrent nested design, both qualitative and quantitative data are collected during the same stage, although one form of data is given more weight over the other (Creswell et al., 2003). In this case, the qualitative data was given more weight. Because most research on public perception and behaviour is based on quantitative research, the main aim was to tackle questions are more widely investigated in the scientific community using quantitative methods.

4 main questionnaires have been used to explore the attitudes and perceptions for ART, That are all quantitative and out of these none have been used in a society like Guatemala. The Fertility Quality of Life (FertiQoL) Questionnaire assesses the quality of life of individuals

experiencing fertility issues. The Fertility Quality of Life (FertiQoL) Questionnaire was developed by a team of researchers led by Dr. Jacky Boivin. Dr. Boivin is a prominent researcher in the field of reproductive psychology and infertility, and she played a key role in creating the FertiQoL Questionnaire (Boivin et al., 2011). Next is the Fertility Problem Inventory (FPI): The FPI measures the impact of fertility problems on individuals' psychological well-being. The Fertility Problem Inventory (FPI) was developed by Professors Denis A. Johnston and Linda J. Kettel, who are well-known researchers in the field of reproductive psychology and infertility. The Fertility Problem Inventory is a widely used self-report questionnaire designed to assess the specific distress and concerns experienced by individuals or couples facing fertility challenges measured by a Likert Scale (Newton et al., 1999).

Fertility Adjustment Scale (FAS): This scale assesses individuals' adjustment to the challenges and stressors associated with fertility treatment. The Fertility Adjustment Scale (FAS) was developed by Dr. Dennis C. Turk and his colleagues. The FAS is a self-report questionnaire (measured via a scale) designed to assess the emotional and psychological adjustment of individuals and couples who are dealing with fertility problems and undergoing fertility treatments (Glover et al., 1999). Lastly, the Infertility Self-Efficacy Scale (ISE) measures individuals' beliefs in their ability to cope with infertility-related challenges. The Infertility Self-Efficacy Scale (ISE) was developed by Dr. Alice D. Domar and her colleagues. Dr. Domar. Self-efficacy refers to an individual's belief in their own ability to perform tasks and overcome difficulties. In the context of infertility, self-efficacy relates to one's confidence in managing the emotional, social, and medical aspects of fertility treatment and its associated stressors, in the ISE this is measured by a Likert Scale (Cousineau et al., 2006).

Indeed, the use of qualitative research is adding a novel aspect of this study as not many studies have combined qualitative and qualitative methodologies.

A quantitative quasi-experimental, questionnaire-based study was designed with independent variables of age, gender, education, religion and ethnicity (Maya and Ladino), and whether they know someone undergoing ART. The dependent variables were 1) responses to the 13 statements selected from actual published research e.g., “Donor egg conceived children have lower IQ scores than naturally conceived children” (Zhan et al., 2013) on a Likert scale (ranging from 1 to 4, Strongly agree, Agree, Disagree to Strongly disagree). Furthermore, the participants were required to add any comments if they wished in support of their choice; 2) rating on a scale of perceived level of knowledge of ART, ranging from 1 = not at all, to 10 = a significant amount.

3.3.1.1 Comments on the choice of questionnaire items

One may argue that the questionnaire items are relatively few and thus may affect the generalisability of the outcomes. For this reason, adding the following comments were found to be necessary:

Firstly, based on the experience of the author, participants (especially the Maya) are more likely to take part and give sincere responses to questionnaire items which is not lengthy. Sahlqvist, Bull, Adams, Preston and Ogilvie (2011) argued that by shortening a relatively lengthy questionnaire in a study on a socially sensitive topic it significantly increased the response rate. This is an issue that is noticeable in most published research especially on controversial topics. For example, Baluch and Kaur (1997) noticed that when students (psychology and medical) were presented with only two statements regarding the use of animals in scientific research there was a very positive and significant involvement by the participants compared to a lengthy questionnaire. More recently and in relation to the current research, Pir Jalian (2020) found a greater involvement and sincerity in responses when assessing Iranian and British men and women's perceptions of children born by egg donation by presenting them with a 12-item statement questionnaire. Thus, the shorter the questionnaire on a sensitive subject to be presented to participants, the more concise and sincere is the responses. For this reason, it was decided to have a relatively short questionnaire and the choice of items to be included governed by key findings of scientific research e.g., 'children born by ART may be socially withdrawn'.

Secondly, as explained above because the intention was to choose items based on actual scientific findings, this restricted the number of items for the study questionnaire. Furthermore, an attempt was made to keep the message (the questionnaire item) as it was reported by scientific findings rather than making the changes to the items to have a balance of positive and negatively worded statements. Thus, if participants are presented with an item and instructed that these are based on what most scientists conclude to be the case about children born by ART, changing the statement (e.g., children born by ART will not be socially withdrawn) would come as a form of deception. Of course, it must be added here that with the passage of time and more scientific research there may be changes in what scientists believe to be the consequences of children born by ART. This would be the task of future researchers to pursue follow up research specifically in a Latin American society.

3.3.1.2 Pre-data collection preparations and complications

Unlike most studies of this nature directed to a population of students or non-students in a Western society, a study on Guatemalan population particularly the Maya has its own difficulties. In Western countries students and non-students are accustomed to being participants in different forms of information gathering. The organisations (e.g., universities and local communities) are prepared for such interventions and provide facilities to enable research. In Guatemala such rich research environment is not readily available. The author (although UK based and of Guatemalan origin) had to engage in several months of negotiations and long-distance correspondence before receiving approvals from two universities in Guatemala to use as a base for research. However, having the base was the first step, the more challenging step was to get the attention and trust of the participants especially the Maya, to take part in the study. Thus, the number of participants and the choice of the different categories of interest in the study such as gender and ethnicity were not the ideal choice of the author but dictated by what one can and cannot do when conducting research in a society such as Guatemala.

3.4 Participants

Maya - (N = 35), 11 males, age M = 27.72, (SD = 5.9). 24 females, age M = 27.02, (SD = 7.56).

Ladino - (N = 146), 58 males, age M = 29.8, (SD = 9.28), 88 females, age M = 28.8, (SD = 11.07).

The participants were recruited from the university and beyond the borders of the University of Galileo and University of San Carlos in Guatemala.

3.5 Materials

As mentioned in the above sections, there is an absence of published questionnaires on Guatemalans perception of factors relating to ART. Preliminary pilot work and extensive literature review was deemed critical to the starting point of the present study. The final list of items selected for the main research are presented below with the reminder that they are topics related to careful selection from published research work and it is with the aim to have as short but as concise as possible a questionnaire, that covers as many key factors about ART as possible.

In what follows are the reasons for why each item has been selected and its significance to the overall research is outlined. Some of the studies reported here have also been mentioned in previous chapters but for the benefit of clarity, it is now classified as it relates to the rationale for the selection of open-ended questionnaire items.

3.5.1 Statement 1- Before embarking on any of the ART techniques the couple should consider what their religion has to say about their action.

The impact of religion on the handling of infertility reflects similarities across different religious groups. Across the Judeo-Christian religious faiths, infertility is seen as punishment for wrongdoing (Sewpaul, 1999). In Islamic scripture, infertility is seen as a God-given impairment, profound feelings of guilt may result from the inability to conceive and perceived as a punishment from God (Inhorn, 2018). The individual's level of involvement with religion, their personal conception of God, and their sense of self in relation to God are important factors in influencing the impact of religion on the experience of infertility (Sewpaul, 1999).

In the Middle East, where the three major religions namely: Judaism, Christianity and Islam emerged, religion has the strongest influence on social behaviours, attitudes, practices and policymaking (Serour, 2000). The Jewish attitude to infertility treatment is based on the fact that the first commandment from God to Adam was “Be fruitful and multiply and replenish the earth and subdue it” (Holy Bible: Genesis, 1:28). Judaism allows the practice of all techniques of assisted reproduction when the egg and sperm originate from the wife and husband respectively (Schenker, 2005). Jewish religion does not forbid the practice of surrogacy, whether complete or partial, as indeed the practice is described in the Bible in the case of Sarah and Abraham with Hagar who bore Abraham a son, Ishmael, and Rachel, who used her slave girl Bilhah to bear a child for Jacob as indicated in Genesis 19 and 30.

The third-party reproduction is based on the importance of maintaining the family structure and integrity among the Shia family. These guidelines and legislation played a major role in comforting patients and physicians. There has been, however, a significant shift in acceptance of ART. In the 80s infertility treatment was associated with secrecy, feelings of shame, doubt and even sometimes guilt, but in the 90s such feelings were replaced by openness about seeking infertility treatment and ART in particular (Serour, 2008).

According to most Muslim scholars, if ART is designated for a married couple as a necessary line of treatment, it is permitted during the validity of marriage contract, with no mixing of genes (Al-Hasani, 2006). If the marriage contract has come to an end because of divorce or death of the husband, ART cannot be performed on the female partner, even if using sperm from the former husband (Al-Hasani, 2006; Serour, 2005). In most Muslim countries, parenting of a donor child by a single mother is unlikely to be socially acceptable (Inhorn, 2006). The welfare of the resulting child is a primary concern, and the existence of a father is regarded as an important aspect in qualifying for the treatment (Larijani & Zahedi, 2007).

In Christianity, although it permits all conventional lines of treatment of infertility, it forbids to its followers all practices of ART as they bypass the sexual union of man and woman. Although the Vatican does not accept ART, the Protestant and Anglican may practice it. Many protestant churches will allow ART with spouse gametes and no embryo wastage. The Eastern Orthodox Church does not oppose ART for couples. However, gamete donation or surrogacy is not approved (Serour, 2006).

Just like in the societies mentioned above, religion and gender roles play a huge part on family planning and it is handled, including infertility. As mentioned preciously, Guatemalans are mainly Catholics, Evangelical protestant, or follow Maya spirituality with Christian influences. In Guatemala, the Catholic Church influences men to dominate the public and private sphere of religion, including private home matters and family planning (Chiappari, 2001). Evangelical Protestantism teaches that everyone should spread the word of God at all times, including in private settings, this is done in a family effort where usually the women hold the domestic dominance in the household (Chiappari, 2001). In Maya culture, many men feel it is their Godly duty to have as many children as possible. Maya men usually have control in family planning and also feel they have the right as a husband to sleep with their wife whenever they wish to do so (Payton, 2015).

3.5.2 Statement 2 - As the costs of ART treatment is too high and the chance of success is relatively low the couples should themselves cover the costs not the government

ART treatments are usually associated with relatively high costs (see e.g., Wang & Sauer, 2006). In the USA for example, the complete cycle of egg donation would cost ranging from $37,000 to $65,000 (Conceiveabilities, 2020). This is considering that the donor is not expecting any payment. According to Fauser et al. (2019), the general feeling in the Western world is that there should be support for public funding for fertility treatment. The question however, that has not been addressed, is to what extent this has universal appeal. Pir Jalian (2020) noticed that Iranians have no option but fund any ART treatment themselves. Ombelet & Campo (2008) argued that in developing countries, the problems of infectious diseases such as malaria, tuberculosis, gonorrhoea and HIV are still very prevalent and that it should be questioned if expensive techniques with low success rate such as ART can be justified in countries where poverty is still an important issue.

Guatemala is a country with prominent economic inequality; nearly 60% of the country is below the poverty line (Central Intelligence Agency, 2022) bringing the GDP per capita to $8,200.00 annually in 2019. The country does not rely on public funding for ART and couples seeking infertility treatment must pay the full treatment amount. The cost of a single cycle of IVF treatment in Guatemala is priced anywhere from $8,100.00-$10,000.00 (Centro de Reproducción Humana, 2020). However, in 2014 it was reported that 60% of people in Guatemala do not make above the minimal wage and the average wage per year for someone who is Maya is around $2,000.00, making roughly about $8.00 a day (Terra Experience, 2014).

3.5.3 Statement 3 - There should be specific educational programmes in schools for children to learn about the ART techniques

There is a host of research aimed at the extent to which children should be taught about fertility issues. Some of the studies related to this topic are reviewed here. A more extensive review will be included in the final stage of the thesis.

The idea that fertility education should be included in schools has been debated in several lines of research. The focus, however, has mainly been in safe sex and unwanted pregnancy. However, it is only more recently that principles underlying fertility investigation and treatment options including IVF has also been added to the suggested curriculum to be taught in schools (Nargund, 2015).

In Guatemala, sexual education starts in primary school as part of the Natural Sciences curriculum. Sexual education is taught in grade six (equivalent to last year of primary school in the UK) and in secondary school; students are educated on sex organs, menstruation and male ejaculation. Although sexual education is part of the curriculum, it is usually taught one day of the school year for a maximum of an hour. According to Chirix, (2009) there is very minimal to no talk about the psychological or affective aspects of sex, and absolutely no discussion of love or pleasure or infertility (García, 2020). Many disadvantaged Maya children drop out in secondary school or soon after primary school to help maintain their family household. When children leave school early, it is quite possible that they miss out on the sexual education all together.

3.5.4 Statement 4 - Considerable funding should be directed to scientific research on the psychological, medical and social consequences of children born as a result of ART

There is a host of research aimed at the extent to which funding should be allocated to research on assisted reproductive technologies and its consequences. Some of the studies related to the latter topic are reviewed here. More extensive review will be in the final stage of the thesis.

As part of a vast European study on the subject of attitudes towards IVF and gamete donation, a survey in 2019 (n = 6,000) conducted online, with participants living in France, Germany, Italy, Spain, Sweden and the UK, found a positive attitude among respondents toward IVF, gamete donation, and support for public funding for fertility treatment (Fauser et al., 2019).

In relation to Guatemala, it has been noted that Guatemala's public spending was the worst in the world. Guatemala spends less than almost any other country in the region. Guatemala also spends less on healthcare and other health services than any other country listed (Entremundos, 2020). Thus, the question of what Guatemalans perceive to be the case with research and public funding is of prime importance.

3.5.5 Statement 5 - There should be strict procedures regarding egg donation procedures in which the donor should be of the same ethnic origin as the recipient

There is a host of research aimed at the extent to which ethnic origins of the donor may be a factor to be considered before any treatment attempts. Some of the studies related to this topic are reviewed here. More extensive review will be in the final stage of the thesis.

It is generally considered that couples want donors to be racially matched. This means matching on features such as skin colour, facial features and hair colour. However, Campbell (2007) noted that most Asian and Middle Eastern women living in or visiting UK requested that the donor egg should be from a white woman (Campbell, 2007). This could suggest that having lighter skin tone in Eastern societies is seen as more desirable.

In Guatemala, inter-ethnic marriages were frequently deemed as taboo for years. Community members often viewed these marriages as culturally disagreeable and would attribute such unions to greediness and bewitchment. Families in the middle of these trans-ethnic affairs would accuse one another of engaging in ‘brujerías’ (witchcraft). Today, many community members (both Maya and Ladinos) still view these marriages as racially offensive. Many times couples that end up marrying someone outside their race, do so once they have migrated and are no longer within the influence of their social groups (Rodman, 2003). Therefore, the question is, what is the Guatemalan perception on measures regarding egg donation procedures? Should the donor be of the same ethnic origin as the recipient? These questions carry great importance.

3.5.6 Statement 6- Because the embryo is fertilised in the lab the child born by this technique may exhibit the following complications more often than a child who is conceived naturally:

6.1-Having a lower IQ
6.2-Chance of being autistic
6.3-Developing yet unknown medical complications
6.4-The likelihood of being infertile

There is a host of research aimed at the extent to which conception by the use of ART may have medical implications for the conceived child. Some of the studies related to IQ, autism, medical complications and the likelihood of the conceived child being infertility are reviewed here. A more extensive review will be in the final stage of the thesis.

Lu, Wang and Jin (2013), in a review of long-term follow-up of children conceived through assisted reproductive technology, concluded that ART conceived children are more likely to have childhood illnesses suggesting a significantly higher risk of requiring medical care, being admitted to hospital and having surgery (see also Ludwig et al., 2009). Research has found that mothers who use donor eggs may actually pass some of their genetic material on to their children through their endometri fluid, this transmission could be a disease, or infertility issues to a resulting child (Lehmann-Haupt, 2016). Gao, He, Cai, Wang and Fan (2017), in a meta-analysis of 11 records (3 cohort studies and 8 case-control studies), revealed that the use of ART is associated with a higher percentage of autism spectrum disorder in the children born as a result of the treatments. Zhan et al. (2013) in an overview of studies on psychological well-being in ART conceived children reported lower IQ scores following IVF children than in the control group. This then could suggest the questioning of medical complications being brought on to the child who is born via ART.

3.5.7 Statement 7 - A child born as a result of egg donation should be told about the precise nature of their conception

There is a host of research pointing to the question if the nature of conception should be told to the conceived child? Some of the studies related to this topic are reviewed here. More extensive review will be in the final stage of the thesis. The right to privacy of the recipients and the donors might be in conflict with the right of the child to know his/her origin. Confidentiality, disclosure to the child and protection of privacy are key ethical issues accompanied by profound legal, religious, social and cultural questions (Larijani & Zahedi, 2007).

In addition to the study that was conducted in 2013 of the attitudes towards aspects of embryo donation in a randomised sample of 1,000 Swedish women and men (see Wånggren et al., 2013), a more recent systematic review of the literature pertaining to donor conceived people's views of their genetic origins was conducted (Blyth et al., 2020). Blyths' review concluded on practices that promote transparency and openness in assisted reproduction enabling donor-conceived people's future choices and opportunities. In the absence of any published research in Guatemala on this topic, it is crucial to examine what the Guatemalan public view is about egg donation and it post-delivery consequences.

3.5.8 Statement 8 - A child born as a result of egg donation will have more psychological problems than a naturally conceived child

There is a host of research targeted to examine what conception used from assisted reproductive technologies by donor, and non-donor may have psychological implications for the conceived child. Some of the studies related to psychological impacts of a child conceived by donor egg are reviewed here. A more extensive review will be in the final stage of the thesis.

Zhan et al. (2013), in an overview of studies on psychological wellbeing in ART conceived children, reported lower self-esteem in adolescents born following IVF than in the control group. It has been argued that the child may not be entirely accepted as part of the family, and that the absence of a genetic tie to one or both parents may have a damaging effect on the child's sense of identity (Burns, 1987). Wagenaar et al. (2009) reported that more IVF children scored in the borderline/clinical range on the syndrome scale withdrawn/depressed behaviour compared with their spontaneously conceived counterparts. A relevant question for

Guatemalans could be if they perceive children born by donor and non-donor IVF to have psychological struggles.

3.5.9 Statement 9 - Parents of a child born as a result of egg donation will not be very welcomed in society.

There is a host of research aimed at the extent to which conception by the use of assisted reproductive technologies may have social implications for the conceived child. Some of the studies related to social impacts of a child conceived by donor egg are reviewed here. More extensive review will be in the final stage of the thesis. Any study in which self-report methods and minority groups are used might be prone to the effect of social desirability bias, whereby parents attempt to present themselves and their children in the most positive light. Egg donation and DI families might be particularly at risk of this, owing to the stigma associated with the use of donated gametes to have a child and, consequently, the view that these families are 'not normal.' One method used to address this problem is the use of multiple measures (standardised interviews and questionnaires) and multiple respondents (mothers and children). In addition, the high response rates attained, particularly for the gamete donation families, who are often more reluctant to take part in research owing to concerns about confidentiality, suggest that the low incidence of adjustment problems among the egg donation children cannot be based on the assumption that those parents and children who were experiencing problems had withdrawn from the study. "This goes some way to confirm the view of, like DI parents, egg donation parents experience a degree of social stigma surrounding the way they conceived their child (Hall, 1997)." One could argue the stigma lingers regardless of the type of infertility treatment undertaken.

Although the statement is now over 20 years old, this statement is important, as it has been reported that the quality of parenting and the psychological adjustment of egg donation children and their parents may differ with Donor Insemination (DI) and IVF conception. For example, in egg donation families, mothers seemed to respond less sensitively to their child's needs, compared with mothers in DI and IVF families (Murray, MacCallum & Golombok, 2006). Although, on the school adjustment, no differences were found between children conceived by any of the three methods of conception. However, no research has been directed at how school adjustment is affected in Guatemalan egg donor families. This thus raises the question that if indeed, school adjustment is affected by egg donor families in Guatemala; teachers should know the origins of the problem and engage in appropriate intervention. Thus, this statement was selected as an option to put forward to the public and to the parents with egg donation conceived children for their comments.

In the 2001 Current Practices and Controversies in Assisted Reproduction, a meeting on 'Medical, Ethical and Social Aspects of Assisted Reproduction' held at the WHO headquarters in Geneva, Switzerland, some ethical and social issues of ART in Latin America were discussed. The issues, particularly those influenced by the culture, religion or region were presented. Among them were fear of long-term consequences or side-effects from these techniques in the woman or in the child. In many Latin American countries there is a vast amount of secrecy surrounding infertility treatments. Women in Chile reported that less than 10% of couples with children born via ART were willing to speak about their treatment and furthermore couples who became parents via donor gametes have not told their children of their origin of conception perhaps in fear of social rejection (Luna, 2001). This could suggest that parents of children born by egg donation could fear social rejection and therefore enforce secrecy around the topic.

3.5.10 Statement 10 - Donor egg conceived children may experience overt prejudice from the wider community, relatives and friends

There is a host of research aimed at the extent to which children conceived by egg donation may experience overt prejudice from wider community, relatives and friends. Some of the studies related to this topic are reviewed here. More extensive review will be in the final stage of the thesis. Fasouliotis and Schenker (1999) stated that negative attitudes might exist towards reproductive technologies, with procedures such as IVF and DI sometimes considered as immoral or unnatural. As a result, families with a child conceived by assisted reproduction may experience overt prejudice not only from the wider community but also from relatives and friends (see also McNair, 2004). Pir Jalian (2019) found that the Iranian public more than the British public would like teachers to know which child in the classroom is conceived by egg donation, this could suggest prejudice in relation to donor conceived child. Zhan et al. (2013), in an overview of studies on psychological well-being in ART conceived children, reported that a higher prevalence of behavioural problems existed in ART children than in the control group. Also, the researchers reported higher incidences of physical aggression and higher rates of being suspended or expelled from school in IVF adolescents than in the matched control group, which did not occur when they were teenagers. Therefore, the question of do Guatemalans perceive that donor egg conceived children may experience overt prejudice from the wider community, relatives and friends.

3.6 Ethical approval and data collection procedure

Approval for this study was sought by Universidad de San Carlos and Universidad de Galileo in Guatemala. Approval was also granted from Middlesex University Ethics Committee. Confidentiality was assured to all participants. Data was collected in person, by the researcher, at university premises and public locations. As the author is UK based, travel was essential. Travel time from the UK to Guatemala, including a layover was 17 hours there and 17 hours back. Travel from accommodation to the universities was about an hour and a half each way. Once at the universities, the author was given a tour by an authorised personnel of the university campus and given access to speak before any psychology lectures, in common areas, as well as areas surrounding the campus. The ethical considerations central to this study were related to privacy and voluntary participation. To comply with privacy requirements, the invitation to participate in the study was explained to the potential participants by the researcher. The researcher explained in detail the purpose of the study and stated that participation was entirely voluntary and that participants were free to withdraw from the study at any time. Furthermore, it stated that the information provided would be treated in the strictest confidence, that only pooled data would be published, and that no identifying information would ever be released. The questionnaire/statements sheet was administered to people on a one-to-one basis following their consent to take part in the study. Once the researcher given was given permission to approach students, staff and members of the public on university grounds to partake in the research, participants were recruited by being flagged down in the authorised areas and asked to take part in the study. Each participant was then told a bit about the study and was given a questionnaire and a pen to write down their answers. Participants generally took about 15-25 minutes to read and answer the questionnaire but would often like to speak about the research for some time after. The ethical considerations central to this study were related to privacy and voluntary participation.

The process of data collection took five months to complete from April to September of 2019. All completed questionnaires were kept in a safe location by the researcher. No participant wished to withdraw their data after taking part in the study (see Appendix B and C for ethical approval, information sheet, consent form, debriefing and letters of collaboration from two Guatemalan Universities).

3.7 Socio-demographic information

The following information was requested from the participants: age, gender, ethnicity (Maya and Ladino), whether they had higher education (graduate) or no higher education (public). Furthermore, if they know someone undergoing ART. See participants section for breakdown by age, gender, and ethnicity. Other breakdown information is listed in the Figures 3.1.1 to 3.1.4 below.

Figure 3.1.1 1

Breakdown of gender by ethnicity

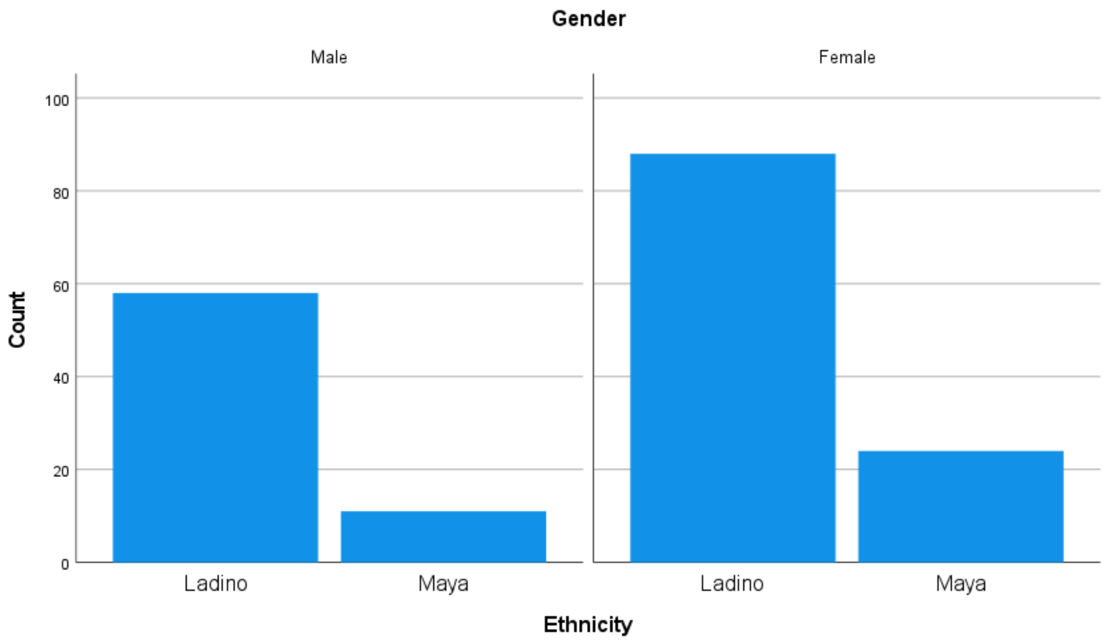

Gender
Male
Female
Count
100
80
60
40
20
0
Ladino
Maya
Ladino
Maya
Ethnicity

Figure 3.1.1 2

Breakdown according to religious orientation

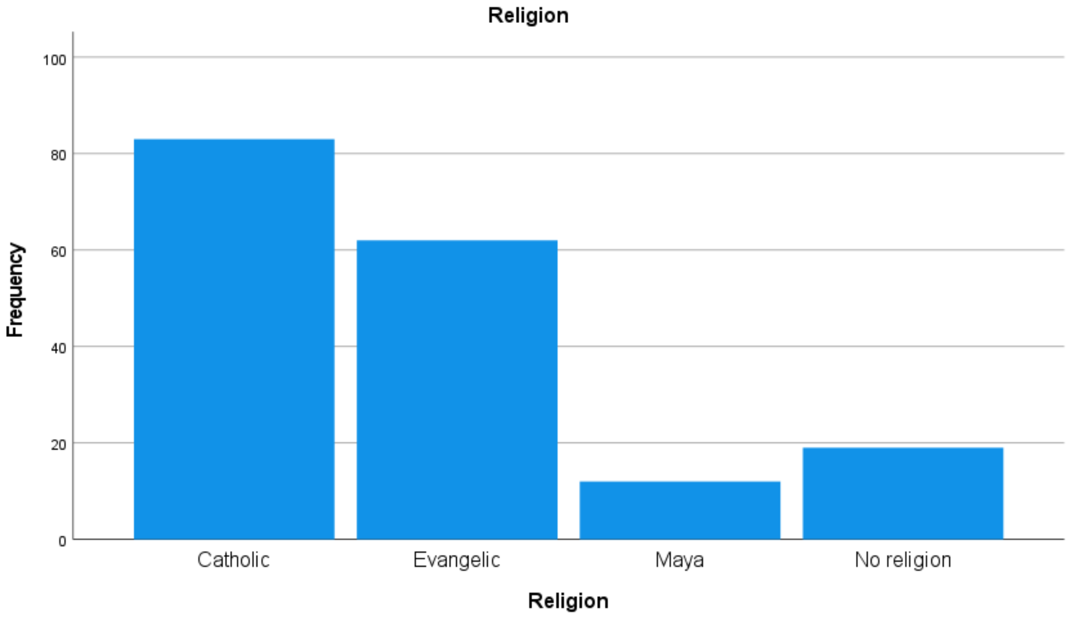


Figure 3.1.1 3

Breakdown according to whether the participant had higher education or not

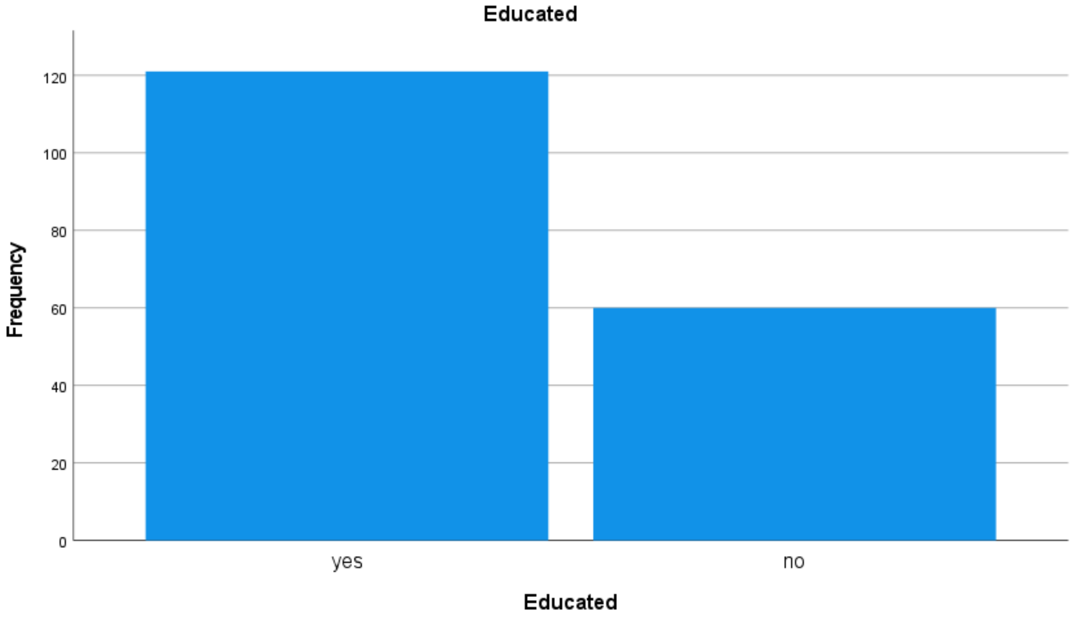


Figure 3.1.1 4

Breakdown of whether the participant knew someone who has had IVF

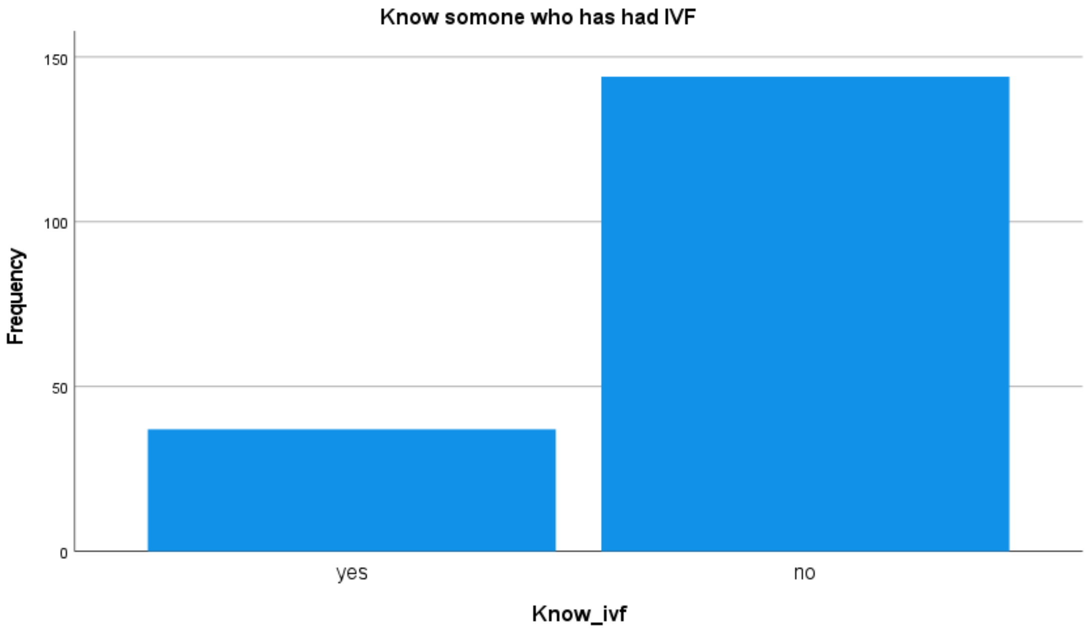


Figure 3.1.1 5

Breakdown by marital status

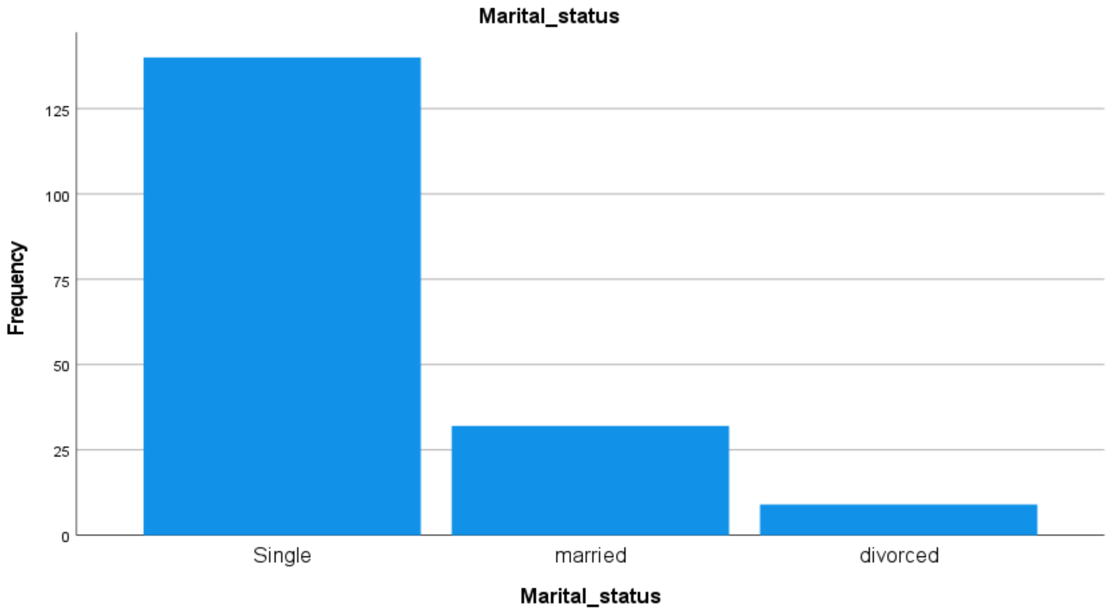
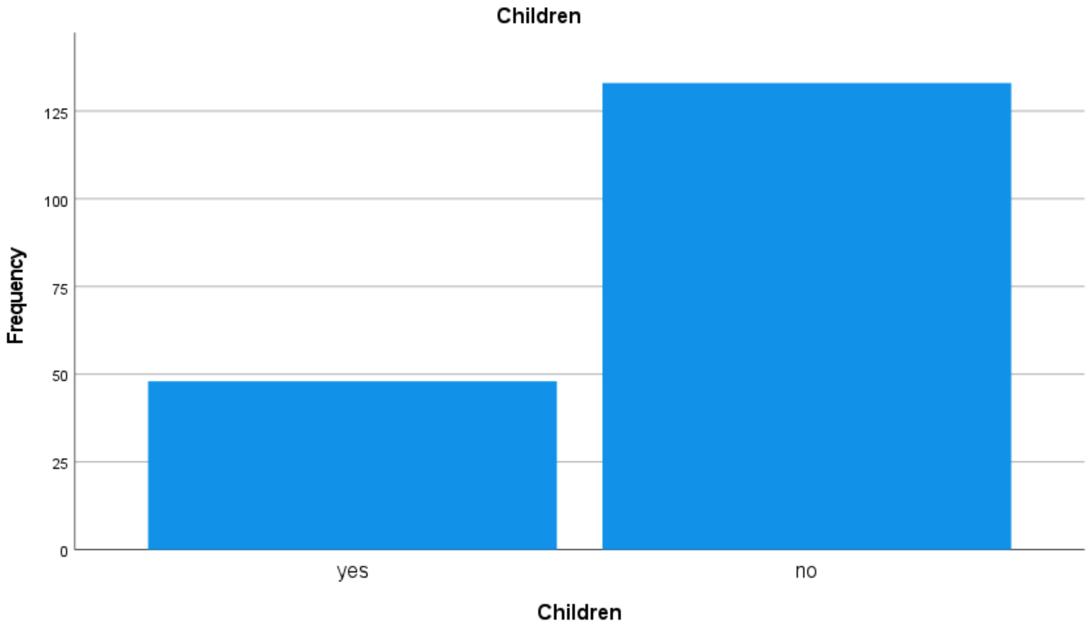


Figure 3.1.1 6

Breakdown by whether the participants had children or not



3.8 Results of Study 1 (quantitative)

Results were subjected to Principal Component Analysis, one way and Factorial Anova, t-tests, correlations, stepwise regression and appropriated post-hoc and simple effect analyses.

Age of participants in relation to Gender and Ethnicity

To ensure that a possible significant age difference of participants is not a factor affecting data analysis, two independent groups' t-tests were conducted for gender and ethnicity. For gender $t(179) = 0.65$, $p = 0.51$ and for ethnicity $t(179) = 1.02$, $p < 0.30$. In view of no significant differences in age of participants in relation to the two main variables in the present study namely, Gender and Ethnicity, age was not used as a covariate in further analysis.

3.8.1 Principal Component Analysis (PCA)

Principle Components Analysis was conducted on the data and a three-factor solution was identified with Eigenvalues greater than one (see Figure 3.1.1). KMO and Bartlett's test was $p < 0.0001$ (see table 2.1.1) thus indicating that a factor analysis may be useful with this data.

Table 3.1.1 1

KMO and Bartlett's test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		.694
Bartlett's Test of Sphericity	Approx. Chi-Square	595.095
	Df	78
	Sig.	.000

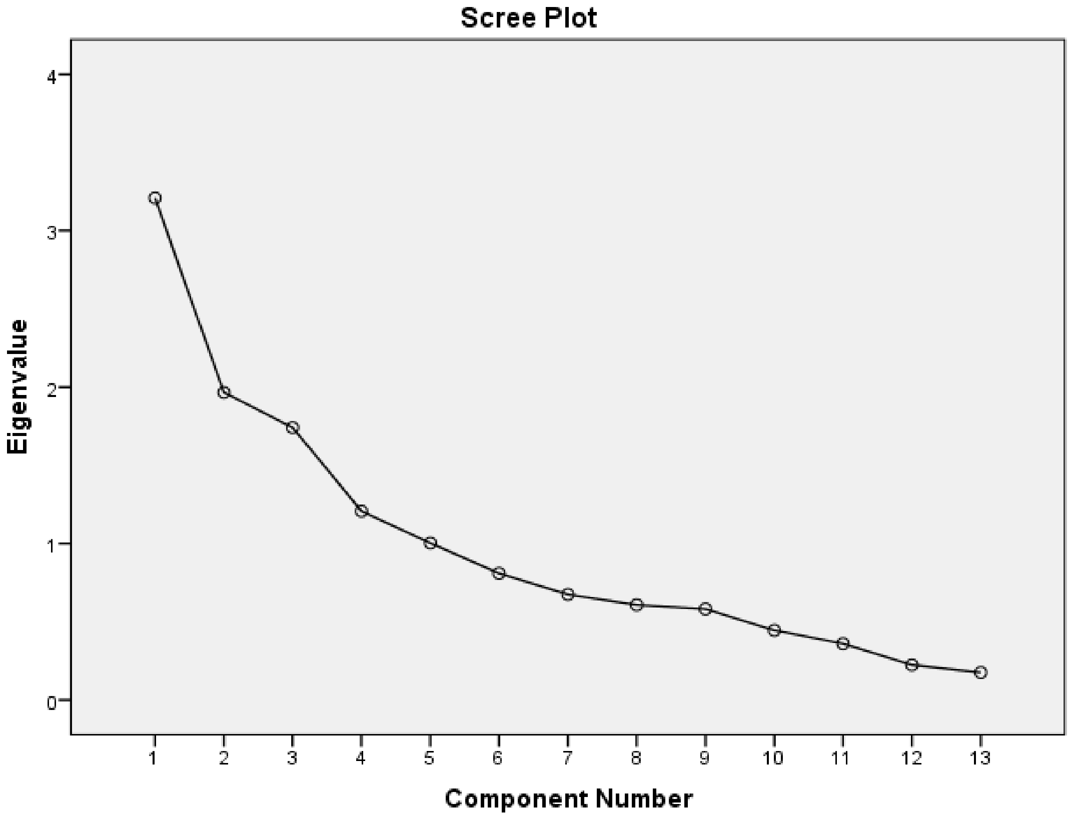
Factor 1 labelled as **Medical Consequences** (of ART) had 3.21 Eigenvalues accounting for 24.6% of cumulative variance, with Cronbach's alpha of 0.89 and consisting of 4 items.

Factor 2 labelled as **Social Acceptance** (of egg donor conceived children) had 1.96 Eigenvalues accounting for 15.1% of cumulative variance, with Cronbach's alpha of 0.79 and consisting of 3 items.

Factor 3 labelled as **Procedures** (of ART) had 1.74 Eigenvalues accounting for 13.39% of cumulative variance, with Cronbach's alpha of 0.5 and consisting of 3 items.

Figure 3.1.1 7

A scree plot displaying the eigenvalues indicating 3 strong factors.



In order to select key variables (namely; Age, Religion, Gender, Ethnicity, whether they know an egg donor, education status [formal education – no education], whether they know anyone undergoing ART, marital status, and finally whether they have children) to analyse in a regression analysis with the 3 factors to show any significant relationship with any of the variables under investigation, the relationship of each variable was analysed independently with each of the 3 factors.

3.8.1.1 Relationship of each variable with the 3 factors from the questionnaire

In order to decide which variables shows strong relationship with each of the 3 factors from the questionnaire namely, Medical Consequences, Social Acceptance and Procedure separate correlational and factorial analyses were conducted on the data. This procedure will reduce the number of insignificant key variables to be included in a further regression analysis.

Age

Age of participants was correlated with the 3 factors that showed a significant correlation with Medical Consequences with $r = 0.27$, $p < 0.0001$ indicating that the older the participants the more strongly they disagree that there will be medical consequences with ART. However, age did not show a significant relationship with Social Acceptance $r = 0.04$, $p = 0.6$ and Procedures $r = -0.02$, $p = 0.76$.

Religion

To examine a possible relationship of Religion, three separate one way Anovas were conducted on the data which showed a significant effect of Social Acceptance with Religion with $F(3, 160) = 8.86$, $p < 0.0001$. For Catholic mean = 3.25, SD = 0.64, for Evangelic mean = 2.94, SD = 0.74, for Mayan Spirituality mean = 2.17, SD = 1.01, for No Religion mean = 3.07, SD = 0.67. The highest rating was for the Catholic religion, Catholics were more strongly agreeing with the statement that children born via ART will not be sociably accepted. Medical Consequences and Procedure did not show any relationship with $F (3, 160) = 1.175$, $p = 0.32$ for Medical Consequences and $F(3, 171) = 1.193$, $p = 0.31$.

Gender

To examine a possible relationship of Gender, three separate independent groups t-test were conducted on the data which showed a significant effect for Social Acceptance with $t (167) = -2.13$, $p = 0.03$. For Gender, Male Mean = 2.9, SD = 0.87, for Female mean = 3.15, SD = 0.67. The highest rating for gender were females, who were more strongly agreeing with the statement that children born via ART will not be sociably accepted. There were no gender differences for Medical Consequences $t (167) = -.02$, $p = 0.98$ and for Procedures $t (178) = -1.42$, $p = 0.15$.

Ethnicity

To examine a possible relationship of Ethnicity, three separate independent groups t-tests were conducted on the data which showed a significant effect for Medical Consequences with $t (167) = 1.65$, $p = 0.05$, and for Social Acceptance with $t (167) = 3.53$, $p = 0.001$, but not for Procedures with $t (178) = -.19$, $p = 0.84$. For Social Acceptance Ladino mean = 3.15, SD = 0.71, for Maya mean = 2.65, SD = 0.83. For Medical, Ladino mean = 2.91, SD = 0.79, Maya mean = 2.66, SD = 0.62 The highest rating was for Social acceptance, the Ladino ethnic group were more strongly agreeing with the statement that children born via ART will not be sociably accepted.

Do they know an egg donor

To examine a possible relationship of whether the participants know someone who is an egg donor (18 Yes and 151 No), three separate independent groups t-tests was conducted which showed no significant effect with any of the 3 factors, t (167) = 1,54, p = 0.12, for Medical Consequences, t(167) = -.49, p = 0.62 for Social Acceptance and t(178) = -1.12, p = 0.26.

Education (formal education–no education)

To examine a possible relationship of Education, 3 separate t-tests were conducted which showed a significant effect for medical consequences with t (167) = -2.9, p = 0.003. For medical, formal education mean = 2.75, SD = 0.77, no education mean = 3.11, SD = 0.69. The highest rating was for was the no education. No education had more positive views than formal education on medical consequences of ART. There was no significant effect for Social Acceptance t (167) = -.30, p = 0.76 or for Procedure t (178) = 0.33, p = 0.73.

Do they have children

To examine a possible relationship of whether the participants have children or not an egg donor (45 Yes and 124 No), 3 separate t-tests were conducted which showed a significant effect for Medical Consequences with t (167) = 3.88, p < 0.0001. For medical, people who had children mean = 3.22, SD = 0.71, people who did not have children mean = 2.74, SD = 0.74. Those who had children had a more positive view than those who did not have children on medical consequences of ART. Social Acceptance t (167) = -0.69, p = 0.48, and Procedure t (178) = -.0.51, p = 0.63 was found not to be significant.

Know someone with ART

To examine a possible relationship of whether the participants know someone who has undergone ART (37 Yes and 132 No), three separate independent groups t-tests was conducted which showed a significant effect for Medical Consequences t(167) = 2.22, p = 0.02. For medical, those who knew someone who had undergone ART mean = 3.11, SD = 0.72, for those who did not know someone who had undergone ART mean = 2.79, SD = 0.77. Those who knew someone who had undergone ART treatment had a more positive view that those who did not know someone who had undergone ART treatment. There was no significant effect for Social Acceptance t (167) = 1.58, p = 0.11 or for Procedure t (178) = 0.4, p = 0.68.

Marital status

To examine possible effects due to Marital Status (130 single, 30 married and 9 divorced), 3 separate one way Anovas were conducted which showed a significance effect for Medical Consequences F (2, 166) = 4.85), p = 0.009, and for Social Acceptance with F(2, 166) = 3.05, p = 0.05. For Social Acceptance single mean = 3.09, SD = 0.69, married mean = 2.81, SD = 0.95, divorced mean = 3.44, SD = 0.77. For medical, single mean = 2.77, SD = 0.75, married mean = 3.15, SD = 0.64, divorced mean = 3.30, SD = 0.98. The highest rating is for people who noted divorced which means that divorced people were more strongly agreeing with the statement that there will be issues with social acceptance, and for medical consequences with ART. For Procedure the effect was not significant with F (2, 177) = 0.9, p = 0.38.

3.8.2 Stepwise Regression Analysis

It is clear in the above analyses that Procedure as a factor did not show any significant relationship with any of the variables under investigation, thus it was excluded from further analysis. Furthermore, the variable concerning whether they know anyone with egg donation showed no significance with any of the 3 factors. Thus, the latter was also not used in any further analysis. However, to establish the independent effect of the above variables and to establish the variable that most strongly related to each of the two factors, namely Medical Consequences and Social Acceptance, 2 separate Stepwise Regression analyses was conducted.

In the first analysis, Medical Consequences was the dependent variable and Age, Ethnicity, Education, having children, knowing someone undergone ART and Marital Status were the independent variables.

Stepwise Regression analysis showed a significant effect with F (1, 167) = 13.9, $p < 0.0001$. R = 0.27, R squared 0.07. Analysis of beta coefficients showed that Age is the most significant variable with Medical Consequences with Beta Coefficient 0.27, t = 3.74, $p < 0.0001$. No other variable reached significance. The significant relationship indicated that older participants more strongly disagree that there will be medical consequences due to ART conception.

In the second analysis, Social Acceptance was the dependent variable and Religion, Gender, Ethnicity, and Marital Status were the independent variables.

Stepwise Regression analysis showed a significant effect with F (1, 162) = 12.3, p < 0.001. R = 0.26, R squared 0.07 (model 1); and F (2, 161) = 10.2, P < 0.0001, R = 0.33, R Squared = 0.11 (model 2); and F (3, 160) = 8.65, p < 0.0001, R = 0.37, R squared = 0.14. Analysis of beta coefficients showed that Ethnicity is the strongest predictor of Social Acceptance with Beta coefficient -0.26, t = -3.64, p < 0.0001, followed by Religion with Beta Coefficient -0.18, t = -2.43, p< 0.01 and followed by Gender with Beta Coefficient 0.16, t = 2.24, p < 0.02.

To provide a further clarification of the above significant results the following analysis was conducted reported below:

Table 3.1.1 2

Mean and SD for responses by Male and Females in response to questions on Social Consequences

Participants	**Mean**	**(SD)**
Male (65)	2.9	0.86
Female (104)	3.15	0.66

As can be seen in the above table men are more strongly disagreeing that children born by ART will not be socially acceptable. Independent groups t-test for Gender shows (110.9) = -2.01, p < 0.04

Table 3.1.1 3

Mean and SD for responses by Maya and Ladino in response to questions on Social Acceptance

Participants	**Means**	**SD**
Ladino (136)	3.15	0.7
Maya (33)	2.65	0.83

As can be seen in the above table, Ladinos more strongly disagree that children born by ART will not be socially acceptable. Independent groups t-test for Ethnicity shows t (167) = -3.53, $p < 0.001$.

Table 3.1.1 4

Mean ratings and SD according to religion in relation to Social Acceptance

Religion	**Mean**	**SD**	**N**
Catholic	3.25	0.63	77
Evangelic	2.94	0.74	56
Maya	2.16	1.007	12
No Religion	3.07	0.67	19

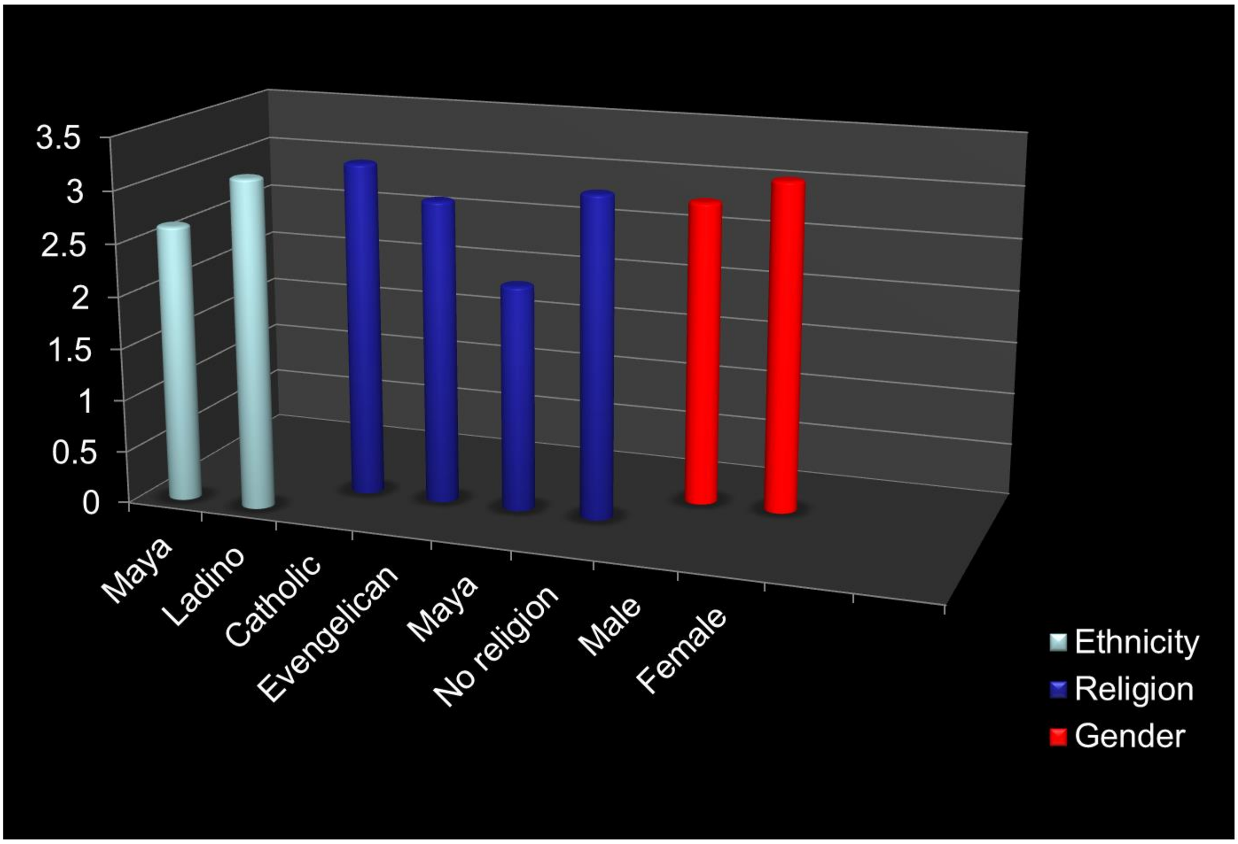
As can be seen in the above table, the Maya scored lowest i.e., more strongly agreeing that ART children will not be socially accepted, whilst the Catholics scored more strongly in the direction of strongly disagree i.e., that children born by ART will be socially accepted.

One way ANOVA, with Religion, as IV and social acceptance as DV showed, F (8.86), MSe = 0.503, $p < 0.0001$. Post-hoc comparisons of the means using LSD showed significant differences between Catholics and Maya $p < 0.0001$, and Catholics and Evangelic with p <

0.013. Furthermore, there were significant differences between Evangelic and Maya with $p < 0.001$ and Maya and no religion with $p < 0.001$.

Figure 3.1.1 8

Mean ratings as per Gender, Ethnicity, and Religion in relation to Social Acceptance



3.8.3 Perceived level of knowledge

To examine whether perceived level of knowledge is affected by participants being introduced to questionnaire items before rating, half of the participants rated their perceived level of knowledge before reading the questionnaire items the other half after reading the items. The participants rated their level of knowledge on ART on a scale ranging 1= very little or none to 10 very much. The results showed that generally there is no significant difference between method of administration on perceived level of knowledge ratings (before-after) with $t(178) = -2.4$, $p < 0.8$.

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Table 3.1.1 5

Mean and SD for responses by rating of knowledge before and after reading the questionnaire items relating to ART

Condition	Mean	SD
Before (84)	3.61	2.36
After (96)	3.7	2.53

Perceived level of knowledge and ethnicity and gender

To examine if perceived level of knowledge is different for Ethnicity and Gender a 2 Gender by 2 Ethnicity (Maya – Ladino) factorial Anova was conducted on the perceived level of knowledge which showed only a significant main effect for Ethnicity with $F(1, 177) = 3.87$, MSe = 5.97, $p < 0.05$, $\eta p^2 = .021$. Other main effects and interactions were found not to be significant.

Table 3.1.1 6

Mean and (SD) for responses by rating of knowledge as per gender and ethnicity

Ethnicity	**Male**	**Female**
Maya	4.72 (3.79)	4.16 (2.94)
Ladino	3.25 (2.17)	3.7 (2.25)

As can be seen in the above table both Maya men and women rated themselves higher on the perceived level of knowledge than Ladinos.

Perceived level of knowledge and formal or no formal education

To examine if perceived level of knowledge is different for those with formal education compared to those with no formal education an independent groups t-test was conducted on the ratings on perceived level of education which showed no significant difference with t (179) = -0.5, $p < 0.56$

Table 3.1.1 7

Mean and SD for responses by rating of knowledge as per level of education

Level of Education	**Mean**	**SD**
Formal education (121)	3.61	2.41
No formal education (60)	3.83	2.52

3.9 Summary key findings - Quantitative

In the absence of any scientifically reported studies on Guatemalans' perceptions and level of perceived knowledge of ART, the present study aimed to identify and select items representing key factors and controversies in relation to ART. Each item was carefully selected based on scientific findings in relation to ART e.g. 'The society will not accept children born by ART'.

The results of this innovative investigation showed a very interesting pattern of results. The short questionnaire used in the study paved way to a 3-factor solution that was labelled as Medical Consequences, Social Acceptance and Procedure. The following key findings, based on extensive statistical analyses, lead to the following key findings:

- The older the participants, the more strongly they disagree that there will be medical consequences associated with ART.
- Social acceptance seems to be a factor dividing different religions. The followers of the Maya religion seem to be more in agreement than other religions that children born by ART will not be socially accepted. The most tolerant seems to be the Catholics.
- Female participants overall seemed to more strongly agree that children born by ART will be socially accepted than male participants.
- Ethnicity was a factor that initially showed to be significant for both medical consequences and social acceptance, however stepwise regression showed that this is a factor that has a strong effect in social acceptance. The Maya participants more strongly agree that children born as a result of ART will not be socially accepted than Ladino.

- Whether someone knew an egg donor or not seemed to play an insignificant role in any of the factors in the present study.
- Having formal education or no education seem to be a significant factor in relation to Medical Consequences, with no education having a more positive views than formal educated on medical consequences of ART. However, stepwise regression showed that this was an artefact of age and not a significant factor once the variance due to age was accounted for.
- Having children seem to have a significant effect on medical consequences with those having children having more positive perceptions of ART than those that did not, however once stepwise regression was conducted, this factor was found not to be significant.
- Knowing someone with ART showed a significant effect with medical consequences with those knowing someone had more positive perceptions than those that did not. However, stepwise regression showed that this was not a significant factor.
- Marital status was found to be a significant factor for both medial consequences and special acceptance; however, stepwise regression showed that this was not a significant factor.
- On the perceived level of knowledge, the ratings were not different between those that read the questionnaire items first and then did the rating compared to those that did before reading the items. Furthermore, gender or level of education was not a factor in perceived level of knowledge. The only significant difference was the higher perceived level of knowledge given by the Maya compared to Ladino.

To untangle more deeply the explanation for the above findings, the next section centres on the qualitative analysis of the written responses.

3.10 Qualitative Results Study 2

Results of written comments by participants to the 13 statements were subjected to thematic analysis.

3.10.1 Thematic Analysis of the Written Comments to the 13 Statements

Methodology

According to Braun & Clarke (2006) qualitative approaches are exceptionally multifaceted, complex, and diverse. Furthermore, they state that thematic analysis (TA) should be a foundational method to qualitative analysis. One of the benefits of thematic analysis is its flexibility, it has theoretical freedom, providing a flexible research tool. Thematic analysis seeks to describe patterns across qualitative data allowing to examine experiences (Braun & Clarke, 2006). TA was deemed acceptable and the best way to analyse the qualitative data provided by the 13 written statements from study 1.

The TA took interpretivist epistemology and critical realist ontology positions, which state there is a shared reality, but one needs to interpret that reality in order to understand it. This allowed to examine the participant events, realities, meanings, and how experiences effected their perceptions towards ART within society. Themes and patterns were approached in an inductive, ‘bottom up’ way, meaning themes were strongly grounded in the data.

The process that was followed once engaged in analysis was Braun & Clarke’s (2006) ‘Phases of thematic analysis’ that consists of 6 phases. Phase 1 was familiarising one’s self to the data, where data was transcribed, read and re-read, making annotations to initial ideas. It is important to note that data was first translated from Spanish to English, and then transcribed. Phase 2 was generating initial codes, this entailed coding the data in a systematic fashion, organising data relevant to each of the codes. Phase 3 was searching for themes, this collated codes into possible themes, gathering data relevant to each possible theme. Phase 4 was reviewing themes, this phase checked themes worked in relation to the codes and the entire data set. In this phase, a thematic ‘map’ was generated. Phase 5 followed with defining and naming themes, where ongoing analysis was refined to clear definitions and names for each theme. This phase highlights the overall story the analysis tells. Finally phase 6, where extracts were selected from the data to represent vivid and compelling experiences from participants that related back to the statements (Please see Appendix D for raw transcript and coding process). In this final phase, a report of the analysis findings is produced.

Participants

The written responses from the 13 statements was a total of 1,150 comments, 219 belonged to the Maya and 931 to Ladinos.

3.10.2 Thematic Analysis findings for Maya and Ladinos

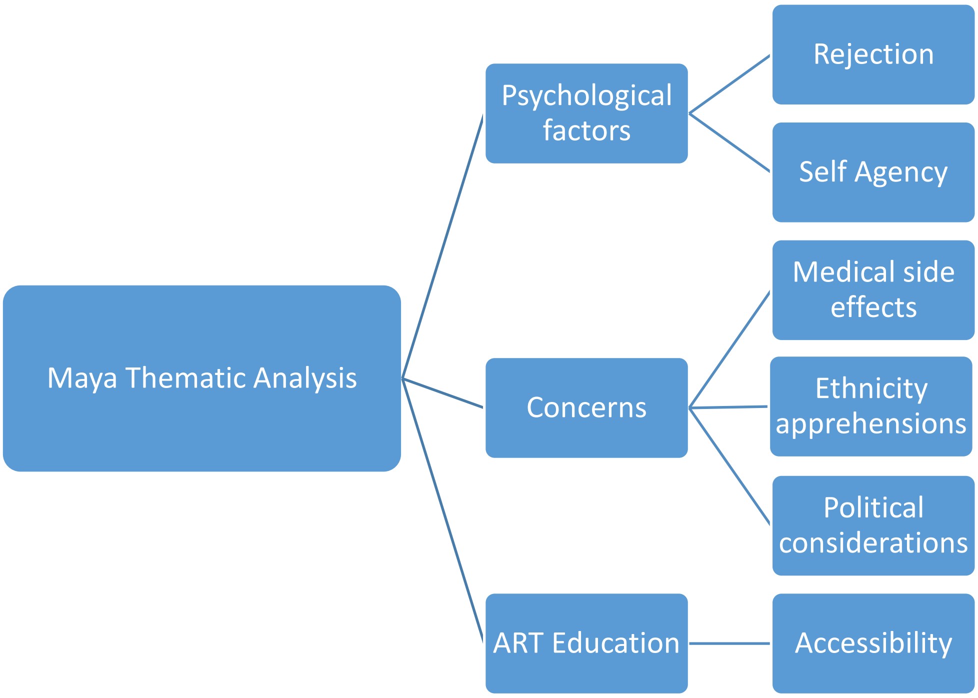
The analysis resulted in several main themes with sub-themes. Each theme and its corresponding subthemes will be discussed in turn of Maya and then Ladino, supported by quotes and enriched by description and interpretation regarding the research question of: What are the perceptions of the Maya on infertility treatments and ART in Guatemala?

Findings

Identified common themes relating to Maya participants surfaced throughout the analysis. The aim of study 1 is to examine Guatemalan public, Maya and Ladino's perception of key issues related to infertility and infertility treatment. Thematic analysis was used to address the written responses and produced three main themes with corresponding subthemes. Figure 3.1.1 highlights these.

Figure 3.1.1 9

Maya Thematic Analysis Map



Psychological factors (main theme)

Psychological factors were continuously highlighted by Maya participants. Particular factors namely rejection and self-agency. These were emphasised by participants which were said to influence their perception and behaviour towards ART. Rejection and self-agency are the two subthemes for psychological factors.

Rejection (subtheme)

The analysis reflected that Maya participants felt participating in infertility treatments could cause religious rejection. *"There are religions that would see this as sin or an intrusion with God's plan. I think they should think about it, our religion wouldn't really like this."* This statement suggests that a 'disruption' to God's plan would not be welcomed. This could make the impact for an individual/family that do something deemed as less desirable by their head of community vast and consequential. The quote also proposed that the Maya spirituality (religion) would not fully accept a couple that has undergone infertility treatments.

Additionally, participants also stated that when it came to community inclusion, religious families that participated with ART may experience overt prejudice from the wider community, relatives and friends *"especially religious people, they have it worse"*. This quote illustrates the how in the Maya community, if one is religious there are certain expectations and rules that one must follow.

The factor of rejection was further elaborated when discussed in the social context. Participants expressed that social rejection is something to consider when thinking about participating in ART. *"Because perhaps society would see it as something bad if the child knows of how it was conceived, the society might care."* This statement elucidates the feeling of rejection in society, highlighting the negative implications that society might have once it is made aware of a child born via ART.

Participants also amplified feelings of rejection as they expanded on the belief that society would indeed be judgemental *"Always, society will always judge"*. These words paint a picture of how the Maya community relate their society and ART. *"People do not like these topics, so I believe there could still be rejection, people do not like different."* It seems that judgment carries negative connotations and can weigh heavily on the perception participants have towards feeling rejected.

Self-Agency (subtheme)

The analysis also showed the psychological factor of self-agency. Participants expressed that it was important that the choice to undergo infertility treatment is well informed and the action is self-generated. "*They must be clear why they will do it and do it with communication. Religion should not decide for them, but the priest might not allow you to do it and still come back [to the religion], so you have to be really sure it's what you want."* This statement underlines the importance and certainty this decision should be made with as it could have potential ramifications.

Self-agency was expressed by participants in the sense that they have the control to make the ultimate choice, and it is up to them (the couple) to decide if they would like to undergo infertility treatment. "*It is the opinion of whoever wishes to make a family or have children, it's up to them if they want this, we control what we want in the end"* The participant states the significance of having the 'the final' say in what they do. Having the ultimate control seems to be very important in making this decisions. The choice to start a family is highlighted as a choice that comes from their sense of self *"One can say when they want children, with who and how, it's something* *that comes within”*. This quote highlights how having self-agency when undergoing infertility treatments is important as it is suggested that this decision should be made with a good sense of control and awareness over one’s actions.

Concerns (main theme)

Concern topics were continuously emphasised by Maya participants. These specific concerns made by participants are in reference to their perception and behaviour towards ART. The theme is composed of three sub-themes namely medical side effects, political/government factors, and ethnicity apprehensions which will be discussed.

Medical side effects (subtheme)

A concern participants had in common was the possibility of medical side effects. Participants felt like undergoing Western infertility treatments and utilising ART could lead to unwanted medical side effects for the couple and child. This concern gives emphasis to the mistrust The Maya hold to Western medical practices *“Western doctors have had more issues than traditional birth attendants, we know what works naturally”.* The Maya community have their own medical practices that draw on naturalistic healing and tradition “*there should be more information about the side effects of these procedures...to make sure there is no disease linked to this treatment”* this statement underlines the uncertainty surrounding ART as the concern lies in the possibility of failure from Western medicine.

Concerns with medical side effects were also brought up when participants made a point of expressing their concerns for the who child born ‘artificially’ discussing the quality of the genes. *“The child could be born with a problem, having a child born by natural creation is different than one done by technology, the genes could be damaged. It's defying nature.”* Participants highlight the genes being damaged could be a medical consequence from going against nature, which is one of the main influences in The Maya medicine. One could argue the Maya participants felt using this type of treatment could alter gene quality.

Ethnicity apprehensions (subtheme)

The analysis highlighted concerns in ART when it came to matters of ethnicity. Concerns were mentioned when expressing how the ethnicity of the child must remain the same to allow the child to remain true to its ethnic origins *“Depends who will want this but it’s important to have pure blood. Ideally it would be to the same origin so they are not false to themselves.”* The statement illustrates concern in the purity of the blood which references ethnicity. The participant appears to feel it is important to undergo this type of treatment with people of the same ethnicity as it would allow them to stay truthful to their Maya identity.

Participants also demonstrated concerns with ethnicity in the context that remaining the same ethnicity improved chances of the treatment to be successful. Participants felt remaining the same ethnicity is important for both the child and parents. *“For good results perhaps [to be of the same ethnicity], to be able to avoid any mutations or harm to the mother.”* The statement shows concern in how the participant could think mutations might occur if the donors or parents are of different ethnicities, as well as possibly indicating possible harm and failure of treatment could come from a pairing outside of the Maya ethnicity.

Political/Government Factors (subtheme)

The analysis illuminated concerns with political factors pertaining to ART. Concerns arose as participants expressed how they believed the government have other priorities, and the funding of infertility treatments was not one of them. Participants felt that Guatemala has bigger problems *“In Guatemala, the conditions to bring more children in is a problem. The resources should be used in the children that are already in Guatemala because we have poor kids, we have bigger problems like malnutrition.”* This statement shines a light on issues that may be seen as more pressing by The Maya, a community that has the lower economic status in Guatemala. *“…in Guatemala this would not be so important as we have so many other important things like the mental and physical health of children that surfer for various reasons.*” This quote demonstrates how the participants feel about what should be the hierarchy of governmental priorities by stating what they felt was more important.

Participants also mentioned how undergoing infertility treatment is a financial choice made by the couple, and the country of Guatemala is not financially responsible for the cost of ART or infertility treatments. *“The government should not have to pay because the people want babies, the couple should be the one paying if they want children. Not everyone gets these types of treatments so I do not see why the government* *has to pay."* This statement made by participants illustrates the concern of the financial responsibility within the couple as they are the ones who want to take on the journey of starting a family and not the government.

ART education (main theme)

ART education issues constantly arose with Maya participants. Specific factors were emphasised by participants which may be believed to guide their perception and behaviour towards ART. The theme of ART education is composed of one sub-theme namely accessibility.

Accessibility (subtheme)

The analysis also revealed, numerous times, the lack of ART education accessibility. Many participants felt like there was not enough information available in their communities and felt that accessing information about infertility practices was very difficult. Participants felt the access to this type of information is important in their communities *"It is important for one to know about these topics because some people may still not understand them. There are couples that cannot conceive naturally and it is important that they know they can conceive in other ways."* This quote shines a light on the importance access to the knowledge could make to a couple suffering infertility in the Maya community.

Additionally, participants also stated how in the Maya communities the lack of access to ART education is potentially harmful. Participants stressed how lack of access to this type of education makes keeping updated with current infertility practices problematic *"Yes, especially for the youth. They need to know about the ART technologies, they need to be up to date with the rest of the world on these types of technologies, living in a country where you're not free to talk about sexuality and to just teach these techniques is difficult"*. Participants conveyed how the lack of ART education made them feel as if they are not up to speed with the rest of the world, insinuating feelings of unawareness to the topic due to inaccessibility.

Conclusion

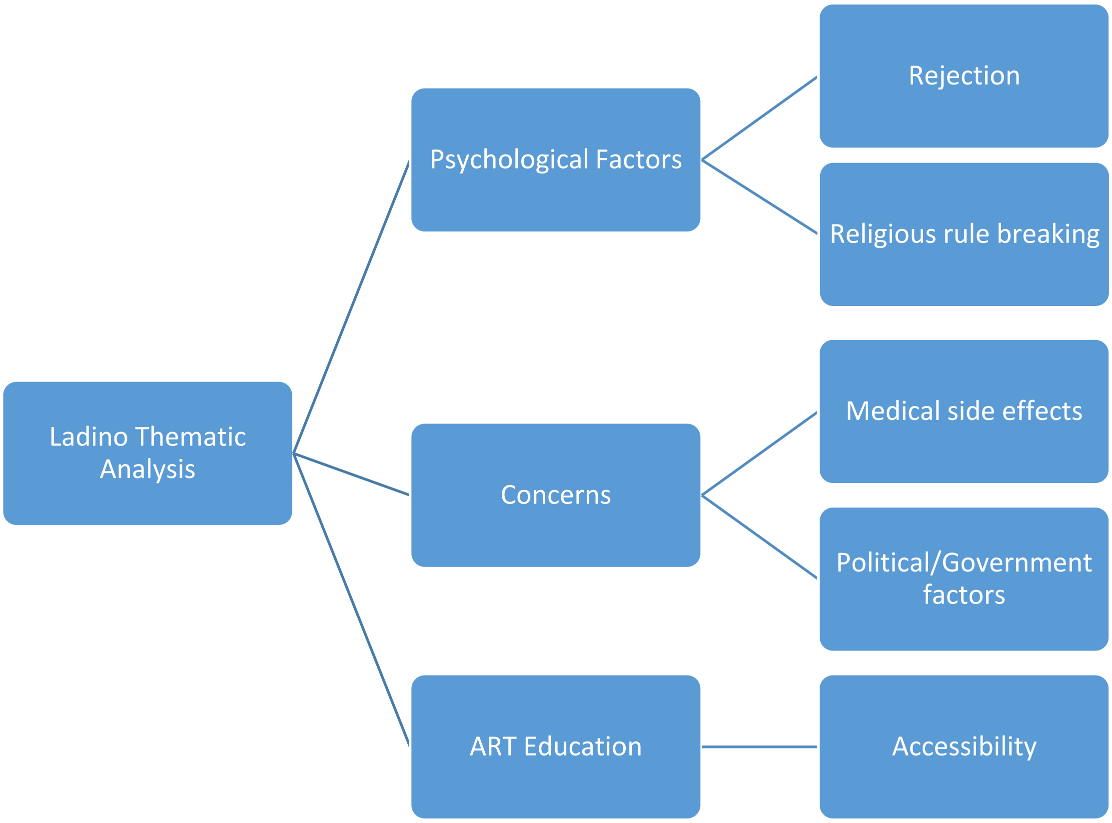
Thus, what *are* the perceptions of the Maya on infertility treatments and ART in Guatemala? Thematic analysis highlighted that Maya participants felt psychological factors, concerns, and ART were aspects of consideration when pertaining to ART.

Thematic Analysis findings for Ladinos

Thematic analysis was also conducted in the exact same way as the Maya to address the written responses by Ladinos. This prompted the research question of what are the perceptions of the Ladinos' on infertility treatments and ART in Guatemala? This produced three main themes with corresponding subthemes (see Figure 3.1.1 10). It is important to note that the same three 'main themes' were highlighted in the Ladino TA and The Maya TA. This did not come to a surprise as both ethnic groups interweave within Guatemalan society, however the difference is illuminated in the subthemes, and will be discussed more in depth in the discussion of this chapter.

Figure 3.1.1 10

Ladino Thematic Analysis Map



Psychological factors (main theme)

Psychological factors were frequently pointed out by Ladino participants in their responses. Particular factors were highlighted by participants which were said to shape their perception and behaviour towards ART. The theme is composed of two sub-themes, rejection and religious rule breaking.

Rejection (subtheme)

Ladinos reflected on psychological factors with an emphasis on rejection. They conveyed that undergoing infertility treatment could cause societal rejection. Ladinos feared the lack of acceptance from their community due to undergoing infertility treatment and expressed their reluctance towards ART due to it being something outside of the ordinary *"People wouldn't accept these types of situations, they discriminate against adopted children and children with disabilities, why not this?"*. This statement proposes that a child conceived by ART will not be accepted, and in fact could be discriminated against. The quote also suggested an attitude of rejection to accepting children born outside of what is deemed normal in Guatemalan society.

Not only did participants express the fear of rejection due to undergoing ART, they also commented on the rejection that could come from the possibility of looking different than what a typical child might look like "*As long as there is no genetic manipulation or the child born with mutations there should be no rejection. There is always people that discriminate for being different."* This quotes conveys the important role that 'looking normal' plays in the acceptance of the Ladino community, it potentially reveals a necessary requirement to be 'typically' conceived to fit in with Ladino society.

Religious rule breaking (subtheme)

Ladinos also pointed out the psychological factor of religious rule breaking. Ladinos stated that when it comes to matters of undergoing infertility treatment it should be deliberated with their religious leaders to confirm the decision is following the rules *“It is necessary to know what the religion permits because the church will say if you can participate in a treatment or not.”* This statement proposes the authority the church has over the couple embarking on their fertility journey and how accepting this authority carries importance.

Following religious rules whilst considering undertaking ART was also perceived by Ladinos as an indication of commitment to their faith *“I think it’s important to listen to the advice of the leaders and members of the church on this matter to keep true to my faith, because according to the Catholic doctrine it would be viewed as toying with what God intended and that isn’t good, it is important to have authorisation.”* This quote suggests that if the rules are broken, or the advice given by religious leaders is not taken into consideration, one could be deceptive to ones’ faith. This statement puts forward the effect disobeying the church could have to Ladinos religious integrity.

Concerns (main theme)

Themes that dealt with concern were constantly highlighted during analysis. Concerns regarding medical side effects and political/government factors are in reference to perception and behaviour towards ART; these two matters compose the sub-themes under Concern and are discussed as follows: The statement highlights how such uncertainties do not revolve around ‘normal baby development’ however the concerns surface for a child who is conceived by ART.

Medical side effects (subtheme)

Ladinos also mentioned the medical side effect of mutations, expressing concern with the quality of the treatment *“The mother could have complications during the pregnancy, something can go wrong during the treatment, like the possibility of unwanted mutations to the child”*. This quote draws on the perception Ladinos have towards infertility treatments, placing concern and speculation around the child and the potential risks of side effects. The concern and speculation for the treatment’s outcome is so great that even mutations are taken into consideration.

Political/Government Factors (subtheme)

Another concern raised regularly by Ladinos spotted in analysis were those of political nature. Ladinos voiced their concerns on government funding for such treatments. Ladinos expressed how Guatemala’s government has priorities that are far more pressing *“Unfortunately a country like Guatemala simply does not have the resources, the government cannot afford to cover the cost. The hospital cannot even take care for our health crisis, let alone this”*. This statement amplifies the urgency that Ladinos feel pertaining to other governmental factors like a health crisis. Ladinos seem to feel that the government resources Guatemala has access to should be allocated to more pressing matters. This means the Guatemalan health system, from the perspective of Ladinos, cannot afford to accommodate any resources for ART.

The data analysed also maintained that starting a family was a responsibility taken by the couple and not the government and therefore the government are not financially responsible for infertility treatment *"The couple should have all the means to bring children into the world that they can afford, the government cannot cope with so many people that might need this treatment, not their responsibility regardless."* Ladinos felt like the responsibility lays solely on the couple to fund their own choice of conceiving a child. The quote amplifies the feelings of responsibility by highlighting that even *if* the government had resources to fund ART, it is still the couple's responsibility.

ART education (main theme)

ART education issues surfaced with Ladino participants. Detailed factors were highlighted by participants that suggests to guide some of their perceptions and attitudes towards ART. The Theme ART education is composed of one sub-theme.

Accessibility (subtheme)

TA illuminated the numerous times the absence of ART education in Ladino communities. Many participants felt like there is no way of accessing ART information and felt that there are no programmes in place to give their community the chance to learn more about the subject *"Our education is not advanced like the rest of the world.*

We don't have access to that type of knowledge unless we look for it ourselves. Our public schools don't have information like that". This statement spotlights how important it is to have access to ART knowledge to the Ladino community. The statement expressed feelings of being left behind in comparison to the rest of the world due to lack of access.

Analysis not only highlighted the importance of access to ART knowledge, but how the lack of knowledge can also be harmful for people in need of treatment *"It's important to have access to knowledge about infertility treatments. Some people won't even know what types of treatments exist because no one's ever told them. How can they get help? We don't have access to that here, Guatemala only teaches the basics in sexual education".* This quote expresses how the absence of ART education in Guatemala could truly impact the reproductive health of individuals. This suggests that the lack of knowledge and access to ART could be impacting the perceptions of Ladinos on infertility treatments and ART in Guatemala.

Conclusion

Thus, what are the perceptions of the Ladino on infertility treatments and ART in Guatemala? Thematic analysis produced three main themes from Ladino participants' written responses; psychological factors, concerns and ART education. As noted previously, although these are the same main themes the Maya TA produced, they do differ in their subthemes. This will be discussed in the following section.

3.11 Thematic analysis findings discussion

This study identified a number of themes arising in the context of perceptions and behaviours in Guatemala on assisted reproductive technologies. The statements analysed were from participants of the two main ethnic groups in Guatemala namely the Maya and Ladinos. The themes explored in depth were psychological factors, concerns, and ART education. These themes converged and diverged in their subthemes throughout analysis, as participants highlighted their specific thoughts on the topics, illuminating the differences in the undercurrents of the subthemes. The themes and subthemes give insight as to what shapes perceptions and attitudes towards ART in Guatemala.

Firstly, the Maya and Ladino converged in expressing psychological factors and thus arose as a main theme for both ethnic groups. The subthemes of rejection were linked to psychological factors in both analyses. The Maya diverged in the subtheme of rejection as it was rooted in fear of rejection of their religious groups. Ladinos' rejection subtheme was embedded in the context of social rejection from their peers. The Maya diverge in the subtheme of self-agency under the main theme of psychological factors. This subtheme illuminated that an aspect of psychological factors that was important in Maya participants was the action of self-generated choices. Ladinos also diverged in the subthemes for psychological factors, namely religious rule breaking. Ladinos expressed that when dealing with psychological factors pertaining to ART, the consequences of going against their faiths' rules is something to consider.

Secondly, the Maya and Ladino converged in expressing factors of concern in their perceptions of ART and infertility treatments. Thus, this arose as the second main theme for both ethnic groups. The Maya and Ladinos converged with the subtheme of medical side effects, as it was a concern of both ethnic groups. The Maya participants diverged as the concerns with medical side effects were rooted in trust of Western medicine and Ladino participants diverged when their concerns of medical side effects diverged in the quality of the treatment. The Maya participants also diverge from Ladinos as the subtheme of ethnicity apprehensions and political considerations stemmed from the main theme of concerns. Ethnicity concerns sprung from feelings of preserving self-identity though conserving ethnic origins. One could argue this concern could come from the 36-year civil war that targeted the Indigenous people of Guatemala (please see Chapter 2). The Maya participants also expressed concerns in political/government factors. This subtheme was rooted in the feeling that the Guatemalan government have other more important health and political issues which have a higher place in importance than ART. Ladino participants also converged in their subthemes political/government factors when it came to the main theme of concerns. Ladino participants felt like their political/government concerns came from feeling like ART and infertility treatments is not the governments' responsibility, nor does the government have the resources to support it.

And lastly, the Maya and Ladino participants converged once again with the main theme of ART education. Both ethnicities converged in expressing the accessibility of education resulting in the subtheme of accessibility. The Maya participants diverged from Ladinos as accessibility factors were rooted in the difficulty to access any ART and infertility education. Ladino participants also diverged in the subtheme of accessibility as they expressed that their accessibility factors were ingrained in the absence of ART education.

In conclusion, this study had a number of themes arising in the context of perceptions and behaviours in Guatemala on assisted reproductive technologies. Although both Maya and Ladino participants had the same main themes come up in analysis, the two ethnicities converged and diverged in their meaning of their subthemes. One could argue that although both ethnicities are in living side by side in Guatemala, their perceptions on ART and infertility treatments are engrained differently in their individual societies.

3.12 Discussion of Study 1

The discussion of the results will take the following steps:

a) A summary review for the quantitative and qualitative analysis of the results

b) The findings of study 1 as paving the way to study 2 and 3

3.13 A Summary Review of the Quantitative and Qualitative Mixed Methods Results

The quantitative and qualitative analyses allowed for an exploration of the Guatemalan public's attitudes and perceptions regarding ART. Results mirrored one another and both had similar themes like psychological, medical, social, and ART education themes that appeared when examining the Maya and Ladinos. For example, in the qualitative analysis the theme of social acceptance (labelled as social on the graph), seemed to be a factor dividing different religions. The followers of the Maya religion seem to be more in agreement than other religions, that children born by ART will not be socially accepted. Ethnicity was a factor that initially showed to be significant for both medical consequences and social acceptance, however stepwise regression showed that this is a factor that has a strong effect in social acceptance. The Maya participants were more strongly in agreement that children born as a result of ART will not be socially accepted than Ladinos. These results were reflected in the qualitative analysis as the Maya expressed that partaking in ART will cause society to reject the family. The quantitative analysis also found that in the theme 'medical consequences' the older the participants, the more strongly they disagreed that there would be medical consequences associated with ART; stepwise regression analysis showed that this was due to level of education and not age. In the qualitative analysis The Maya expressed concerns with side effects caused by donor genetics due to Western medicine, which is deemed as 'un-natural, and not traditional medicine, which is deemed as ‘natural’. Ladinos also expressed that side effects could be caused because ART are ‘unnatural’, side effects are a risk with any medical procedure, and that side effects could cause deformities or mutations.

One interesting aspect of the findings was in perceived level of knowledge. The Maya rated themselves to have higher level of knowledge than Ladino. This was surprising as most research, in particular one that was conducted very recently amongst different ethnic groups in USA, found that Hispanic and Black Americans scored lower on questions relating to reproductive technologies compared to Caucasian counterparts (Maher et al., 2022). The difference however between the study by Maher et al. (2022) and the present study is that Maher et al. studied actual level of knowledge rather than perceived level of knowledge. An interesting question to pursue in future studies could be to what extent is there a relationship between actual and perceived knowledge.

3.14 Limitations

In an ideal world of scientific research, one would be able to access all intended participants, include as many variables as possible, have access to an already developed and validated set of questionnaires for using in any language of interest. However, the reality of conducting investigations in a sensitive area of human reproduction, on a subject that has not been studied before in Guatemala, with no documented tested materials and questionnaires this research has its own unavoidable limitations. It was clear that there is no published questionnaire that could be used for assessing Guatemalans’ perceptions of any aspect of ART. The social and logistical barriers were also factors hindering access to as many participants as one would wish to due to lack of resources. There could have been more participants of different socio-economic status, have used materials from previously reported studies on

Guatemala, like Maya that live in rural areas, but in Guatemala City where the study took place, they were limited.

3.15 Reflexivity

I was able to address reflexivity throughout the research process. Throughout my research I kept a reflexive journal where I was able to express my research experience. I also had discussions about my thoughts, feelings and frustrations with my supervisors which allowed me to have a conversation about different aspects of my research that came to my attention such as bias and values.

As I am Guatemalan born, Spanish speaking native Ladina, I found myself in a position of acknowledging my bias and advantages. Throughout the data collection for study 1, I noticed that the Guatemalan public trusted me more when I explained my background as I was able to do so in Spanish. I was aware that by doing so it will work in my advantage for data collection. I benefited from this advantage as I was able to access universities by connections, as I still have family and friends in Guatemala. This then brought thoughts of bias towards the Ladino ethnic group in my research. After speaking to my supervisors about the bias, I decided I would address this by making a point to make myself readily available for any questions, concerns and reflective chats to my participants, especially The Maya participants. This worked out well as I was able to have a few of these chats throughout my stay in Guatemala. I was even able to attend a comadrona focus group at the University of Galileo, where I was invited by a Maya woman who led the group to speak about my research as they were having a chat about traditional birthing rituals. I feel this was able to address some of the bias but I can acknowledge one cannot be completely unbiased.

Throughout the data collection and analysis of study 1, I also wanted to make sure I stuck to my values such as remaining honest, as objective as possible, open, and fair. I was able refer back to those values in times of questions by exchanging phone calls and emails with my supervisors throughout the time of data collection and analysis where they provided guidelines and reassurance. In these conversations I was able to address the values I had in question, and was able to remain as close to those values as possible.

3.16 Summary of Chapter 3 and paving the way to Study 2 and 3

The present chapter reported a study on the perceptions of the Maya and Ladino showing although they may be living in the same country, in relation to ART, they are very much apart. A notable difference was the belief of the impact an ART child born in Guatemalan society would be accepted and what consequences this would have for the child, for the parents and for the community. This, however, was based on general public and not reflecting the actual perceptions and behaviour of patients intending or undergoing ART treatment. There are two possible ways one could examine the latter subject. i) to engage actual patients intending or undergoing ART treatment or ii) to examine the perception and behaviour of the intending or undergoing patients from the point of view of medical experts with extensive experience in dealing with ART treatments. Both approaches have their own unique significance for understanding patients' responses to ART. However, due to the worldwide Covid-19 pandemic by the end of 2019 (highlighted in the next section 3.17) examining the perception and behaviour of the intending or undergoing patients, from the point of view of medical experts, was considered the more practical option.

3.17 Covid-19 and the impact on research

On the 31st of December 2019 the World Health Organization (WHO) was informed of the first case of a pneumonia of unknown cause in China (Wuhan City). A few months later in mid-March 2020, the WHO Director-General and the WHO European Region announced the outbreak of the Covid-19 pandemic beyond the borders of China (World Health Organization, 2022). This meant lockdowns of global proportions that affected many aspects of life, including all levels of academic research. A survey conducted in March 2021 reported that 58% of academics stated Covid-19 made it impossible to do the research as they planned (National Institutes of Health, 2020). For example, virtual instead of in-person interactions, cancellations, and limitations impacted what could be done during the peak of the pandemic, was now something to consider. The impact on research also affected doctoral research. Several blogs by PhD students indicated how their planned research had to be changed in view of Covid-19 (e.g., Dhungana, 2020; Taman, 2020).

The National Health Service provided guidelines and changes to manage research studies in healthcare and human participants during the pandemic (National Health Service, 2022). This included changes to pre Covid-19 protocols of research to ensure safeguarding participants in research and investigations involving lab-based studies. However, whilst most of the academic community was gripped by uncertainty of the outcomes of their planned research and consideration of changes, there seemed to have been a massive increase in publications since 2020 with Covid-19 as a key factor in the study (396,000 papers listed in google scholar since 2020). For example, "the Covid-19 emergency meant that far more biomedical research than ever before was published as preprints, without peer review" (Smocovitis, 2011, p.1152). An article in Nature (December 2020) highlights how a torrent of

Covid-19 science changed research publishing “A flood of coronavirus research swept websites and journals this year. It changed how and what scientists’ study” (Else, 2020, p. 553). This suggested that the original plan for the thesis research had to be revised.

3.17.1 Covid-19 and current research

The aim of the present thesis was to study the perceptions and behaviour of Maya and Ladinos regarding ART. The literature review and study 1 was conducted before the outbreak of the pandemic. Participants were approached in different locations in Guatemala and data collection was conducted on a face-to-face basis with each participant. The outbreak of Covid-19 meant that no face-to-face study could be planned and protocols for approaching patients was under revision and hard to get any form of approval during the peak of the pandemic. However, that was not the main reason for concern, as recent reports at the time indicated major impact of Covid-19 in Guatemala, especially in healthcare (United Nations Development Programme [UNDP], 2020).

In view of the above, this necessitated several considerations and innovations in follow up research plans on the intended topic of this thesis: a) to conduct online in-depth Zoom semi-structured interviews with practitioners in two countries, namely Guatemala and the UK to assess their experiences of patients’ perceptions and behaviour of ART before Covid-19 and as a result of Covid-19; And b) to engage in a widespread literature review (post outbreak) to examine the latest scientific studies on the impact of Covid-19 on the key factors that were considered significant in study 1 in particular, trust in medicine and religion in the format of a scope review on 3 key factors namely, Covid-19, ART and Patients. This would provide up-to-date and more comprehensive materials to conclude in relation to the aims of the present thesis and the ongoing impact of Covid-19.

The next chapter is the first qualitative case study of a semi-structured interview with a Guatemalan fertility practitioner, during the peak of the pandemic, taking into account the Covid-19 effect on patients’ perceptions and behaviour towards ART.

CHAPTER 4 Study 2 An Interpretative Phenomenological Analysis of a Guatemalan Fertility experts' Perception and Behaviour of their Maya and Ladino Patients towards Assisted Reproductive Technology

Preface

COVID-19 has changed the way research is now being conducted. Ideally the next step of the research would be to conduct a study examining infertility patients' perceptions and attitudes. Due to limitations on travel and accessibility to Guatemala, that was no longer attainable. However, valuable information is attainable by accessing the perceptions of Guatemalan fertility key coordinators.

The views of healthcare practitioners are important to evaluate, and they matter. It enables researchers to study what is being practiced and if it reflects on patients' perceptions and attitudes towards the procedure being carried out. Better use of the healthcare system and improved health outcomes have been reported in situations where patients felt satisfied and understood. Knowledge obtained from a systematic inquiry by Janet and Bronya (2019) found that perception in relation to expectation, patient demographics, personality, and market competition were regarded as preconditions of patient satisfaction (Janet & Bronya, 2019). Thus, it is important to study the views that Guatemalan fertility key coordinators may have on their patients to compare and see if they coincide and reflect those of the Guatemalan public. This would be a valid line of research and with a worldwide pandemic such as COVID-19, and restrictions and preventative measures put in place because of this, one could argue the expectations are changes to fertility treatments in Guatemala.

4.1 Predicted changes to fertility treatments in Guatemala due to COVID-19

The COVID-19 pandemic has placed limitations to life as we know it, and the world has now begun to adopt what we know as ‘the new normal’. The WHO has provided guidance as to how to adjust to this ‘new’ life; these adjustments highlight the technicalities of how to keep society functioning whist avoiding the virus. However, they do not address the consequences the virus may have on the perceptions of medical treatments, specifically in assisted reproductive technologies in developing countries (World Health Organization, 2020).

As previously mentioned, Guatemala is on the list of the top 48 nations offering ART; unusually, no scientific research had been conducted on the behaviour and consequences of the ART experience (Inhorn & Pasquale, 2015) until this doctoral research which started in 2019. This was the first systematic research on the behaviour and consequences of ART in Guatemala (study presented and discussed in previous chapter) and established that The Maya and Ladinos differ in their approach to ART; differences between groups included topics like religion, attitudes towards government help and views on the ethnicity of the child conceived.

Presently, in a Covid-19 pandemic, countries, cities, and communities around the world are facing an uncertain and unpredictable future that includes changes to all aspects of life as we know it. In Guatemala, many Indigenous and non-Indigenous people have already begun to adapt to the new normal. The ‘new normal’ can bring economic hardship and delays in providing services which may affect fertility chances. Adjusting to a post Covid-19 lifestyle could bring major challenges to Guatemalan couples seeking assisted reproduction. Delays and disruptions in fertility treatment can have substantial impact on the outcomes of fertility treatment, there is also the recognised fact that women who are more socially withdrawn and are in a heightened emotional state, have more difficulties for a normal birth and successful post birth (Johnston & Brown, 2013). The NHS states that pregnant women have been included in the list of people at moderate risk from Covid-19 (clinically vulnerable) as a preventive measure (National Health Service, 2020). In April 2020, a systematic review of pregnancy and Covid-19 observed 18 studies of infected pregnant women around the world. Out of the infants: 1.2% were stillborn (as a comparison point, about 0.6% of babies in America are stillborn, according to the CDC), 1.2% died in utero, 21.3% were born preterm (compared to the average of 10% of babies born in America generally, according to CDC), 5.3% had low birth weight, 10.7% experienced fetal distress, 1.2% experienced neonatal asphyxia (Yang et al., 2020). These figures suggest that out of the 18 studies observed, infants may have a chance of being born prematurely if their mother has contracted Covid-19 whilst pregnant.

Ethnicity and culture can also be factors to consider; ongoing research suggests that race could be a factor in which pregnant women are most exposed to the virus. Data collected from Philadelphia in the USA, points to Black and Latin (Guatemalan women would be considered as Latin descent) pregnant women having 5x the risk of coronavirus exposure than white pregnant women (Flannery et al., 2020); researchers speculate this could be because black and Latin women have more exposure to the virus compared to white Americans. Another important point to make is cultural issues with the preventative design for Covid-19. Indigenous peoples have been historically persuaded to dilute their culture and traditions to accommodate Western views and beliefs. The procedures for prevention and control of Covid-19 were designed for a Western capitalist society, disregarding the individualities of Indigenous people, for example: sleeping in communities at times, leisureliness, social fraternisation or even rituals (sometimes medical) that require gathering (Gonçalves Júniora, et al., 2020). The lack of access to protective gear and preventative plans that could work in these communities are examples of issues that could impact the accessibility and willingness to have fertility treatments in Indigenous societies.

The fear of catching Covid-19 in a medical setting has begun to become a consequence to the current global pandemic. Research has begun to show that people are becoming reluctant to receive medical treatment due to the pandemic. Physicians in the US, Spain, and the UK have all noticed a serious drop in the number of patients seeking out medical care. One reason for this decline could be that many people are afraid of catching the Covid-19 virus in the hospital (Masroor, 2020). Ladinos tend to have more Westernised views and would have some similarities with the views of the Western world therefore this could significantly impact the fertility seeking behaviours in Guatemala and begin to affect couples looking to conceive.

In the Maya communities, views are more rooted in customs and traditional beliefs, and many Maya prefer their own traditional medicine (See chapter 2). As stated previously, the

Maya have expressed their distrust for Western medicine (see study 1) and have stated they feel mistreated and discriminated against in public health care. According to a study published in 2016 (Cerón, et al., 2016), participants who belonged to Indigenous communities expressed that their ethnicity was the reason behind the abusive treatment they received. They disclosed that physicians and nurses would yell out disrespectful comments along with commands or orders. Many of the participants described feelings of powerlessness after being yelled at by a health care provider. Due to the nature of Western ART, they are carried out in Westernised hospital settings. If it was difficult for the Maya to trust the public health before, it will be much more difficult now with the feelings of uncertainty revolving around the worldwide pandemic. Unfortunately, this could also affect the willingness to seek out non-traditional fertility treatments in Indigenous communities. In view of this information, it can be predicted that Guatemalan women (Maya or Ladino) could postpone fertility treatments due to Covid-19 because of feelings of fear, uncertainty and mistrust.

4.1.1 Key considerations over the choice of a single case study design and Interpretative Phenomenological Analysis (IPA)

The current study

The main key reason this study employed a single case study design is the limited number of Guatemalan ART medical professionals. Thus, this determined the boundaries for the sample size. Extraction of the experiences of one experienced medical professional working with both Maya and Ladino infertile patients in relation to ART was preferable to involving more medical professionals with less expertise in this defined area. Therefore, a single case study, using Interpretative Phenomenological Analysis (IPA) to analyse the data, was carried out.

A case study is ideal when an observation does not fall under the propositioned aim and therefore the aim is considered not valid (Flyvbjerg, 2006). In this instance, the proposition is the perception and behaviour of Maya and Ladino's towards ART. However, a case study is needed when the observation is made that the general Guatemalan population will not have the same perceptions and behaviours towards ART as a Guatemalan ART patient. This proposition 'generalises' Maya and Ladino's perceptions and behaviours towards ART and would therefore be invalid. Adopting a case study design would be ideal to explore how the experience of Maya or Ladino ART patients can differ in attitude and perception to that of the general Guatemalan population through a Guatemalan medical expert's lived experience.

The method of analysis that study 2 will undertake will be IPA as it is a dominant qualitative research method in many academic disciplines, especially in social and health psychology. It focuses on what makes up an experience, it emphasises on its mission to unravel in detail, and it analyses those lived experiences for participants (Tuffour, 2017). "IPA was first articulated in the UK in the 1990s and initially was picked up as an approach to the psychology of experience in health and clinical/counselling psychology. Since then, it has considerably widened its reach. It is now one of the best-established qualitative approaches in UK psychology but is also used increasingly by psychology researchers throughout the world" (Eatough & Smith, 2017, p. 196). Meaning IPA is a valuable method of analysis for qualitative data.

Not only does IPA incorporate the person's experience, but it also takes into consideration a participant's beliefs, attitudes, and general reflections on the topic being. The total number of people for whom this is a relevant experience is small and therefore this immediately determines the boundaries for a possible sample discussed. IPA has five stages of analysis: reading the cases over all meaning, identifying themes of meaning, structuring the themes extracted, producing a summary table, and integrating cases. Once the steps have been followed a write up should be conducted with a results/findings section with themes and direct quotes from participants supporting those themes.

IPA is particularly useful when analysing semi structured interviews in social and health psychology, it allows for researchers to unravel interpretive meanings in a participant's experience (Langdridge & Hagger-Johnson, 2009). IPA is ideal in health psychology when analysing structured interviews as it enables the researcher to make sense of the participant trying to make sense of what is happening to them. It has been noted that IPA is particularly suitable in health psychology research as it highlights the processes of operating within models as opposed to the traditional focus on outcome measures (Brocki & Wearden, 2006).

Health psychologists have recognised the significance of understanding patients' perceptions and interpretation of their experiences, and the implications, values, and meanings which they assign to them (e.g., Leventhal et al., 1984). IPA has also been valuable when used in social psychology. IPA in social psychology allows the researcher to participate devotedly with important viewpoints and pursue to develop methods such that meet the continuingly evolving needs of people, communities and societies through intensive analysation of a participant's experience (Langdridge, 2008). IPA in both social and health psychology is very useful when conducting research on the consequences of an event; namely the current research of perceptions, attitudes and consequences of fertility seeking behaviours in Guatemala. Like most research methodologies, a question may be raised as to what the most relevant sample size for a particular study is, IPA is of course of no exception. Questions could be raised as whether one case study would be sufficient for an IPA analysis? Smith et al., (2009) argue that in IPA research there is no right answer to the question of what the appropriate sample size is. In fact Smith et al., (2009) argue that IPA is specifically suited for a single case study due to its emphasis on ideographic commitment to explaining the detailed experience of each case. Indeed, IPA studies have been published with sample size ranging from one to fifteen participants (Pietkiewicz & Smith, 2012).

For example, a single case study conducted at Nottingham Trent University in 2005 by Bramley and Eatough, on the experience of living with Parkinson's disease. The study explored one individual's experience of living with Parkinson's disease. Semi-structured interviews with a female participant were employed and later analysed with Interpretative Phenomenological Analysis (IPA). The semi-structured interviews followed a temporal pattern allowing for the experience of Parkinson's disease to unfold naturally (Bramley & Eatough, 2005).

Theoretical aspects of IPA for the current single case study

IPA has 3 pillars which make up its underpinnings (Smith et al., 2009). The first is phenomenology, which places an importance on the lived experience of the person taking into consideration their place in the world in relation to the world and others, rather than focusing on the person in isolation. The second pillar is hermeneutics, which is the theory of interpretation. This focuses on studying how a phenomenon appears, as well as making sense of the appearance by understanding its past and the new phenomenon being addressed. Finally the third pillar is ideography which pinpoints emphasis on the 'particular'. This means it focuses on the detail of the phenomenon by understanding the perspective of a particular group of people or person, in a particular context. Thus, as IPA utilises small carefully selected samples, it is ideal for a single case study.

The underlying stance for the IPA is a critical realist ontology approach with an interpretivist epistemology. The critical realist stance focuses on the nature of things, and the ontological realism addresses that reality exists and operates independently of our awareness or knowledge of it (Scott, 2014). Interpretivism refers to the approaches which emphasise the meaningful nature of people's character and participation in both social and cultural life (Elster, 2007; Walsham, 1995), and epistemology refers to the theory of finding out what is truly happening, distinguishing between belief and opinion. Accordingly, the theoretical aspects of IPA method undertaken, deemed appropriate for the single case study design.

In the current thesis, IPA has been chosen as the method to analyse studies 2 (the current study) and 3 (the next study, discussed in the next chapter) which are single case studies with semi-structured interviews of key medical professionals in ART.

4.2 Background

As reported in Study 1, Maya and Ladino populations differ in their perception and behaviour towards Assisted Reproductive Technology (ART) particularly with regards to religion, secrecy of ART, social acceptance of children born by ART, side effects due to medical complications and rights of conception. The present case study employing a single case study, investigates these experiences in how the Guatemalan population differences from the perspective of a Guatemalan medical fertility expert and the extent to which there has been an impact due to the worldwide Covid -19 pandemic.

4.3 Aim

The current case study is aimed to examine the extent to which findings in study 1 is also reflected in the views of health care practitioner in Guatemala (study 2). This proposes the research question of: How are factors of the perceptions and behaviours of Maya and Ladinos towards ART, illuminated by the meaning of a Guatemalan key ART medical experts' patients experience? And from their perspective, how has Covid-19 had an impact on these patients' experiences?

The findings have implications for understanding ART in Guatemalan society and for practitioners and other agencies involved in the infertility treatment.

4.4 Participant

Guatemala's constitution states that every citizen has the right to universal healthcare, but in reality, very few have access to comprehensive healthcare as Guatemala's ability to provide healthcare is greatly hampered by weak tax systems (Stewart, 2015). The author was able to access a key medical coordinator in ART, with experience in the public universal health care system as well as the private health care system.

The pseudonym of 'Dr. A' was given to the participant in this case study. Specific demographic information was omitted as this could disclose the identity of the doctor due to their unique expertise with both Maya and Ladinos. The demographic information omitted is namely, age, sex and ethnic identity. Dr. A is a key medical coordinator in Guatemala, with 20 years of experience in gynaecology and obstetrics practice, having worked in rural areas in the Guatemalan countryside, highlands (predominantly Maya). In the 8 years they worked in rural Guatemala, Dr. A was able to volunteer their time with a main hospital to treat mostly Maya infertile patients with ART and infertility treatments. This programme was informally funded by them and other doctors (and at no cost to low–income patients) but proved too costly and had to come to an end. Dr. A currently practices in Guatemala City (predominantly Ladinos with private health care). Dr. A has experience 8 years in the public health sector and 12 years in the private health sector. Dr. A was recruited by connections established by the author when collecting data for study 1 in Guatemala.

4.5 Method

A semi-structured interview was used (please see Appendix D) where Interpretative Phenomenological Analysis (IPA) was deemed the most appropriate method for qualitative analysis for the current case study.

As mentioned in the preface, IPA is ideal when analysing semi-structured interviews as it enables the researcher to make sense of the participant trying to make sense of what is happening to them, which was part of the aim in this study. IPA is a dominant qualitative method of analysis, focusing on the meaning of lived experience, beliefs, attitudes, and general reflections in many specific disciplines, especially in social and health psychology (Tuffour, 2017).

Furthermore, a proposition to understand what some of the similarities and differences might be in experiences, ART patients from the UK were also taken to consideration and will be the subject of study 4 (to be discussed in the next chapter).

4.6 Materials

A semi-structured interview schedule was deemed appropriate to conduct this study as it allowed Dr. A to truly share their points of views and experience related to each question. The semi-structured interview schedule was based upon the findings of study 1. This case study included question topics like how the influence of Maya and Ladino's religion on participation in ART treatments; as well as the role of religion before, during and after treatment, and how any religious influences were resolved. A separate section on how the Covid-19 pandemic influenced decisions towards undergoing ART treatments and how this influenced their decisions was included (see below for interview schedule).

Religion:

Part 1- Participants in my research considered religion to play a role in deciding to engage in ART treatment. To what extent did religion play a factor before, during or after any treatment? How were these issues finally resolved?

Part 2 - Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Government:

Part 1- Participants in my research considered that the government should not fund any fertility treatments as there are other priorities. To what extent were concerns linked to the funding of the treatment and whether or not the government should offer financial support towards the cost of the treatment? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Assisted Reproductive Technology (ART) and Secrecy:

Part 1 Participants in my research expressed that in general society should not know the origins and method of conception. However, it was stated that the parents should be honest regarding the method of conception. To what extent were concerns about secrecy and information regarding how a child was conceived a factor before, during or after conception? How were these issues finally resolved?

Part 2 - Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Social acceptance:

Part 1 - Participants in my research considered that society may not accept a child born via egg donation. To what extent is social acceptance a factor to consider before, during or after conception? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Side effects (medical complications):

Part 1- Participants in my research considered that there may be many unknown side effects and medical complications linked to new Assisted Reproductive Technology, which could cause medical complications for the conceived child. To what extent were medical complications a factor to consider before, during or after conception? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Self-agency:

Part 1- Participants in my research commented that the couples should be in mutual agreement to undergo treatment and they should be responsible for incurring any costs of fertility treatments. Furthermore, these participants also stated that couples should bear the financial responsibility regarding their treatment. To what extent were couples in agreement with their decisions, and were they willing to pay the bill for costs incurred before, during and after treatment?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Knowledge of Assisted Reproductive Technology:

Part 1- Participants in my research generally commented that they are not very knowledgeable about Assisted Reproductive Technologies and that there are not enough programmes available on this subject. To what extent did you see your participants having knowledge about ART before, during, or after treatment? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Ethnicity:

Part 1 - Participants in my research considered that to have fertility treatments, the couple must be of the same ethnic group. To what extent were concerns about ethnicity a factor to consider before any treatment options? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Rights:

Part 1 - Participants in my research commented that they must have access to rights pertaining to their body and the right to access knowledge about the method of their conception. To what extent were concerns about rights a factor to consider before, during and after treatment? How were these issues finally resolved? Do you think this will change due to the COVID-19 pandemic? If so, how?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Your (The coordinator's) observations:

1. Based on your experience of working with infertile patients, were there any specific points observed that are not covered in this series of questions? If so, what were they and how were they resolved? Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

2. What major changes do you anticipate in patients' needs and the future of fertility coordination/approach during the current COVID -19 pandemic in Guatemala?

3. To what extent has the COVID-19 pandemic affected both Maya and Ladino in whether they may choose traditional fertility treatments?

4.7 Procedure

Ethical approval was granted by Middlesex University. This process ensured that the research conducted was carried out in conformity with the law, and in agreement with the best current practices and principles and follows both the British Psychological Society and the University’s Code of Practice for Research: Principles and Procedures. Due to global travel restrictions imposed by the Covid-19 pandemic, it was not possible to collect data in person and an electronic approach was taken. The participant was emailed consent, information sheet, and debriefing information, and asked to sign it and send the information back (see appendix D). The interview took a little over 2 hours and was recorded via Zoom video so that it could facilitate verbatim transcription for subsequent analysis.

4.8 Data collection

This study consists of 1 semi-structured interview with Dr. A. The interview investigated the specific findings of study 1 as mentioned previously. The one–to–one interview was conducted via a recorded Zoom meeting where the participant was assured anonymisation by the use of a pseudonym, as well as ensuring that any possible identifying information was irreversibly altered. The recording stored securely in accordance with Middlesex University Ethics Committee guidelines. Opportunities were provided during the interview for the participant to allow Dr. A to expand beyond what was the topic of conversation and provide even more insight in to the topic mentioned in the interview. Following informed consent, the semi-structured interview took place in Spanish by the first author, a fluent Spanish-English bilingual. The interview recording was then able to facilitate verbatim transcription for subsequent analysis.

4.9 Analysis

The interview was translated from Spanish to English from the Zoom recording which was transcribed verbatim. It was sent to a PhD supervisor who is also a fluent Spanish-English bilingual. Bailey-Rodriguez checked and verified the translation was accurate. Data was then analysed allowing for the data to remain as close to its original meaning as possible.

The analysis of the transcript followed the method outlined by Smith and Osborn (2003). Once translated, the data was transcribed and subjected to analysis. The data was read several times in order to provide an opportunity to re-engage with the material and gain a holistic picture of Dr. A's account. The transcript was then studied in detail and notes/memos on points and observations were made in the margins, and then categorised as emergent themes. The transcript was then examined again, and the themes were adjusted, shaped and developed, together with further considerations as to what was relevant, links and analysis and the final subordinate themes, grouped within their respective superordinate themes, were formed. Each theme was supported by quotes to illustrate their foundation in the text.

4.10 Findings/results

The following explores one individual's personal experience of treating Maya and Ladino Guatemalan patients. Four superordinate themes were identified namely ART secrecy, racial integration issues, religious factors, and risk factors (see Table 4.1 1). Each superordinate theme was also associated with subordinate themes.

For ease of explication, the four themes are presented separately although there are several interrelated elements.

Table 4.1 1

Master table of superordinate and subordinate themes generated from IPA

Superordinate Themes	**Subordinate Themes**	**Participant Quote Sample**
ART Secrecy	• Fear of rejection	“…he [the child] will feel very rejected [from parents], its best to not know…” "...they move because they do not want their relatives or friends to know what they did..."
Racial Integration Issues	• Racial norms • Racial rules	"...in the end they don't, in the end they stay with their same race..." “…the truth is, that it is not allowed to cross with the other ethnic group…”
Religious Factors	• Religious guilt • God’s punishment	"...they say this [ART] is like a sin, that cannot be done, it should not be done..." "...and they say it is a punishment [from God] because I did this treatment, it’s because I didn’t wait for it naturally, I'm forcing it..."
Risk Factors	• Risk taking • Covid-19 impact	"...then with the age, risk rises [with ART] with genetic diseases, neurological diseases, heart problems, but they go ahead with it..." "...During the pandemic, there are many patients as I had explained at the beginning, that they have postponed their treatments due to the pandemic..."

Superordinate theme: ART Secrecy

This superordinate theme based upon the Dr. A's experience with their patients revealed a general sense of secrecy across Maya and Ladino populations regarding the use of ART to conceive. In Guatemala stigma around being infertile is still very prevalent, this stigma also arose in the interview when discussing infertility treatments. Dr. A explained that he deals with secrecy concerns from their patients often and furthermore many of them felt they must keep the treatment secret to avoid societal consequences. Even when Dr. A tells their patients they cannot disclose the treatments with anyone due to patient confidentiality laws, still they feel that they must reassure their patients whilst under their care. One subordinate theme developed form the superordinate theme of ART Secrecy, which was the fear of rejection.

Subordinate theme: Fear of rejection

Dr. A stated that both Maya and Ladino couples felt a lack of support from the people in their personal life and were afraid of rejection. They mentioned that their patients make it a point to make sure the treatment is kept in secret.

> *"…people should not say anything to anyone including the child, to avoid any rejection from the rest of the family…"*

Dr. A expressed that both Maya and Ladino patients mention the fear of rejection from their loved ones to them, and their child. They believe they will be rejected from their family due to undergoing infertility treatment. The secret must be so guarded, that in cases the child itself will not know of its origins, suggesting a significant secret must be kept in order to avoid rejection.

> *"…he [the child] will feel very rejected, its best to not know, it can have negative impact...*"

> *"We are very discriminatory [Guatemala], we never leave a couple alone, including family. Nor do we know how and if they can have their children, and in the end what*

> *we do is expose or criticise them and especially the child. Things like how he was born, he will feel very rejected. It's best if no one knows."*

The above extracts described what Dr. A's patients experienced, their patients fear telling their ART born child how they were conceived, as they fear the people in their personal life are not very accepting. This suggest that rejection fear in personal life could be a factor when undergoing infertility treatments in Guatemala.

The analysed interview revealed the importance of concealing any infertility treatment and the origin of conception in the patients' social life. Dr. A reflects on their Maya and Ladino patient's experiences and how they felt. Dr. A expressed that their patients felt an enormous fear of rejection in their social life from their friends, co-workers and neighbours as stigma around infertility treatment is still widespread.

> *"…Personally, I think that in the end it is better to tell the truth [instead of keeping infertility treatments and method of conception a secret]. However, that would never work in Guatemala. There is stigma and even in my own patients, I see it. They are afraid of their child thinking it's not loved, or it's not accepted. They're afraid of the public bullying them…"*

This quote illuminates how Dr. A's experience of his patients feeling afraid of the Guatemalan public not accepting them or their child meaning the patient is concerned of their choices being stigmatised.

> *"…When the child is born, they have to continue with the treatment process but generally many patients no longer return, they no longer go to the psychologist. The patient moves, goes to another area of the capital, goes to another city, they move because they do not want their relatives or friends to know what they did…"*

Dr. A felt patients feel like disclosing this information could be considered as out of bounds. Dr. A stated that the fear is so great many patients go out of their way to ensure the secret is hidden to the point where they will not complete the follow up stage of the treatment once the child is conceived. Dr. A will no longer hear from the patient after this. This suggests that infertility treatment is important to conceal, meaning patients are willing start new lives in order to avoid rejection from their social circles; rejection fear in social lives could be something worth considering when undergoing infertility treatments.

Superordinate theme: Racial Integration Issues

Dr. A spoke widely of how racial integration issues between Maya and Ladinos are still strongly embedded in the Guatemalan society. Dr. A felt that whilst both races are culturally acknowledged as Guatemalan, they live side by side rather than integrated. Developing from the superordinate theme of ‘Racial Integration Issues’ the subordinate themes of racial norms and racial rules were identified. The following extracts show how this ongoing issue seems to be a superiority benefiting Ladinos.

Subordinate theme: Racial norms

Dr. A stated how Maya and Ladinos typically do not marry each other. They mentioned that they have never helped a Maya-Ladino couple, and this would be out of the ordinary. They also stated that although it is unusual, it is seen from time to time. Dr. A mentioned that in Guatemala keeping to one’s ‘own’ race is normal, as each race will usually form a family within their own racial community. Dr. A expressed that although it can happen rarely, it would be seen as taboo and it carries stigma if marrying each other.

> *“...in the end they don't, in the end they stay with their same race because it would be weird not to…”*

Dr. A explained that the Maya community is very conservative and reserved, and they prefer to marry within their own community. They elaborated by stating that much of this stigma is carried within the Ladino community, as the ongoing joke is to ‘better the race’. This joke is that throughout generations, people should continuously marry people of lighter skin tones (European decent) so that eventually they will resemble more European features like lighter eyes and hair, and not have any physical traces of indigenous features, including a darker skin tone. Dr. A expressed they felt this type of behaviour is so embedded in Guatemalan culture, that these micro-aggressions reflect on every aspect of everyday life and are unfortunately part of the ‘norm’.

> *“…So it is not overt racism, but for example there are jokes, for example one goes; the one who courts with the lighter race, will improve their race…”*

Dr. A mentioned that they themselves have witnessed prejudice and discrimination against Maya patients due to their ethnicity and colour of their skin. These integration issues shine a light on how racial norms could be a problem when undergoing infertility treatment (e.g. the use of donor egg or sperm).

> *“…basically stating that the lighter the better, ladinos are usually lighter…”*

This quote also suggests how colourism might be highlighted when participating in ART for Guatemalans, especially for Maya and interracial couples. This could mean that racial norms could be a factor to deliberate when undergoing infertility treatments in Guatemala.

Subordinate theme: Racial rules

Throughout the interview, Dr. A expressed their feelings towards unwritten ‘rules’ in Guatemala orbiting around race. They mentioned they felt the ‘rules’ were unfair but followed by the majority of Guatemalans, including their patients. Dr. A also mentioned that even when the ‘rules’ are questioned by people politically, the issue usually doesn’t get the attention it deserves. Dr. A felt these ‘rules’ are carried throughout every aspect of life in Guatemala, including family planning.

> *“...The truth is, that it is not ‘allowed’ to cross with the other ethnic group. Education, values, points of views, religion, and everything that is inherited [culturally] is very different [for each race]. It is not seen in society, even less seen in assisted fertilisation treatments...”*

Dr. A felt their patients have experienced significant issues with regards to racial integration issues in Guatemalan society. They also said their patients seem to have to follow these racial rules. This is an ongoing issue Guatemala has been trying to combat since 1995. In 1995 the Agreement on the Identity and Rights of Indigenous Peoples was created (Sieder & Witchell, 2001). This agreement pledged to change the attitude of culture as a means of acknowledgement and inclusion of indigenous peoples. It has been implemented to battle a deep-rooted heritage of discrimination, racism, and colourism within Guatemalan society (see chapter 2). However it is an agreement that is continuously broken and rarely adhered to. The lack of importance placed on following the agreement in society demonstrates the struggles the Maya have to face in everyday life, including infertility treatments. This could mean that racial rules could be a factor to consider when undergoing infertility treatments in Guatemala.

Superordinate theme: Religious Factors

Dr. A reflected on how in their practice, Maya and Ladino patients' decisions and attitudes towards infertility treatments relied heavily on religious morality. Dr. A stated that in Guatemala, religion is something that is considered in everyday decisions by the majority of society and therefore their patients were no exception. The analysis showed that from Dr. A's perception, only the Ladino patients displayed religious factors namely the subordinate themes of religious guilt and fear of God's punishment.

Subordinate theme: Religious guilt

Dr. A felt that most of their Ladino patients expressed feeling religious guilt. They stated that many of the patients felt like they are going against their religious values and feel negatively towards the treatment, as they feel shameful and contradicting to their religious identity. Dr. A expressed that even though their patients felt this way, the need to form a family was felt much more than the guilt, and therefore they completed the treatment regardless.

> "*…Ladino patients have many conflicting feelings because they want a baby but they cannot have it the way God 'intended', and they feel bad. They feel sinful and guilty that they're not following their religions' rules…*"

> *"…the pros and cons of that decision, of a medical treatment, and in the end, they make their decision to do it regardless of the guilt or the religion. Even if they feel shame…"*

Dr. A acknowledged that their patients have a two-way struggle where they want to form a family but also want to adhere to their religious rules. In Dr. A's experience this is something that happens with their Ladino patients regularly meaning their decision to undergo infertility treatments could often be made with guilt attached to it.

Subordinate theme 3.2: God's punishment

God's punishment was also an important experience of Dr. A's perspective of their patient's lived experiences. Dr. A conveyed that in their experience, about 80% of their Ladino patients expressed being worried about punishment from God. 40% of the population in Guatemala identify with the Evangelic Protestant religion (United States Department of State, 2012) and around 70% identify with the Roman Catholic religion (Encyclopædia Britannica, inc., 2018). Dr. A stated that patients continuously bring up feeling that they are being punished by God for being infertile or will be punished by God for undertaking fertility treatment. Dr. A mentions that he feels that their patients express feelings of unworthiness of a child.

> *"…They blame themselves for undergoing this kind of treatment. They think God has punished them and taken away their ability to reproduce and form a family…"*

Across the Judeo-Christian religious faiths, infertility is seen as punishment for wrongdoing (Sewpaul, 1999). Dr. A stated their patients expressed being infertile was a punishment from God. They felt their patients believe they are going against a punishment that is justified by God himself.

> *"… she is not comfortable with it, it's not meant to be because God hasn't blessed them, they may not deserve it, they may not deserve children."*

In the quote Dr. A elaborates that patients feel a sense of pressure adhering to religion and having to undergo infertility treatment is contradictive to 'God's blessing', meaning patients could believe their infertility is a punishment.

Superordinate theme: Risk factors

Dr. A believed people understand there are risks with everything in life, and also believed The Maya and Ladinos share this belief. From the analysis the superordinate theme of risk factors was identified and is supported by subordinate themes of health risks and financial risk.

Subordinate theme: Risk taking

Dr. A explained that their patients experience was not deterred by the health risk involved, in fact even when the risks were explained, their patients still underwent treatment. Dr. A felt that their patients were willing to risk their own health with side effects in order to start a family.

> *"...side effects, they will have a lot to do with the effects of the medications that they are taking, most of them are hormonal treatments to stimulate the ovaries, and for men to stimulate what is sperm, and many patients understand some of the uncomfortable side effects that have to happen, and they decide to continue with the hormone treatments..."*

Dr. A felt their patients believe health risks are only a slight inconvenience compared to what could be a positive outcome. Dr. A explained that although patients know about the risks of unpleasant side effects the need to form a family outweighs the health risks they warn patients with.

> *"...You also have to wait after the treatments and hormones, to see if the reaction was positive, or a negative one, even when couples understand they may not have a positive result they do it anyways..."*

In the quote Dr. A illuminate how patients understand that even after undertaking infertility treatments and putting their body under stress, their patients still chose to do it. This could mean that accepting health risks could be a factor to consider when undergoing infertility treatments in Guatemala.

Dr. A felt that the hope of achieving a family was expressed through financial risk taking by both Maya and Ladino couples. They explained that in a developing country like Guatemala the majority of the population must live frugally as government support is extremely hard to come across as well as the majority of the country live in poverty. However this ‘frugal living’ is not reflected when Dr. A’s patients undertake fertility treatments as they are extremely costly, and are not subsidised in any way by the government.

“…Most use credit cards, they don’t care if it’s affordable…many couples find it hard to pay but they always find the money in the end…”

In these quotes Dr. A suggests that patients find a way to fund the treatment even if they cannot afford it. Dr. A also explained that in their experience, their patients will take financial risks in hopes to form a family. Dr. A felt their patients would explore most avenues to make sure they fund their treatment.

> *"…There are also occasions where couples pay a prepayment and the rest in repayments. Others will even borrow money from the bank, their families or friends…"*

In this quote Dr. A suggests the patients’ needs to start a family is felt so deeply, that even when they cannot fund the treatment themselves, they pay in instalments or use loans to fund the treatment. This illuminates the financial risk patients take in hopes to start a family and could be a factor to deliberate when undergoing infertility treatments in Guatemala.

Subordinate theme: Covid-19 impact

Communities around the world face an uncertain and unpredictable future with the current Covid -19 pandemic, especially in developing countries. This virus has brought changes to all aspects of life including ART. Dr. A’s interview magnified the changes their Maya and Ladino patients have implemented due to the coronavirus pandemic and Covid-19 factors that affected their patient’s behaviour towards risk taking in ART.

Health advisors around the world encouraged people to stay home as much as possible to avoid contracting Covid-19. The lengthy time of infertility treatments has often been associated increased psychological distress, furthermore psychological distress has shown to affect medical decision making (Lawson, et al., 2021). Dr. A stated that this mirrored the behaviour of their patients. Dr. A felt their patients were scared about their future and were afraid to take any risks and make any life choices, especially medical ones during this time.

> *"...yes, the patient especially the Maya, really thinks more about Covid-19 than about the treatment. In the case of a donor, they ask do you think the donor has the disease? Is the donor of the egg or sperm going to pass the disease to me? Could it be that the baby is sick?..."*

This quote illuminates the anxieties around Covid-19 that surfaced for patients when considering infertility treatment. Patients feel anxious about their health and the child's health, fearing contracting the Covid-19 virus.

> *"...Yes, generally at this time [December 2020] it is considered that this virus generally circulates in the environment, and that anything can be Covid. [Dr. A referring to their patients] A flu? It is already Covid. A diarrhoea? It is already Covid-19, and if the woman is pregnant they are very afraid, they run to me and say 'Doctor look, look at my family, my relative has the virus or a neighbour two houses 10 blocks away, has Covid-19, what do I do?! Am I safe?'..."*

Dr. A felt many of their patients were very uncertain and anxious because of the pandemic. Dr. A stated that their patients would contact him regularly and seek out reassurance about the treatment or advise on how Covid-19 could affect them or the child. This could mean that health anxieties due to Covid-19 could be a factor to contemplate when undergoing infertility treatments in Guatemala.

Dr. A felt that in their experience their patients have stated they rather postpone their treatment until the Covid-19 pandemic is over. Dr. A mentions how patients have begun to look at the risks involved and have begun to weigh them compared to the fertility treatment especially when it comes to financial risks.

> *“… People are now thinking about the economy, they worry about the future next years, and many people will not make the decision to undergo treatment, economically speaking, and because of Covid-19 fears, they are scared to catch it, and lose their job due to sickness…”*

In the quote Dr. A suggested that before the pandemic, patients would take risks, understanding that they could potentially lose some financial stability, however that changed and patients are not willing to do so and will rather postpone treatment because of the uncertainty Covid-19 has introduced.

Dr. A also stated that patients began to feel so uncertain about the future that postponing treatment seemed like the better thing to do until patients feel more secure.

> "...she is taken to a higher degree of anxiety [referring to the anxiety that is already felt when undergoing infertility treatment], they are already afraid [referring to being afraid of the pandemic] and start to reject treatment, they start to wonder why not wait a bit until after Covid..."

In the quote Dr. A felt that their patients’ priorities have changed, before the pandemic patients understood health risks and would still chose to undergo treatment. However now even if patients want to start a family, it could be put on hold until they are more certain about their future. This means that postponing treatment due to Covid-19 could be a factor to deliberate when undergoing infertility treatments in Guatemala.

4.11 Discussion

The present IPA study provided an ideal opportunity to examine the perception and behaviour of Maya and Ladino patients from the point of view of a Guatemalan fertility expert towards ART. The findings indicated that ART secrecy, racial integration issues, religious factors, and risk factor elements to be considered when dealing with the treatment of Maya and Ladino patients. These findings mirrored the results of study 1 as they also reported that the Maya and Ladino differ on factors such as ART secrecy, racial integration issues, religion and risk factors.

A deeper understanding was revealed towards ART secrecy indicating that secrecy is brought on by the fear of rejection in both personal and social life for people undergoing infertility treatment. One could argue that the perception of undergoing infertility treatment for Dr. As' patients is to keep the treatment as a secret. Although a recent systematic review of the literature pertaining to donor conceived people's views of their genetic origins (see Chapter 3, Blyth et al., 2020) this was concluded on practices that encourage openness in assisted reproduction in a Westernised society and not a developing nation like Guatemala. Thus the interview IPA sheds light on issues around secrecy in Dr. As' patients, instead of openness.

This study also expanded on factors of religion like religious guilt and fear of God's punishment. As stated in Chapter 1, 2 and 3, different cultures and religion view infertility treatments differently. In Christianity, ART is forbidden to its followers as it bypasses the sexual union of man and woman. Although the Vatican does not accept ART, the Protestant and Anglican may practice it (Serour, 2006). As previously stated a large majority of Guatemala follow a Christian faith or may have Christian influences in their spirituality, and therefore what arose from the analysis was a light shun on the guilt and fear of the punishing that may come from going against religious rules.

The study amplified issues with racial integration revealing that discrimination and prejudice are established through racial norms and racial rules, despite the fact that Guatemala has been combating these types of issues for many years (Sieder & Witchell, 2001). This shed light on the feelings Dr. A sensed their patients had when it came to matters of ethnicity acceptance and racial equality. As mentioned in Chapter 2 the 36 year civil war in Guatemala hindered the relationship between people and government. The cultural result of the civil war is one of mistrust in equality and racial prejudice (Dyrstad et al., 2021). The study findings illustrated these feelings towards ART.

Lastly the IPA of this interview gave some insight into the risk taking that's involved and how that changed due to the Covid-19 pandemic. As stated in Chapter 1, people may not fully know what the risk is when undergoing infertility treatment. This feeling was echoed in the sense that Dr. As' patients did not know what risk they could be taking when undergoing infertility treatments at the same time of a Covid-19 pandemic, and it ultimately played a part in their medical and health decision making as different risks were involved.

Thus, this study allowed for insight into factors that affect the perception and behaviour of the Maya and Ladinos towards ART. It illuminated on the understanding of a Guatemalan key ART medical experts' patients experience, and it shed light on how Covid-19 had an impact on these perceptions and behaviours.

4.12 Reflexivity

During the course of my research for study 2, I continued with a reflexive journal to express my research experience. I also continued discussions with my supervisors which allowed me to have a conversation about different aspects of my research, which had completely changed from the original plans, as the world adopted the ‘new’ normal. It was during this time, like many countries around the world, the UK went into lockdown due to the Covid-19 pandemic.

I found myself questioning how I could move forward? As the plans were to collect data in person, however that was no longer possible. After many brainstorming sessions with my supervisors we came up with a solution to continue my research path. I was able to acknowledge that this resolution was attainable because my initial position as a native Guatemalan. Due to the connections and trust that established during the data collection for study 1, I was able to recruit a medical key expert (Dr. A) for study 2. This allowed me to collect data ‘in real time’, meaning I could gather insight from my participants as they, and their patients, were also experiencing the impact of Covid-19. I felt like I was able to use this to my advantage in the sense that it was an experience being reported in the ‘here and now’ during data collection. This was also in line with keeping true to my values as it felt like I truly keeping honest to the research for this study.

During data collection I also found myself reflecting on my position of privilege. It was impossible for me to not think about the suffering in the world during the beginning of the Covid-19 pandemic, especially in developing countries like Guatemala. I reflected on the fact that although millions of people around the world found themselves in a state of uncertainty, I was privileged enough to continue research and data collection from the safety of my own home, with the support from my supervisors and university. This was a truly grounding experience as after my interview with Dr. A, I felt overwhelmed by the anguish the Guatemalan people were dealing with during this time. This was especially true for Dr. A’s infertility patients, as so many of them were already suffering with infertility, and now had to add Covid-19 to their stress. I felt grateful to find myself in such a privileged position. After this interview, I was able to chat to my supervisors to decompress by having an introspective discussion of the general impact the Covid-19 pandemic was having at the time.

Chapter 5 Study 3 An Interpretative Phenomenological Analysis of a UK Fertility Experts' Perception and Behaviour of Their UK Based Patients Towards Assisted Reproductive Technology

Preface

As argued in chapter 1, several researchers e.g., Pir Jalian (2020) have addressed the question of whether attitudes of patients across different cultures, and continents towards ART follow a universal or culture specific pattern. Pir Jalian (2020) reported that Iranian women with egg donor children were more concerned about social, medical and psychological consequences of their actions compared to UK women. There are very few studies aimed at addressing the fertility experts in different countries (Western or non-Western) on their perceived behaviour and perceptions of their patients undergoing ART. One study (Huisman et al, 2009) in the Netherlands compared fertility experts and patients perceptions during treatment of IVF. The authors reported that the most frequent questions from patients to physicians and nurses concerned fertility drug-related side effects, followed by concerns about how to perform their injections. More than half of patients (57%, n = 106) had concerns about the injection process. Within the fertility expert group, almost half (47%, n = 80) expressed concern about whether their patients injected themselves correctly, with 26% (n = 44) raising concerns about patient compliance. Issues regarding possible social, medical or psychological consequences or indeed the rise of Covid-19 has not widely been addressed in studies involving medical experts. This is the aim of the present in-depth single case study of a UK fertility expert with a view to providing insight into the extent to which the present findings are shared by experts from a Western orientation.

There is, however, a note to add there regarding the term UK fertility expert i.e., would the term UK fertility expert be appropriate for the participant in this study or should it be an English fertility practitioner? This is because the expert is English and works in England. The answer is that all UK countries are regulated by the British Fertility Society and as documented on their latest web page (2022) "There are currently over 80 IVF centres in the UK licensed by the Human Fertilisation and Embryology Authority (HFEA). The vast majority of these clinics have worked effectively for many years within this framework providing the highest quality of care for patients". Thus, in the present thesis the term UK practitioner as far as their practice and medical interventions are concerned could be generalised to any practitioners working in England, Scotland, Wales or Northern Ireland (British Fertility Society, 2006).

5.1 Aim

The current case study is aiming to examine the extent to which findings in study 1 and 2, are also reflected in the views of health care practitioner in the U.K. (study 3). This proposes the research question of: How are factors of the perceptions and behaviours of UK patients towards ART, illuminated by the meaning of a UK key ART medical experts' patients experience? And from their perspective, how has Covid-19 had an impact on these patients' experiences? has Covid-19 had an impact on these patients' experiences?

The findings have implications for understanding ART in Guatemalan society and for practitioners and other agencies involved in the infertility treatment to have a Western case study comparison.

5.2 Participant

The UK has a socialised healthcare system called the National Health Service (NHS). The NHS consists of a series of publicly funded healthcare systems in the UK. Citizens are entitled to healthcare under this system, but also have the option to pay for private health insurance. In 2020, the UKs' socialised health system was ranked number 13 in the world, with 10.5% of its citizens using private health care (Girvan et al., 2020). Over the last few years however, there have been a few concerns as inflation and over utilisation of healthcare services led to restrictions and longer treatment wait times.

The pseudonym of 'Dr. B' was given to the participant in this case study. Specific demographic information was omitted as this allowed this case study to remain comparable to study 2. The demographic information omitted is namely; age, sex and ethnic identity, however the researcher insured both doctors were similar in their demographic information. Dr. B is a key coordinator in the United Kingdom, with 22 years of experience in NHS gynaecology and obstetrics practice as well as experience in the private sector. Dr. B has worked in very culturally diverse areas such as London and Manchester, as well as predominantly white traditional English areas such as the county of Hertfordshire. Dr. Bs' experience in the private health sector comes alongside working for the NHS as it is common for medical practitioners to do so in the UK. Dr. B was recruited through connections provided by Middlesex University.

5.3 Method

Similar to study 2, a semi-structured interview was used (please see Appendix G) where Interpretative Phenomenological Analysis (IPA) was deemed the most appropriate method for qualitative analysis for the current case study.

As mentioned in study 2, IPA is ideal when analysing structured interviews as it allows the researcher to make sense of the participant trying to make sense of what is happening to them. A single case study, using IPA to analyse the data was carried out. This study proposes a keeping it as like-for-like as possible of the perception and behaviour of UK patients undergoing infertility treatment through a UK medical expert's lived experience; to Guatemalan patients undergoing infertility treatments through a Guatemalan medical expert's lived experience (study 2).

A case study is needed when the observation is made that a Guatemalan ART patient (non-Western) will not have the same perceptions and behaviours towards ART as UK ART patient (Western).

5.4 Materials

A semi-structured interview schedule was thought suitable to conduct this study as it allowed Dr. B to truly share their judgements and experience related to each question. The semi-structured interview schedule was based upon study 1 in views to compare to study 2.

This case study incorporated the same questions from study 2, question topics like how the influence of religion impacted participation in ART treatments; as well as what the role of religion before, during and after treatment was, and how were any religious influences were resolved. A separate section on how the Covid-19 pandemic influenced decisions towards undergoing ART treatments and how this influenced their decisions was also included (see study 2 for interview schedule).

5.5 Ethical Approval

Ethical approval was granted by Middlesex University. This process ensured that the research conducted was carried out in conformity with the law, and in agreement with the best current practices and principles and follows both the British Psychological Society and the University’s Code of Practice for Research: Principles and Procedures. Due to global travel restrictions imposed by the Covid-19 pandemic, it was not possible to collect data in person and an electronic approach was taken.

5.6 Procedure

The data for this study consists of 1 transcribed semi-structured interviews with Dr. A. The interview investigated the specific findings of study 1 in views to compare to study 2. For example, the interview began with a question on religion and to what extent did religion play a factor in patients before, during or after any treatment? The question followed by how were these issues finally resolved? Do you predict this will change due to the Covid-19 pandemic? If so, how? The interview schedule allowed a degree of openness, so that given answers or stories could be further probed at that time

An interview was conducted via a 1.5 hour long Zoom meeting where the participant was assured anonymisation by the use of a pseudonym, as well as ensuring that any possible identifying information was irreversibly altered. The recording stored securely in accordance with Middlesex University Ethics Committee guidelines. Opportunities were provided during the interview for the participant to allow Dr. B to expand beyond what was the topic of conversation and provide even more insight into the topic mentioned in the interview schedule. Following informed consent, the semi-structured interview took place in English.

5.7 Analysis

The interview was transcribed verbatim. Data was then analysed allowing for the data to remain as close to its original meaning as possible. The analysis of the transcript followed the method outlined by Smith and Osborn (2003). Once the data was transcribed, it was subjected to analysis. The data was read several times in order to provide an opportunity to re-engage with the material and gain a holistic picture of Dr. B's account. The transcript was then studied in detail and notes/memos on points and observations were made in the margins, and then categorised as emergent themes. The transcript was then examined again, and the themes were adjusted, shaped and developed, together with further considerations as to what was relevant, links and analysis and the final subordinate themes, grouped within their respective superordinate themes, were formed. Each theme was supported by quotes to illustrate their foundation in the text.

5.8 Findings/Results

The following explores one individual's personal experience of treating UK ART patients. Three superordinate themes were identified namely ART secrecy, self-agency, and risk factors (see Table 5.1 1). Each superordinate theme was also associated with relevant subordinate themes. For ease of explication, the three themes are presented separately although there are several interrelated elements.

Table 5.1 1

Master table of superordinate and subordinate themes generated from IPA

Superordinate Themes	**Subordinate Themes**	**Participant Quote Sample**
ART Secrecy	• Fear of social rejection	"…they [patients] express secrecy [regarding ART] around their social circles…"
Self- Agency	• Commitment to treatment	"…[if] they don't meet the criteria [to get treatment via the NHS], but most of the time the appeal will be denied and they will just go private…"
Risk Taking	• Covid-19 risk taking aversion	"…sometimes they have to alter, cancel, or postpone the treatment depending on how they feel about Covid exposure…"

Superordinate theme: ART Secrecy

ART secrecy is a superordinate theme based upon the Dr. Bs' experience with their patients. This theme revealed a general theme of secrecy across Dr. Bs' patients regarding the use of ART to conceive. Dr. B explained that they deal with secrecy concerns from their patients often, and many of them feel the need to keep the treatment secret to avoid societal judgement.

Dr. B expressed the importance of patient confidentiality in their practice and how their patients expect a level of secrecy from them. Dr. B explained how they feel like the UK still has some stigma towards infertility treatments and their patients' express hesitation towards their social circles becoming aware they are undergoing treatment. One subordinate theme developed form the superordinate theme of ART secrecy namely the fear of social rejection.

Subordinate theme: Fear of social rejection

Dr. B stated that their patients felt a lack of support from the people in their social life and were afraid of social rejection. They mentioned that their patients generally reference their hesitations about the stigma ART has amongst their peers.

"…They express secrecy around their social circles, they have nothing to worry about as we don't disclose that information, but they worry…"

Dr. B felt that their patients fear rejection from their peer groups, and many of them do not want to lose social support. They believe they will be rejected from their social groups due to undergoing infertility treatment.

"…They're scared of what their co-workers may think, or what their neighbours may say. They want to make sure they don't get alienated I think, they don't want to lose anything…"

The above extracts described what Dr. B's patients express they are afraid of. Dr. B feels their patients fear telling their social groups that they have conceived an ART born child, as people in their social life will not be very accepting. This suggests that rejection in social life could be a factor when undergoing infertility treatments in the UK.

Superordinate theme: Self-agency

Self-agency is a superordinate theme based upon Dr. B’s involvement with their patients. This theme illuminated Dr. B’s general sense of self-generated actions in patients regarding the use of ART treatments. Dr. B expressed that their patients are very sure about wanting this type of treatment, and often patients like to have a sense of control over their infertility treatments.

Dr. B’s experience was that their patients usually are well informed and determined to go through with treatments. One subordinate theme that was identified from the superordinate theme of self-agency, namely commitment to treatment.

Subordinate theme: Commitment to treatment

Dr. B stated that their patients felt extremely committed to receiving this treatment. Dr. B stated that because the NHS has limited funding for ART, patients that get awarded the funding aver very determined to go through with it.

> *“…in my opinion, I do not have patients that defer their treatment due to the religious views or society stigma or whatever, they tell me they are very sure they want this…”*

“...sometimes women may ask me to alter treatments to their needs, but they do not defer treatment regardless of changes…”

Dr. B felt that their patients’ determination is very strong. Dr. B illuminated that patients’ need to conceive and determination for this type of treatment is something that will overcome many changes and hurdles if needed, including lack of NHS funding.

“…they can appeal the decision not to fund them because they don't meet the criteria, most of the time the appeal will be denied, and they will just go private…”

The above extracts described how Dr. B felt their patients’ determination is conveyed when overcoming issues. Dr. B believes patients will overcome an issue like lack of funding from the NHS, by switching to private healthcare. As mentioned before, only about 10.5% of the UK population pay for private healthcare (Girvan et al., 2020). This suggest that the commitment to treatment could be a factor to be considered when undergoing infertility treatments in the UK.

Superordinate theme: Risk Taking

Risk taking is a superordinate theme extracted from the interview. Dr. B’s experience was that their patients understood the risks involved with their treatment, however because of the Covid-19 pandemic, some patients were more risk-adverse. From the interview analysis the superordinate theme of risk taking arose and is supported by subordinate theme of Covid-19 risk aversion.

Subordinate theme: Covid-19 risk taking aversion

Dr. B stated that their patients felt very educated on the risks that they face when undergoing ART and it is generally not a problem when undergoing treatments. However, Dr. B illuminates the hesitation patients now have on risk taking due to the pandemic.

> *"…well my patients are more anxious now with the pandemic than before, they become very cautious of health and sickness…"*

> *"…you see before they would take the risks of side effects for example, but now [with Covid-19] they don't feel comfortable…"*

Dr. B felt that their patients' risk taking has changed, and now Covid-19 has had a very strong impact on patients' decisions. Dr. B felt that their patients have begun to show levels of risk aversion.

"…now, sometimes they even cancel or postpone the treatment. They want this [the pandemic] to pass, they feel too exposed…"

The above extracts describe that in Dr. B's experience, their patients' risk taking has changed because of the Covid-19 pandemic. Before, patients did not mind the risks involved, but now with the pandemic, many patients have become uncertain on whether to take such risk. This suggest that the Covid-19 impact on risk taking could be a factor to consider when undergoing infertility treatments in the UK.

5.9 Reflexivity

During study 3, I continued to reflect on my research. I also continued meetings and conversations with my supervisors, as I was now conducting research taking the Covid-19 pandemic in mind.

For study 3, at times I found myself in a position of uncertainty. At this particular stage of data collection, the UK (where I am based) was under lockdown restrictions, as the cases of Covid-19 were rising. This made access to a medical practitioner difficult as the NHS was under an immense amount of pressure. I was conscious of the fact that to a doctor, taking part in research might a priority. This was in fact echoed as the initial doctor I reached out to, had to withdraw their participation as they were far too busy. This allowed me to reflect and understand that medical practitioners were very difficult to recruit as their duty was to help people during such times; and rightly so.

One of the values that was important to me during my research was openness. I specifically drew on that value during this study, as it allowed for flexibility throughout data collection. On my second attempt to recruit a UK based practitioner, I was able to secure an interview with Dr. B. After rescheduling a couple of meetings I was finally able to speak to Dr. B who very kindly took their lunch break to speak to me. I conducted the interview aware that this opportunity was rare given the circumstances. I made sure that this time was used to truly grasp Dr. B’s voice by acknowledging my position, which I felt was lucky. This was through recognising Dr. B’s time frustrations, thoughts, and remarks when they brought them up. After completing the interview, I was able to converse with my supervisors to discuss the impact the Covid-19 pandemic was having, and how it was affecting the NHS and medical practitioner.

5.10 Discussion

The present study provided an ideal opportunity to examine the perception and behaviour of UK patients from the point of view of a UK fertility expert towards ART. The findings indicated that ART secrecy, self-agency, and risks factors are elements to be considered when dealing with the treatment of UK patients.

A more in-depth understanding was shown towards ART secrecy in UK patients indicating that secrecy is brought on by the fear of rejection in social life. This is slightly different from the study conducted by Fauser in 2019, as it found a positive attitude among respondents toward infertility treatments (see chapter 1). Although secrecy is not necessarily always linked to negativity, in this instance it has negative connotations as it relates to social rejection. This illuminates that Dr. Bs' patients prefer their treatment to remain secret due to negative reactions from their peers.

The findings also expanded on factors like self-agency and the importance of commitment UK ART patients have towards infertility treatments. A study looking into willingness, preference and decision-making about planning for the possibility of needing multiple cycles of IVF/ICSI treatment among infertility patients was conducted in 2021 via online surveys. This study stated that the majority of patients seem to value the opportunity of multiple cycles of treatment, even when faced with challenges like a failed cycle, patients' willingness for treatment was in agreement with the benefits of continuing treatment (Harrison et al., 2021).

Lastly, the findings expanded on risk factors and the changes Covid-19 have brought to Dr.Bs’ ART patients’ risk taking when it comes to undergoing infertility treatments. As stated above, people (in Western societies) seem to be willing to undergo ART treatments. This feeling however did not resonate in the sense that Dr. Bs’ patients did not know what risk they could be taking when undergoing infertility treatments at the same time of a Covid-19 pandemic, and in the long run played a part in their medical and health decision making.

Thus, this study allowed for a look into factors that may affect the perceptions and behaviour of UK based infertility patients towards ART. It shuns a light on the understanding of a UK based doctors experience with their patients, and it illuminated how Covid-19 had an impact on these perceptions and behaviours.

5.11 Shared views and differences in Guatemalan and UK interviews (study 2 and study 3)

Study 2 allowed for an insight into the difference between general public perception of ART in Guatemala, and the perception and behaviours of people actually using ART in Guatemala, to see how they may compare and coincide. Furthermore, study 3 offered a unique comparison of a non-Western country (Guatemala) to a Western country (UK) on the perception and behaviours of people undertaking infertility treatments.

The interviews analysed from the two key ART medical practitioners (Dr. A and Dr. B) explored the in depth the experiences the doctors had with their patients in regards to ART perceptions and behaviours, and the impact Covid-19 had on them whilst undergoing ART. Both key ART medical practitioners had similar backgrounds with omitted demographics like age, sex, ethnicity due to issues surrounding confidentiality mentioned in chapter 4. Both participants are doctors in gynaecology with around 20 years of experience. Both doctors have worked in the private and public health sector and both doctors have worked in cities and the countryside. The analysed experiences illuminated themes that converged and diverged throughout analysis, the doctors highlighted their specific thoughts on their experiences, illuminating their differences. The themes and subthemes found in the analysis, give an insight as to what shapes perceptions and attitudes in a Guatemalan (Dr. A) and UK (Dr. B) medical experts' patients experience, and how Covid-19 had an impact on these patients' experiences.

Firstly, the doctors' experiences converged in the superordinate theme of ART secrecy. This theme illuminated how in the doctors' experience, their patients feared rejection and therefore chose to keep ART treatments a secret. However, the experiences diverged in their subordinate themes, as the fear was embedded in their patients' experience differently. In Dr.A's experience with their patients, they felt that they feared rejection in their religious and personal life. In Dr. B's experience with their patients, it was different as their patients kept ART treatments secret in fear of social rejection only. Secondly, the analyses diverge as only study 2 showed superordinate themes of integration issues and religious factors. Integration issues had the subordinate themes of racial norms and racial rules, and religious factors had the subordinate themes of religious guilt and God's punishment.

The analyses converge again with the superordinate theme of risk factors. In both study 2 and 3 the doctors' experiences illuminated risk factors in their patients ART experience. The analyses diverge in the subordinate themes. Dr. A's experience with their patients illuminated the subordinate themes of factors of risk aversion and the impact Covid-19 had on risk taking. However, Dr. B's experience with their patients only shed light on factors of Covid-19 risk taking aversion. The analyses also diverged in the superordinate theme of self-agency with the subordinate theme of commitment to treatment, which was only reported in Dr. B's experience in study 3.

Thus, studies 2 and 3 gave an insight to the difference between general public perception of ART, and the perception and behaviours of people actually using ART in Guatemala and the UK. Furthermore, a unique comparison of a non-Western country (Guatemala) to a Western country (UK) on the perception and behaviours of people undertaking infertility treatments was illuminated.

CHAPTER 6 Study 4 Impact of Covid-19 on Patients' Perception and Behaviour Towards Assisted Reproductive Technologies: A Scope Review

6.1 Preface

A generally accepted PhD format is to engage in an extensive literature review to provide the background and rationale for the empirical and/or non-empirical research that follows. The result of the research is then analysed with the reported studies and discussed. Whilst the starting point of the present thesis followed this tradition (study 1) the outbreak of worldwide Covid-19 pandemic made a significant impact on most aspects of life in particular health related factors. Studies 2 and 3 incorporated Covid-19 into the thinking and rationale for the investigation. This left a gap between a host of published work on ART perceptions and behaviour reported before Covid-19 and what impact Covid-19 had on the latter. In particular to what extent the public's perception and behaviour about Covid-19 has changed as a result of the worldwide pandemic. The scope review (a hybrid between traditional and systematic review) is considered as the most appropriate approach to fulfil this gap, this will be explained below.

6.1.1 Introducing scope reviews

Collecting, evaluating and presenting the available evidence are the underlying aims of any literature review, but what distinguishes them is their approach to how they collect, evaluate and present the available evidence. According to Grant and Booth (2009) there are 14 different types of literature review. However, the main popular reviews come under 4 types of reviews. The Traditional Literature Review (TLR) is most widely used with different types of research and covers a wide range of reported literature in terms of methods of research, dates of publication and often 'quality' of the outlet and/or authors not taken into account. TLR is not necessarily based on a well-defined 'pre-search' research question, but it could end up in providing more specific questions for the researcher.

Systematic Review (SR) and Meta-Analysis (MA) reviews are relatively more recent in scientific research as compared to TLR. Both approaches aim to answer a defined research question e.g., is there a relationship between classroom size and pupils achievement? This is done by collecting and summarising all empirical evidence that is considered to be of quality, based on a predetermined criterion. Both approaches use statistical analysis to find an answer to their research question. SR for example, typically involves a detailed and comprehensive search strategy, with the goal of reducing bias by identifying and synthesising the appropriate studies on a specific topic. MA, also known as the 'analysis of the analyses' examines the effect size of each carefully selected study and determines if the outcome is statistically significant. Both approaches are time consuming and require well defined protocols and questions to address (see Grant & Booth, 2009)

A Scope Review (ScR) dating back to the 1990's (in particular in health care studies) takes into account broader topics and designs. A scope review is less likely to address very specific research questions or to scrutinise selected studies on the basis of quality of the research outlet and authors. A scoping review is more rapid by comparison to the above reviews. Most notably the scope review is aimed at drawing conclusions from existing literature in a specific time period, reflecting the overall state of research activity and findings, producing guidelines for practitioners, researchers and policy makers. Scoping reviews, like systemic reviews and Meta-Analysis, could lead to publication in their own right. Often Scope Review may open pathway for a Systematic Review or Meta-Analysis.

ScR is specifically a valuable review that can be a tool to identify knowledge gaps, scope or coverage of a body of literature on a given topic. A ScR can give a clear indication of the volume of literature and studies available as well as an overview (broad or detailed) of its focus. Scoping reviews are useful for examining emerging evidence when it is still unclear or in infancy stages (see Arskey & O'Malley, 2005). However, in its initial phase of development there was no universally recognised definition of scoping reviews nor a commonly acknowledged purpose or indication for conducting.

Arskey and O'Malley (2005) published the first methodological framework for conducting Scope review. Follow up researchers, in particular Levac et al. (2010), argued for the inclusion of numerical summary and qualitative thematic analysis of the selected literature. Peters et al., (2015) made further clarification and recommendations and enhanced each stage of the framework. The broad stages of ScR are as follows:

1- Identify the research question
2- Identify relevant studies
3- Study selection
4- Charting of data

5- Collating, summarising and reporting the results

To date, despite its short history (ScR only dating back to the 1990s) according to Google Scholar, there have been 3,820 publications (as searched in 2021) under the heading of ‘Scope review’ which include a wide range of topics but more significantly in health care.

6.1.2 Scope review rationale for the present thesis

The aim of the present thesis was to examine the perceptions and behaviour of Maya and Ladinos in relation to Assisted Reproductive Technologies. Although limited research suggested that the Maya and Ladinos differ in the approach to family and the use of new technologies (e.g., lack of trust in modern medicine amongst the Maya), nevertheless there was a significant absence of any specific scientific research in Guatemala on perceptions and behaviour towards ART. Thus, the first phase of the present thesis was to administer a specially developed questionnaire with items addressing significant and often controversial aspects of ART (e.g., Children born by ART will not be accepted in the society) to the Guatemalan population. The results of which are reported in Chapter 2. However, the outbreak of Covid-19 meant that the pandemic had to be taken into account in the future conducting of this doctoral investigation. Indeed, this is not specific to this research. According to a recent survey (National Institutes of Health, 2020), 58% of researchers reported that Covid-19 had made it impossible to carry out the research they planned. More than half of academics reported that Covid-19 restrictions impacted other work activities, including teaching and administrative activities which reduced their time for research. The plan for the follow-up to the present thesis was then to engage in in-depth interviews with medical practitioners in Guatemala and in the UK as single case studies, rather than the original pre Covid-19 pandemic plan, which was to engage with patients undergoing ART. The result of a lengthy search led to getting the agreement of a key medical expert in the field of ART in Guatemala and one in the UK. The interviews were scheduled as such (see chapter 4 and 5) so that the findings of study 1 could be cross validated against actual experiences of a Guatemalan expert dealing with ART (e.g., from your experience with patients undergoing ART do you think their children are not accepted by the society?). The interview was then extended to the Covid-19 pandemic, and asking if they think that Covid-19 had an impact on patients' perception and behaviour towards ART. In addition, for the reasons of cross-cultural comparisons the same questions were asked from a UK medical expert (see chapter 4 and 5).

The findings from the two interviews, whilst unique and of great interest to the aims of the present thesis, begs the question of what has the scientific community reported since the outbreak of the pandemic in relation to patients' perceptions and behaviour towards ART (worldwide)? Since Covid-19 there has been a growing body of research on various aspects of the pandemic in the fields of medicine, psychology, and economy to name a few. A Google scholar search (in 2021) shows 452,000 publications with Covid-19 as the main focus of the investigation. A further search of the literature also indicates a growing body of studies aimed at the impact of Covid-19 on various aspects of human reproduction including ART. Thus, to have a comprehensive understanding of the finding of the present thesis conducted before and during Covid -19 (especially the interviews with Guatemala and UK practitioners) there is a need to capture available evidence and findings from the reported studies on patients aiming or undergoing ART during the Covid-19 pandemic. A ScR, as argued, provides this opportunity to identify, summarise and provide a comprehensive understanding of the state of affairs regarding ART, patient's perception and behaviour and the impact of the Covid-19 pandemic.

For this reason, a protocol was developed to provide key stages of the ScR review and reporting of the findings and conclusion.

6.2 Scope review study report as recommended in the guidelines of scope studies

Objective: The objective of this scope review is to understand the evidence and the extent to which assisted reproductive technologies perception and behaviours have changed in patients as a result of the Covid-19 pandemic. [3]

Introduction: This scope review will shed light on the emerging data of the perception changes that the Covid-19 pandemic has brought to patients on their infertility treatment journey. Ever since the pandemic broke in late 2019, infertility patients around the world have become more conscientious about their infertility treatments. This is now starting to affect the decisions infertility patients make towards starting a family.

Inclusion criteria: Using the PCC (participants, concept, and context) framework, this scope review will be looking at the population of infertility treatment patients (participants) in any stage of their fertility journey, up to successful conception (concept). This will allow for the review to explore through the expertise of medical professionals trained in the field of infertility treatments and will gain access to valuable data reflecting their patients' perception during Covid-19 (context).

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[3] It is important to note here that the ScR study is to be reported following PRISMA guidelines (Tricco et al., 2018).

Method: The key information sources searched were PubMed database and Google Scholar database. The majority of evidence will be located, from years 2020 to -2021. All publications in English and Spanish were considered. The search was conducted by two of the authors of the study independently, and later cross referenced for reliability. The search excluded studies where students and general public were participants. Both qualitative and quantitative studies were considered. The data was extraction was conducted by two independent reviewers using a customised data extraction tool that was independently prepared using SPSS. The tool was designed to record the key information relevant to the scope review question and any differences on data extraction was resolved by the reviewers by discussion. Search key words used for Google Scholar were "Assisted Reproductive Technologies" "Covid-19" "Patients" "Infertility treatments". Search key words used for PubMed were Assisted Reproductive Technology AND Covid-19 AND patients AND infertility treatments.

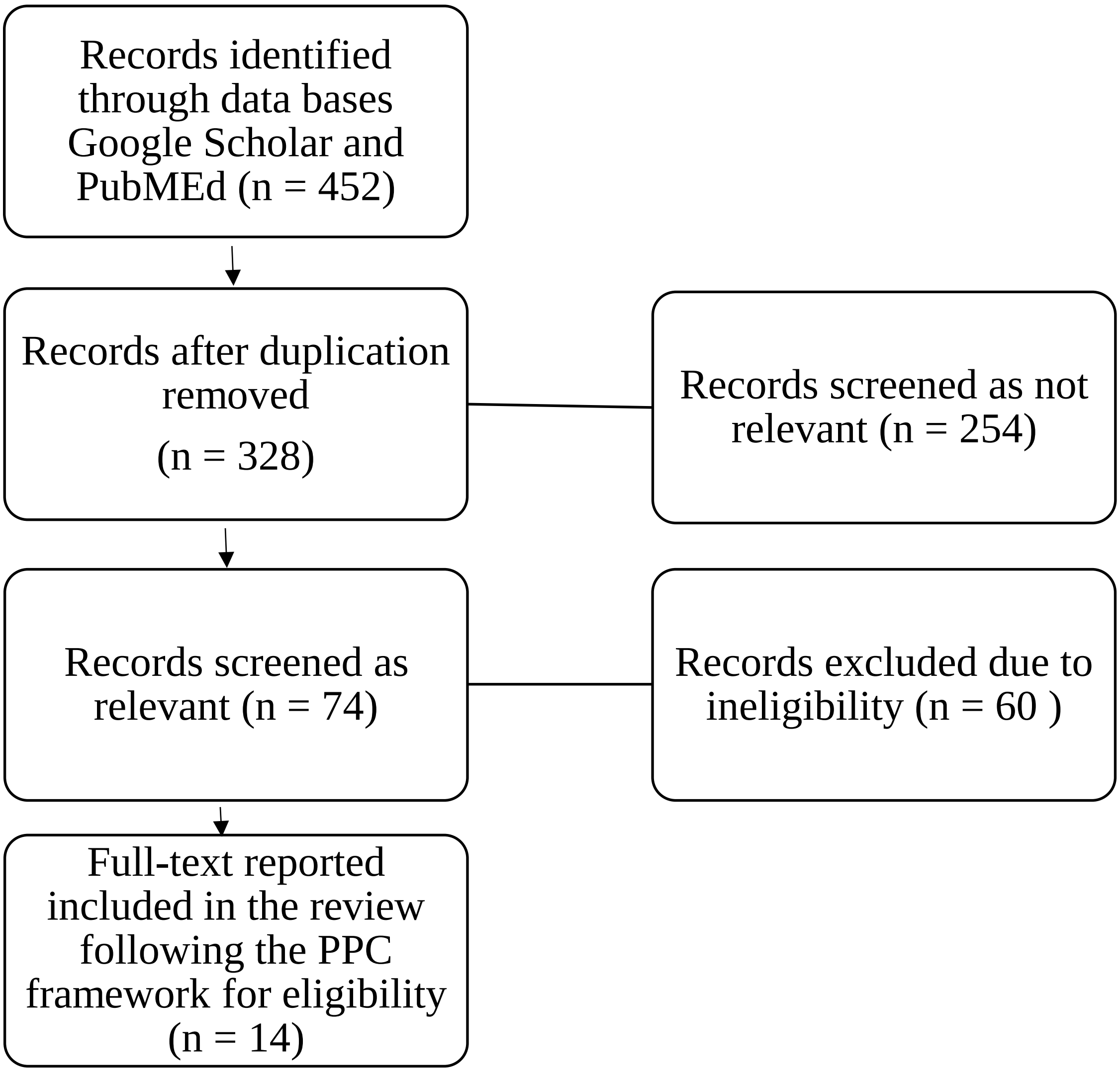
6.3 Results-Analysis

The result of the review is reported in 3 stages.

Stage 1 - Figure 6.1 represents the search process in which intended records were identified and later undergone the final selection stage. As seen in the Figure 6.1, 452 records reported between 2020 and 2021 in PubMed and Google scholar. Of these, 328 records were left after duplicate documents were removed. Out of those, 74 records proved to be relevant, 60 of those were discarded due to ineligibility, meaning participants did not fall under the PCC framework. This left 14 full text records that were truly relevant to be reported in the review.

Figure 6.1 1

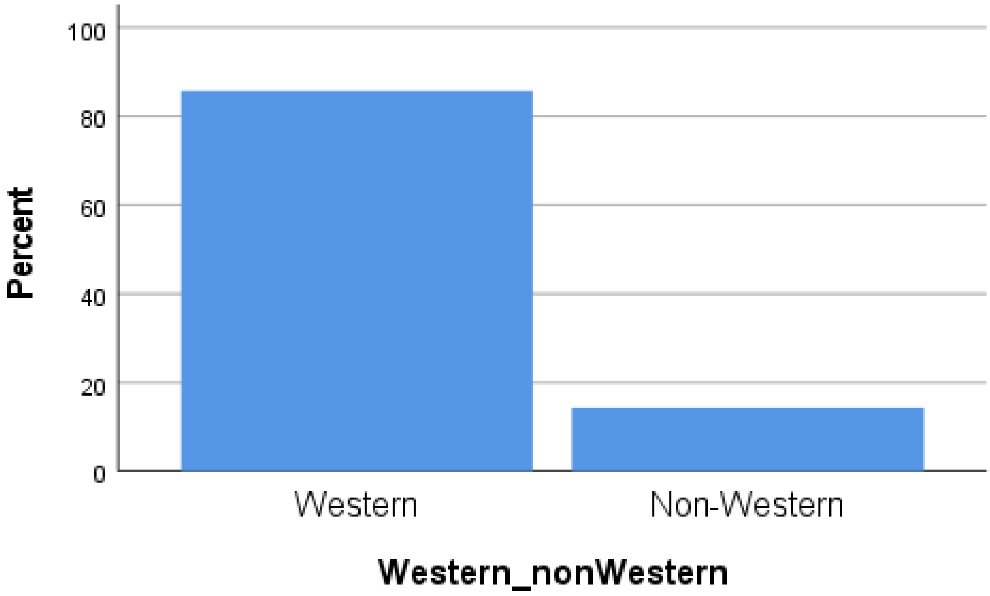
Scope Review Protocol



Stage 2 - A quantitative descriptive representation of the demographic and methodological profiles of selected records that was screed as relevant (n = 74 see Figure 6.1 2) are reported in Figures 6.1 2- 6.1 4 as bar charts presented below.

Figure 6.1 2

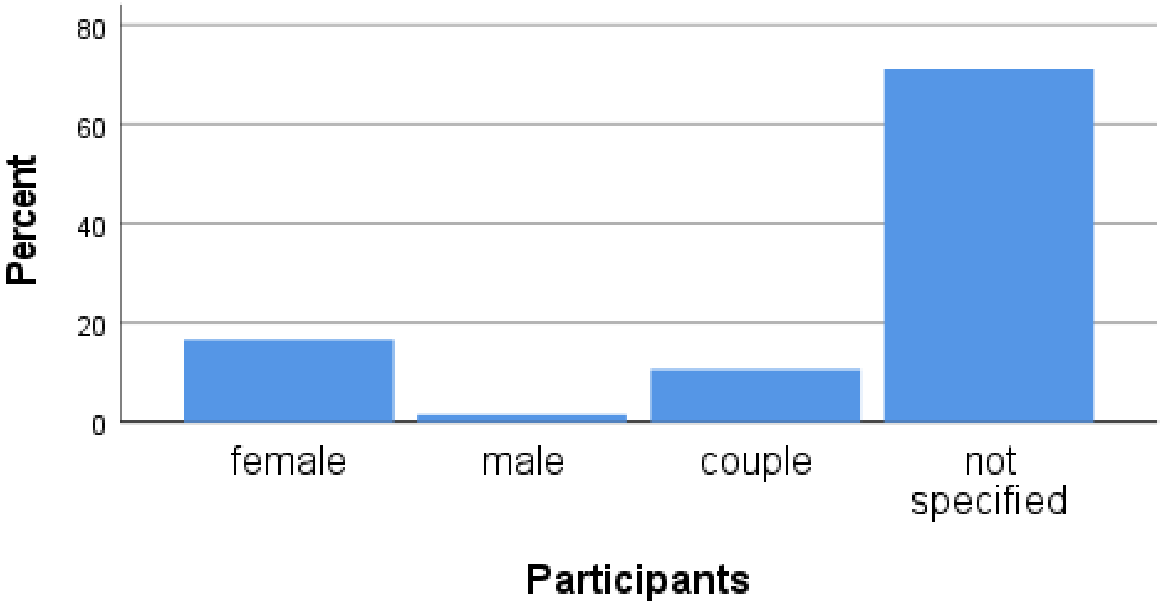
Bar chart representing percentage of the Western and non-Western articles on ART during Covid -19 outbreak (n =74)



As can be seen in the above bar chart over 80% of the studies that have relevance to the key factors related to ART and Covid-19 (up to 2021) was conducted on Western populations.

Figure 6.1 3

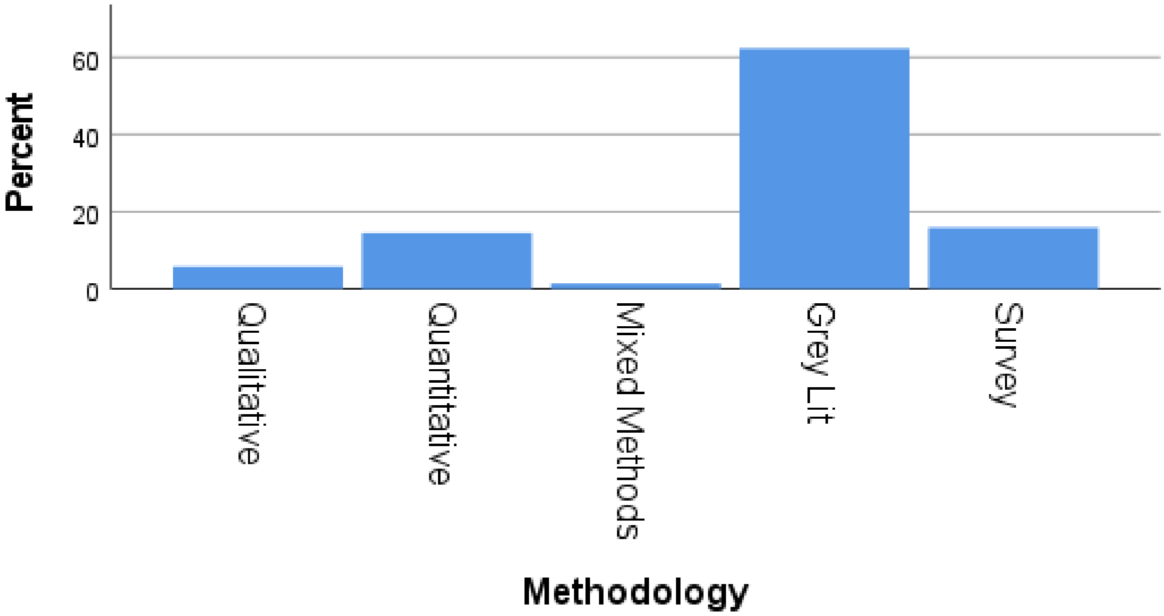
Bar chart representing percentage of demographic features of the participants reported in the articles on ART during Covid -19 outbreak (n = 74).



As can be seen in the above bar chart over 60% of the studies that have relevance to the key factors related to ART and Covid-19 (up to 2021) did not have a clear specification of the participants' gender or marital status breakdown. Less than 20% specifically mentioned female participants were the target whilst a negligible number of studies targeted only males.

Figure 6.1 4

Bar chart representing percentage of Methodologies employed in the Articles on ART during Covid -19 outbreak (n = 74).



As can be seen in the above bar chart over 60% of the studies were considered as ‘grey literature’ outlets with no specific mention of a clear methodology. The remaining studies with well specified methodologies fell far lower than 20% of the overall publications.

6.3.1 Summary of stage 2 findings

Overall, the pattern of descriptive analysis indicates similarities with pre-Covid-19 literature that shows significant number of studies on ART and public perception and behaviour aimed at Western populations. There is, however, the interesting realisation that since the breakdown of Covid-19 there has been a deluge of published materials mainly listed as grey literature and not specifically informative of the population under investigation. This is perhaps an interesting topic for future researchers to see how and why during the short period during the Covid-19 outbreak and subsequent months that followed so many ‘grey literatures’ flowed the date bases as prestigious as Google scholar and PubMed.

Stage 3 - Analysis of the final selection in terms of key findings. Key findings and recommendations were reported verbatim, as written by the authors, following PRISMA guidelines on Table 6.1 1.

Table 6.1 1

Analysis of the final selection for ScR in terms of key findings

Tittle	Author(s)	Key findings and recommendations	Country of study	Number of participants
Fertility patients under COVID-19: Attitudes, perceptions and psychological reactions	Reut Ben-Kimhy, Michal Youngster, Tamar R Medina-Artom, Sarit Avraham, Itai Gat, Lilach Marom Haham, Ariel Hourvitz , Alon Kedem	Patients wished to resume treatment at the time of survey. Furthermore, as the pandemic is stabilising, resumption of treatment should be considered as soon as appropriate according to local conditions.	Israel	168
Assisted reproductive technology, justice and autonomy in an era of COVID-19	Sarah J Martins da Silva , Lisa Campo-Engelstein	Fertility services were significantly curtailed or suspended as an initial response to the coronavirus (COVID-19) pandemic earlier this year, following guidance from European Society for Human Reproduction and Embryology. Although halting assisted reproductive technology (ART) as the pandemic unfolded was ethical, it is difficult to argue with triage of medical care and resources in the face of anticipated overwhelming	N/A Recommendations only	N/A Recommendations only

		demand, this situation resulted in considerable distress.		
Considerations on the restriction of Assisted Reproductive Technology (ART) due to COVID-19	Laura C Gemmell , Zev Williams , Eric J Forman	The rapid rise of novel coronavirus disease 2019 (COVID-19) cases led the American Society for Reproductive Medicine (ASRM) to recommend immediate cessation of all new fertility treatment cycles on March 17, 2020. However, dropout from care during this pandemic remains a serious concern. Fertility treatment is an urgent, essential service that can be performed safely and responsibly during this pandemic.	N/A Recommendations only	N/A Recommendations only
Navigating assisted reproduction treatment in the time of COVID-19: concerns and considerations	Mara Simopoulou, Konstantinos Sfakianoudis, Polina Giannelou, Anna Rapani, Charalampos Siristatidis, Panagiotis Bakas, Nikolaos Vlahos, Konstantinos Pantos	Infertile couples were similarly left in limbo unable to exercise their reproductive autonomy unlike fertile couples-where achieving a pregnancy via natural conception is a matter of decision. When pursuing pregnancy through IVF treatment during the pandemic, distancing and caution have the lead role in an effort to defend the health of the intended parents and future children. To promote patient autonomy along with ethical, moral, and legal duty towards patients, emphasis should be given on ascertaining shared decision-making, and ensuring that an appropriate all-inclusive informed consent is signed prior to initiating any IVF treatment.	N/A Recommendations only	N/A Recommendations only
How to provide fertility treatment during COVID-19 pandemic	M Cruz, Antonio Requena	There is a challenge of balancing between responding to the committed efforts of infertile couples to achieve pregnancy and safeguarding the health of the future parents and their children during this time of pandemic. Ensuring a safe practice both for patients and	N/A Recommendations only	N/A Recommendations only

		staff, it is important to detect asymptomatic patients, so reproductive medicine centres must take special care with screening and testing procedures.		
COVID-19: New adaptation for IVF laboratory protocols	Andrabi SW, Jaffar M, Arora PR	ART services must return to operation, since infertility is also a disease and treatment has to start. Change is mandatory, to set back to successful ART treatment without compromising on quality, and to minimize the spread of COVID-19 among staff and patients; and for this measured and vigilant step are needed.	N/A Recommendations only	N/A Recommendations only
COVID-19 Pandemic and Infertility: Gynecological Dilemma from an Indian Perspective	Avir Sarkar, Pradip Kumar Saha, Aashima Arora	During this critical hour, commencement of infertility treatments including assisted reproductive technologies (ART) will add to additional burden upon the crippled medical fraternity. Fate of thousands of patients seems to hang by a fine thread. In the resource-poor countries, it is our duty to divert maximum medical power to curtail this contagious pandemic rather than focusing on non-urgent treatment services.	N/A Recommendations only	N/A Recommendations only
Infertility remains a top stressor despite the COVID-19 pandemic	Denis A Vaughan, Jaimin S Shah, Alan S Penzias, Alice D Domar, Thomas L Toth	At all three time-points, infertility was noted to be the most frequent top stressor. Coronavirus was noted to be the third most common stressor among the respondents in early March but, at the time of writing, is similar to that of infertility (63% and 66%, respectively). A total of 6% of patients stated that infertility treatment, including IVF, should not be offered during the COVID-19 pandemic. Despite the unprecedented global pandemic of COVID-19, causing economic and societal uncertainty, the stress of infertility remains significant	United States of America	2,202

		and is comparable a stressor to the pandemic itself.		
The issue of infertility in times of COVID-19: what do we know about it?	F Negro, G Napoletano, R Votino, I Banchelli, L Giorgi	In addition to its significance as a social problem, infertility is a medical issue which requires a strict and clearly defined path of diagnosis and treatment, particularly in times of COVID-19, when access to essential care has often been delayed with potentially harmful repercussions for patients seeking to achieve parenthood or to keep their fertility.	N/A Recommendations only	N/A Recommendations only
Influence of COVID-19 pandemic on the psychological status of infertile couples	Veronica Esposito, Erika Rania, Daniela Lico, Sara Pedri, Alessia Fiorenza, Marina Francesca Strati, Alessandro Conforti, Vinenzo Marrone, Andrea Carosso, Alberto Revelli, Fulvio Zullo, Costantino Di Carlo, Roberta Venturella	To evaluate the impact of the COVID-19 pandemic on infertile couples' emotions, anxiety and future plans of COVID-19 pandemic itself and the recommendation to stop ART program generated higher distress levels in infertile couples. The psychological impact of COVID-19 pandemic in infertility patients should not be underestimated, and a specific psychological support should be planned.	Italy	627
The effects of COVID-19 lockdown on lifestyle and emotional state in women undergoing assisted reproductive technology: Results of an Italian survey	Michela Cirilloab Francesca Rizzellob Laura Badolatob Denise De Angelisb Paolo Evangelistib Maria Elisabetta Cocciabc	Observed changes in body weight during lockdown in 80 % of women, and a significant increase in BMI in comparison to that observed before. Increased levels of anxiety and sadness were observed in about 30 %, and of boredom in 25 %. The percentage of women worried about their planning infertility treatment was more than 50 %. Future researchers could help to evaluate if the	Italy	140

	Cinzia Fatiniab	effects of COVID-19 on the emotional state and CV burden in women planning ART would affect ART outcomes.		
Infertility Distress Management in Couples Treated with Assisted Reproductive Techniques (ART) in COVID-19 Pandemic	Fatemeh Hamidi , Farzaneh Babapour , Zeinab Hamzehgardeshi	Currently, the lives of many people around the world are affected by the crisis caused by the outbreak of Covid-19 disease, which despite efforts in many countries to reduce the risk and negative effects of this crisis, the damage and the resulting costs are increasing. This crisis may affect infertile couples, and it may have a negative impact on the mental health and all aspects of an individual's life. Therefore, for distress management, health care providers can use a variety of safe methods such as online counselling, online supports, social networks, peer supports, thereby continuing treatment with a full explanation of the existing conditions and giving the right of choice to couples, especially for infertile couples who are being treated with assisted reproductive techniques (ART) in Covid-19 pandemic.	N/A Recommendations only	N/A Recommendations only
First Trimester Outcomes of Patients Seeking Infertility Care After Covid-19 Infection	Kyle Nguyen Le, MD, Leah M. Roberts, MD, Cheri K. Margolis, MD, Amber M. Klimczak, MD, Nola S. Herlihy, MD, Julia G. Kim, MD, MPH, Brent M. Hanson, MD Emre Seli, M.D., Richard T. Scott Jr., M.D., Marie	In an infertile population, a recent history of COVID-19 diagnosis did not negatively impact pregnancy outcome as measured against a control population. One of the limitations of this study was the relatively small sample size, which may have conflated our data on COVID-19 patients who underwent IUI, whose higher rate of pregnancy is unlikely to be clinically significant. Patients who have had COVID-19 and then proceeded with infertility treatment were no more likely than our control population to have first trimester complications in one fertility	United States of America	178

	D. Werner, MD	clinic. The findings from this study should provide reassurance that attempts at pregnancy do not need to be delayed after recovery from a COVID-19 diagnosis.		
Anxiety Level During the Second Localized COVID-19 Pandemic Among Quarantined Infertile Women: A Cross-Sectional Survey in China	Lian-Bao Cao, Qianjie Hao, Yan Liu, Qiang Sun, Bing Wu, Lili Chen and Lei Yan	To conclude, although the second wave of quarantine during COVID-19 epidemic did not significantly increase anxiety in infertile women, it did lead to an increase in other negative emotions and worse family relationships. Patients with long-term infertility treatment and those who have had IVF are more anxious subgroups. However, quarantine could still lead to an increase in negative emotions and deterioration of family relationships; infertile patients of quarantine are people who need more psychological counselling and care. Patients with long-term infertility treatment and those who need to do IVF are more anxious	China	759

Summary of key themes

Emerging themes from the 14 abstracts reported were psychological distress, and the importance of continuing infertility treatments during Covid-19.

Psychological distress is mentioned several times (9 out of 14). This distress is caused by the Covid-19 pandemic and the pressures triggered when undergoing infertility treatments during this difficult time. The importance of continuing infertility treatment during Covid-19 pandemic was also a theme that arose (6 out of 14). The papers mentioned the importance to continue treatment during this time as it would be detrimental to patients and the scientific community if infertility treatments were to stop. Thus the themes give an insight to the data reported as it allows to understand the extent to which ART perception and behaviours have changed in patients as a result of the Covid-19 pandemic.

6.4 Discussion

The present Scope review study was felt necessary in view of the outbreak of the worldwide pandemic and the impact that it had on many aspects of life in particular issues related to health and wellbeing. It was inevitable that one would expect that peoples' perceptions and behaviour around the world regarding ART has been and will be significantly influenced by the pandemic. Thus, it was felt necessary to choose the starting point of the pandemic followed by a 12 month post this date as a snapshot for a Scope type literature search. This search using the procedures explained in this chapter revealed that a) the pandemic has provided opportunities for a vast amount of research on the topic of ART and Covid-19 mostly subject to no peer review, b) the trend of research more significantly aimed at Western populations still continuing as pre Covid-19 era and c) there is evidence of psychological stress and dilemma about continuing or discontinuing ART treatments amongst the papers reviewed in the Scope study. Of course, with passage of time and people coming into terms with the realities of Covid-19 the above findings may be subject to a degree of changes and different interpretations.

CHAPTER 7 General Discussion

7.1 Preface

In line with most PhD work the opening rationale for the present research is that this is the first scientific work on perceptions and behaviour of the Maya and Ladinos regarding ART. Whilst this aim has been achieved, an addition is needed to the latter. This study was the first and the last scientific work on the perceptions and behaviour of the Maya and Ladinos regarding ART before the outbreak of worldwide Covid-19 pandemic. With no doubt and in view of the vast surge of the scientific and unscientific (see chapter 6) research following the pandemic, there is a realisation that many aspects of life, in particular health related, has to make reference to before Covid-19 and what happens next as a result. Any future study aimed at perception and behaviour of Maya and Ladinos about ART before Covid-19 would be based on retrospective data.

Furthermore, and not intended at the start of the PhD, was a shift in aims of the study namely, how two medical fertility experts in two different continents and two different cultures regard the perception and behaviour of their infertility patients during the peak of the worldwide pandemic (2020-2021). Any future study aimed at perceptions and behaviour of patients towards ART at the peak of the pandemic, would be retrospective and at best, based on evidence of peoples' recollection of the events. Such findings, whilst of interest, has the inevitable weakness of being based on retrospective data. With this context in mind, what follows is the summary and implications of the findings of this prospective investigation.

7.2 Key findings and their implications

The present thesis aimed to examine the impact of ethnicity, religion, age, and education, in perceptions of ART between Maya and Ladinos. Specifically, the more traditional participants like the Maya were anticipated to be holding more conservative views than the more ‘Westernised’ Ladinos.

When it came to age, there were differences in agreeableness of ART medical consequences. What was concluded from the thesis was:

- The older the participants, the more strongly they disagree that there will be medical consequences associated with ART (study 1, quantitative).

Generally, an extensive survey conducted in the UK in 2015 concluded that older respondents were more likely to trust doctors and nurses ‘just about always’ than younger respondents. They argued that this reflects in part greater contact that the older members of the public had with health services and partly due to generational differences in attitudes and expectations regarding ‘professional’ status (Charles, 2015). Thus, one could argue trust could be a factor why participants disagree that there will be medical consequences associated with ART.

When it came to religion, social acceptance seems to be a factor.
What was concluded from the thesis was:

- The followers of the Maya religion/spirituality seem to be more in agreement than other religions that children born by ART will not be socially accepted. The most tolerant seems to be the Catholics (study 1, quantitative).

As documented in chapters 1 and 2 religion and advances in human reproduction have been in continuous battle. An article by Broyde (2005) gives an interesting insight of how all faiths have as their duty of direct interference with advances in human reproductive technologies ‘Every legal, religious, or ethical system has to insist that advances in technologies be evaluated against the touchstones of its moral systems’ (Broyde, 2005). In 2017 a published blog by University of Oxford concluded that Religion and social factors top IVF concerns (University of Oxford, 2017). A strong relationship was reported between ART, religious beliefs and orientations in different countries and furthermore, social acceptance (cultural attitudes towards ART) was found to show relationship with religious beliefs. An example of this is in a country like Italy, where the Catholic Church is openly against ART it has heavily influenced policy agenda and social acceptance. This relates to the findings as The Maya have their own traditional ways of dealing with infertility and may therefore not be socially accepted.

When it came to gender, there were differences in agreeableness of ART social acceptance. What was concluded from the thesis was:

- Female participants overall seemed to more strongly agree that children born by ART will be socially accepted than male participants (study 1, quantitative).

Since the early pioneering study by Baluch et al (1994) in which the attitudes of British and Iranian women examined on various aspects of ART there has been very little research on this topic. Back in 1994, Baluch et al. found significant differences between the two cultures on various aspects of ART, with Iranian women with a more religious orientation to show more negative opinions than British women (Baluch et al., 1994). This was different to findings, as female participants seemed to more strongly agree that children born by ART will be socially accepted in Guatemala.

It seems the finding dating back to several decades ago still stand with regards to studies conducted in Western countries. Fortin and Abele (2016) examined the social and demographic factors that affect American women's attitudes towards assisted reproductive technology (ART) in general, as well as their opinions of specific issues related to ART. The study concluded that whilst women have generally positive attitudes about various aspects of ART religious beliefs, political orientations were significantly associated with women's attitudes towards ART (Fortin & Abele, 2016). One could argue that because Guatemala has western influences women with western influences may feel more positive attitudes towards ART, thus strongly agreeing that children born by ART will be socially accepted in Guatemala.

When it came to ethnicity, there seemed to be differences in agreeableness of ART medical consequences and social acceptance (study 1, quantitative).

What was concluded from the thesis was:

- Ethnicity was a factor that initially showed to be significant for both medical consequences and social acceptance, however stepwise regression showed that this is a factor that has a strong effect in social acceptance. The Maya participants more strongly agree that children born as a result of ART will not be socially accepted than Ladino.

Indeed, people with more traditional and non-Western orientations have shown to continuously demonstrate negative attitude regarding ART intervention, especially in the form of donation. In a 2006 article, entitled “He Won't Be My Son” by Inhorn, highlighted how Suni Muslims will regard their feelings if they have a child born by donation (Inhorn, 2016). Similar expression of great disagreement regarding any forms of ART intervention was also noted amongst In India in a study by Bharadwaj (2003).

In addition to the above analysis what was also noted are the following:

- Whether someone knew an egg donor or not seemed to play an insignificant role in any of the factors in the present study.

- Being a student or not a student seem to be a significant factor in relation to medical consequences, with non-students having a more positive views than students on medical consequences of ART. However, stepwise regression showed that this was an artefact of age and not a significant factor once the variance due to age was accounted for.

- Having children seem to have a significant effect on medical consequences with those having children having more positive perceptions of ART than those that did not, however once stepwise regression was conducted, this factor was found not to be significant.

- Knowing someone with ART showed a significant effect with medical consequences with those knowing someone had more positive perceptions than those that did not. However, stepwise regression showed that this was not a significant factor.

- Marital status was found to be a significant factor for both medial consequences and special acceptance; however, stepwise regression showed that this was not a significant factor.

There have been very few studies in the literature that has directly addressed the above topics on public perceptions and behaviour towards ART. One recent study by Diundeva and Szalma (2018), argued that age and level of education are amongst key factors. For example, younger and more educated participants had higher level of acceptance of ART. This was rather different from the results of the present thesis in which older participants had more acceptance than younger participants.

On the perceived level of knowledge, it was decided to administer the ratings at two different time phrases. Half of the participants before responding to the statements, the other half after responding to the statements. The results showed that generally there is no significant difference between ethnicity and method of administration (before or after). The reason for this change of order in self rating of knowledge was that it is possible participants consider themselves more knowledgeable about a topic after reading a lengthy questionnaire about the topic. Indeed, this might have been a possible reason for the recent findings reported amongst Hungarian participants in which self-rated knowledge about general fertility was high, and this differed significantly by gender. More than four-fifths of the respondents claimed that they were very or knowledgeable about general fertility, and only approximately 1% of the respondents reported no knowledge about general fertility (Szalma & Bitó, 2021). Although this order of administration of self-rating did not seem to affect the present findings, the methodological control was needed to avoid any further criticism of the present findings.

In the present study however, a significant difference in Ethnicity indicated that Maya participants rated their perceived level of knowledge higher than Ladinos. An interesting and somewhat unexpected finding. The reason being that one would have expected that more ‘Westernised’ Ladinos have had more exposure, access and interest in ART and perhaps read more about it than the Maya.

As discussed in Chapter 3 a very recent study amongst different ethnic groups in USA, found that Hispanic and Black Americans scored lower on questions relating to reproductive technologies compared to Caucasian counterparts (Maher et al., 2022). The difference however between the study by Maher et al. (2022) and the present study is that Maher et al. studied actual level of knowledge rather than perceived level of knowledge. An interesting question to pursue in future studies could be to what extent is there a relationship between actual and perceived knowledge. More generally, one can conclude this is a further indication of a history of distrust in government and ‘Western’ medicine. It could also be that The Maya felt they have a good understanding on infertility treatments as they practice traditional infertility treatments within their own communities.

To untangle more deeply the explanation for the above findings, the next section centres on the qualitative analysis of the written responses.

Thematic analysis for the Maya and Ladino written responses diverged and converged in themes. Analysis showed that the Guatemalan participants, both Maya and Ladino, converged in the main themes of psychological factors, Concerns, and ART education. These themes then diverge in their subthemes where analysis was able to shine a light on their distinctions within ethnicities (study 1, qualitative). For example, when Maya and Ladinos converged in the main theme of psychological factors, they diverged in their subthemes as follows:

- One of the Mayas' subtheme for psychological factors was 'self-agency'. This came from the Maya stating that having control over their decisions was important. They stated it is up to them to use ART, and not others to make the decision for them such as family or their religious leaders. Wicclair (1991), argues that medical decision making requires a few conditions, one of them is the ability to imagine possible consequences of different decisions, he states that where risk is high people tend to make more carefully considered decisions. One could argue that The Maya consider undergoing ART an important decision and having control over decision making is important.

- One of the Ladinos' subtheme for psychological factors was 'religious rule breaking', diverging from the Mayas' subtheme. This came from the Ladinos stating that following the advice from their religion was important as they would feel like breaking these rules would be like deceiving their faith. Christianity forbids all practices of ART, although some branches of Christianity may practice it, the Vatican does not accept ART (Serour, 2006). One could argue Ladinos feel ART is in breach of Christian religious rules, and therefore triggers feelings of deceit.

Although the three main themes from the thematic analysis for the Maya and Ladinos converge, like listed above, they diverge in their individual subthemes shining a light on their different perceptions of ART.

Indeed, we found support that any new innovations are resisted especially by people with strong religious beliefs and rooted traditions. In Disruptive Innovation Theory Christensen (1997) maintains that any new innovation may come into conflict with public perceptions due to existing traditions and norms. Not all innovations can be categorised as ‘disruptive’, although they could be revolutionary in other ways. It is thus important that practitioners, scientists and government officials find ways of addressing these issues and any concerns and points of conflict that arise from new innovations with well-established religious and traditions for example ART. This thus led to think how does the perception of the Guatemalan public differ to Guatemalan fertility patients?

To more deeply understand the perceptions of ART in Guatemala, it was important compare and see if fertility treatment patients' perceptions coincide, reflect or differ those of the Guatemalan public. Given the Covid-19 pandemic, it was deemed necessary to study this through the view of a Guatemalan fertility key coordinators' patients' experience. The next section centres on the qualitative analysis of a semi-structured interview. Important to note is that the interviews with Western and non-Western medical practitioners in the UK and Guatemala were conducted at the height of the pandemic and thus has its unique status in the ART literature. Any further interviews with medical practitioners regarding patients’ behaviour and perception during the height of the pandemic would be based on retrospective data.

For study 2 and 3 IPA was utilised to analyse each case study. Each study had a semi-structured interview with a doctor, namely Dr. A based in Guatemala and Dr. B based in the UK. The analyses were able to provide a unique insight into people undergoing infertility treatments in Guatemala and the UK. IPA illuminated several superordinate themes that had corresponding subthemes from the semi-structured interviews. Although they were carried out as separate studies, they both had superordinate themes that diverged and converged. The following is what was illuminated.

- Study 2 and 3 converged with the superordinate theme of ART secrecy was illuminated. In study 2, ART secrecy had the subordinate theme of fear of rejection. This was highlighted in the analysis as Dr. A explained how their patients preferred to keep their fertility treatment a secret in fear of social and personal rejection. The studies here diverge as in study 3, ART only had the subordinate theme of fear of social rejection. This echoed a study conducted by Tallandini et al. (2016), where a systematic review and meta-analysis was carried out, analysing studies published from January 1996 through January 2015, aiming to address secrecy; namely the question of does a genetic link and/or a child's age influence a parent's willingness to talk to a child about how they were conceived? The study concluded that the presence/absence of a biological link and the child's age clearly influences the disclosure process. Fasouliotis and Schenker (1999) and, Golombok et al. (1995) state that families with a child conceived by assisted reproduction may experience overt prejudice not only from the wider community but also from relatives and friends. Thus, suggesting this could be one factor as to why patients of Dr. A and Dr. B chose to engage in ART secrecy.

- Study 2 and 3 converged once more in the superordinate theme of risk factors and Covid-19 impact. Both studies 2 and 3 highlighted the effect Covid-19 had on medical decision making and risk taking. Dr.A stated that patients' risk taking had an impact when they considered the pandemic as they were stressed due to uncertainty. Dr. B stated their patients risk taking was changed by Covid-19 as patients were more risk averse since the pandemic and therefore were more cautious when choosing to undergo infertility treatment. A study 2020 study, conducted by Vaughan et al. that aimed to look into what the psychological impact of the Covid-19 pandemic was on infertility patients. An anonymous online survey was sent to patients who attended a large university-affiliated infertility practice in the USA between 1 January 2019 and 1 April 2020. At three different time-points, participants were asked to note their top three stressors, from a list of 10 commonly reported life stressors. The study concluded that at all three time-points, infertility was noted to be the top stressor. Meaning that one could argue that the stress of infertility remains significant during the pandemic itself, affecting medical decision making.

Study 2 and 3 also diverged in their subordinate themes. The divergence showed in the superordinate themes of religious factors and racial integration issues, illuminated by Dr. As' interview; themes that did not come up in Dr. B's interview.

- The superordinate theme of religious factors arose as Dr. A described his patients' experience with ART and religion, shining light on the feelings of guilt and the fear of god's punishment. Dr. A explained that patient's religion really came into play especially for Ladino patients. When Pir Jalian (2020) studied British and Iranian cultures on ART, they acknowledged that it was a contrast of Islam (Iran) vs Christian (UK), and thus it was hard to tell that any perceptions are due to deeply rooted religious beliefs or cultural constructs. This demonstrated differently as in study 2 the superordinate theme was deeply rooted in religion. A paper presented by Schenker (2005) presented the attitude of monotheistic religions to therapeutic procedures, such as IVF–embryo transfer, spermatozoa, oocytes, embryo donation, cryopreservation of genetic material, surrogacy, posthumous reproduction, gender preselection, reproductive and therapeutic cloning. When addressing Christian faith, the paper concluded that the beginning of life is at conception, the embryo has moral status as a human being, and thus most assisted reproductive technologies are forbidden. One could argue that as Guatemala is mainly a Catholic and Protestant country, religious factors come into play when undertaking ART.

- Racial integration issues was also a superordinate theme in study 2 that diverged form study 3. This was elaborated on as Dr. A described their patients experience with what is racially accepted, as well as what can and cannot happen within races, especially when it comes to forming a family. A study conducted on whether phenotype, captured by skin colour, is a significant dimension of ethno-racial status in Guatemala found that respondents’ skin colour is negatively associated with ladino self-identification. Indeed, several cultural or physical characteristics suggested that for individuals perceived as indigenous, whiter traits ‘improve’ their status by ‘softening’ their indigenousness (Paredes, 2017). Thus, one could argue that race is a factor taken into consideration for Guatemalan patients undergoing ART.

- Themes diverged once more with the superordinate theme of Self-agency. This superordinate theme followed with a subordinate theme of commitment to treatment. Dr. B expressed that the patients they treat are very committed to treatment. Even when faced with financial obstacles and failed cycles, the patients remained committed to their decision of undergoing infertility treatment. A study investigating the perceptions of infertility patients and the factors correlating with their psychological distress, following suspension of fertility treatments during the Covid-19 pandemic found that most patients preferred to resume treatment given the chance, as feeling helpless was associated with higher distress (Ben-Kimhy, 2020). One could argue that commitment to the treatment and the importance of continuing treatment is a factor when undergoing ART.

The final study was Study 4 which was a scope review. This review was aimed to examine the gap left between a host of published work on ART perceptions and behaviour reported before Covid-19 and what impact Covid-19 had on the latter. In particular to what extent the public's perception and behaviour about Covid-19 has changed as a result of the worldwide pandemic. The following is what was illuminated from the scope review.

- The overall review revealed that the pattern of descriptive analysis indicates similarities with pre-Covid-19 literature, which shows significant number of studies on ART and public perception and behaviour aimed at Western populations and not many for non-Western populations.

- Psychological distress due to Covid-19 circumstances whilst undergoing fertility treatment was mentioned several times, as well as the importance of continuing infertility treatment during Covid-19 pandemic as stopping treatment would have a detrimental to patients and the scientific community if infertility treatments were to stop.

This Scope review study has provided the opportunity to gain insight from a vast amount of research on the topic of ART and Covid-19, although mostly subject to no peer review. The review also illuminated trends of research available was more significantly aimed at Western populations, still like pre Covid-19 era. This review also shed light on the psychological stress and dilemma about continuing/discontinuing ART treatments amongst the papers reviewed in the Scope study.

7.2.1 Conclusion and take-home message and recommendations of the research

Perhaps reminiscence to an ethnographic approach to impact research one must reflect not only on the ‘data’ and the statistical and qualitative analyses to draw conclusions and recommendations, but the overall experiences gained as a doctoral student. The time spent with Maya and Ladino communities for data collection, taking notes while visiting participants and meeting with their wider communities and their daily life, completing self-diaries of daily events from the start of the PhD, gaining the agreement of eminent medical experts to take part in the study and finally being a doctoral student before, during and post Covid-19 necessitates an extended set of conclusions and recommendation.

1. **Ethics communities and guidelines should allow some flexibility and diversion from the protocol to enable a more sincere information collection**

Often during the process of data collection, thousands of miles away from the home base, and meeting with various people in the community, one gets to learn and hear ‘stories’ that could be used as part of the data collection processes. However as this would divert from the ethical protocol approved, one has to listen, reflect but not document. Perhaps some flexibility to record, collect data at specific time during research not entirely in line with the signed ethical approval would help to capture this rich body of information. For example, a Maya woman who was traditional birth attender (comadrona) was explaining to me about the different types of fertility treatment her community has. She went on to talk about how she, and women of the generations before her, all received a spiritual calling to be traditional birth attendants. One feels that such rich information could have been used.

2. **Literature search whilst of benefit and providing rationale for the study does not prepare you for what to expect when attempting to begin your research.**

When reading previously published work (literature review) especially on a sensitive health related topic, no mention is made of difficulties particularly participant participation and sincerity of responses. It often comes across that just getting the materials in place and ethical approval is enough to ensure a smooth data collection. The reality of asking sensitive questions about fertility from a community that are not accustomed to research intervention, is very much different. Considerable time and effort are needed to gain the trust of the community, to ensure sincerity of responses and to leave them with the feeling that their contribution has been very valuable and appreciated.

3. The Western/non-Western divide in research on ART is still very much noticeable and the categorisation could be misleading.

As seen in in results of religion and perceptions and behaviour towards ART what one would expect from ‘Catholics’ regarding acceptance of ART is very different from the Maya with Christian influences. It is noticeable that the religion aspects of ART were mainly studies in a Western context with Western interpretation of the results. It is a realisation of the present author that ‘labels’ and ‘classifications’ of Western vs non-Western, or different religious orientations may not be meaningful unless they are studied in its own merit. Furthermore, as seen from the Scope review, significant research on topics relating to people’s health is aimed at Western people with Western narrative of the data and Western implications and recommendations. Not much to generalise to people in far corners of the world unless being subject to scientific investigation comparable to Western population.

4. Would I do this research differently?

This would be hard to tell as the present thesis aims and intension were at times affected by the world-wide pandemic and other factors hindering data collection in a country not accustomed to external research intervention. In an ideal world of scientific research, one would have clear and effective access to participants, materials, collaboration and participations of all parties involved. In that case I would have had as many participants as I could get my hands on, engage in follow up intervention if needed and so on. In reality when aiming at populations not as accustomed to research intervention as Western populations are in a land far away from one’s own research base (and when unexpected worldwide tragic events happen) it would be hard to say how if I have to run this research again what plan I would have in mind. It has to be one of aim high and hope for the best.

5. **What message would I give to a Guatemalan couple intending to do ART**

There is clear evidence that in most aspects there is an ethnic divide in perceptions and behaviour, and anyone involved in ART must be aware. This also ties with the issue of medical ethics and the extent to which greater care and consideration should be taken into account before introduction of ART for ethnic groups such as the Ladinos, but especially the Maya. Would the desire to have a child overcome possible consequences of social isolation and/or religious conflicts? Or will there be a regret of what has been achieved inevitably with considerable cost and distress.

7.2.3 Limitations and strengths

The limitations of the present thesis can be inferred from the issues discussed throughout the thesis regarding lack of any previous published materials on perception and behaviour of Maya and Ladinos and difficulties of accessing participants and the pandemic that came as a surprise halfway through the study. It is with no doubt that having more participants, having more time and opportunities to elaborate and discuss topics with participants in the 3 studies reported would have enriched more the findings and their interpretations.

One of the strengths of the present thesis lays in the interpretation of the qualitative analysis. Having roots in Guatemala and understanding participants' culture and language allowed for in-depth comprehension of participant responses. This was achievable by remaining as grounded as possible to the data, ensuring the correct steps were taken during analysis, and by acknowledging and correcting bias when needed.

7.2.4 Reflexivity

Throughout the thesis I was able to use several outlets to reflect on my research. I mainly had formal and informal conversations with my supervisors, as well as kept a journal where I occasionally wrote down my thoughts and feelings.

I was able to recognise my overall positionality whilst doing research by acknowledging my background. Being a Guatemalan Ladina, I am aware that it places me in a position of privilege. My background gave me an advantage when conducting research in Guatemala as I feel like I was able to obtain participants trust more easily than a researcher without any connection to Guatemala. Growing up in Guatemala, and having so many past experiences there, shaped the way I approached participants. This also made me reflect on my bias as my parents went through infertility treatments (both traditional and ART). Although being unbiased is impossible, I tried to remain focused on the research, and true to the participants' voice as much as possible. I specifically found my meetings with my supervisors very helpful for acknowledging bias as I felt our conversations were grounding.

During my research my supervisors helped keep me true to my values of honesty, objectivity, openness, and fairness. I would often find myself asking, is the way I'm approaching my research in line with my values? If I found myself dwelling on my research values, discussions with my supervisors always gave me more insight as to how to approach such questions.

I also reflected on my positionality as a young Ladina woman. I contemplated with my own views on starting a family and the effects this may have on my research. As a feminist, I also thought about my position on machismo and caballerismo. I was able to acknowledge that although I do not agree with machisomo, growing up in Guatemala gave me an insight of how these believes and values are imbedded in society and are not all negative. Many positive aspects, like caballerismo, are celebrated and encouraged as well.

I was able to experience somewhat ‘reconnection’ to my roots after going to Guatemala for study 1 data collection. I felt a sense of familiarity, belonging and comfort. I couldn’t help but reflect on my feelings of disappointment and was saddened as not much changed in terms of prejudice, racism, and the stigmatisation of the Indigenous people of Guatemala. These feelings of disappointment were shared by many Maya and Ladino people I spoke to, many of them making a point of stating that something had to change. I reflected on the fact that on ‘paper’ things should have changed due to the peace agreement, however nearly 30 years later, prejudice, racism, and the stigmatisation of the Indigenous people still occurs.

As the Covid-19 pandemic broke out, feelings of uncertainty were at an all-time high for many. This again allowed me to reflect on my positionality of privilege. I was able to acknowledge that living in the UK, a country that has strong social security compared to Guatemala, allowed me to carry on with research. Many people had to prioritise many aspects of their lives, however I was able to keep my research a priority through such turbulent times. This was something that I was thankful for.

7.2.5 Epilogue

The thesis opening remark was “Today, encouraged by the rapid advances in the field of assisted reproduction that took place in the past decades, we dare to predict that the field will continue to evolve, and evolve rapidly”. Indeed, the field is evolving and evolving rapidly. With each new and novel research, there is an insight of the continuation of human battle with infertility. The understanding of people’s perception and behaviour towards ART from a universal, as well as from a culture specific perspective will deepen with each new and novel research.

CHAPTER 8 References

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CHAPTER 9 Appendices

Appendix A- English and Spanish versions of the questionnaire employed in study 1 and 2

Questionnaires (Study 1)

English version of the questionnaire employed for study 1 – The questionnaire is also to Spanish.

The aim of this questionnaire is to assess Guatemalan men and women's perception towards ART and the impact it may have on the child and the couple who have a child conceived via one of the two most popularly used ART treatment options namely; In vitro Fertilisation - IVF and conception via egg donation.

Following completion of a brief demographic information section there will be a section explaining IVF and Egg Donation procedures. This is then followed by 10 short statements. Please read each statement carefully and decide which response best describes how you feel about it by choosing either Strongly agree, Agree, Disagree or Strongly disagree. Please respond to every statement. It is important that you answer each question as honestly as possible. It is important for us to also hear the reasons for your choice and therefore we would appreciate if you give a brief explanation regarding your selected response below each statement. All information will be treated with strictest confidence.

This is a brief explanation for two ART treatments:
In Vitro Fertilization (IVF): Is a fertility treatment procedure in which the couple who have not achieved pregnancy by natural means will have to attend the clinic for well over two weeks to undergo a treatment in which the woman's egg is fertilized by the man's sperm in the laboratory. The resulting embryo is then transferred into the womb and approximately less than half of the cases will result in pregnancy.

Egg Donation: Is a fertility treatment procedure in which the couple who have not achieved pregnancy by natural means (particularly because of the women's poor egg quality or age) must attend a clinic to undergo a treatment in which the woman will receive a donated egg for the purpose of receiving reproduction assistance. The egg will have been fertilized in a laboratory and the resulting embryo will be placed in the woman's uterus to complete the remaining development process.

Demographic Information:
Age:
Gender:
Religion:
Catholic Church [ ]
Christian Orthodox [ ]
Non-Religious [ ]
Evangelic Christianity [ ]
Mayan Spirituality [ ]
Other:_____________
Religious strength:

Practice very frequently [ ] Practice frequently [ ] Practice sometimes [ ]
Practice very little [ ] I don’t practice [ ]

Ethnicity:

Ladino/Mestizo [ ] Maya [ ] Other:____________

Marital status:

Single [ ] Married [ ] Divorced [ ] Separated [ ] Widowed [ ]

The higher degree you achieved:

No formal education [ ] Diploma [ ] Foundation degree [ ] Bachelor’s degree [ ] Master’s degree [ ] Doctoral [ ]

Occupation:

Are you currently a student? Yes [ ] No [ ]

Do you have any children? Yes [ ] No [ ]

Do you know anyone who has IVF treatment? Yes [ ] No [ ]

Do you know anyone who has egg a child by egg donation? Yes [ ] No [ ]

1- Before embarking on any of the ART techniques the couple should consider what their religion has to say about their actions

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

2- As the costs of ART treatment is too high and the chance of success is relatively low the couples should themselves cover the costs not the government

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

3- There should be specific educational programmes in the schools for children to learn about the ART techniques

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

4- Considerable funding should be directed to scientific research on the psychological, medical and social consequences of children born as a result of ART

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

5- There should be strict procedures regarding egg donation procedures in which the donor should be of the same ethnic origin as the recipient

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

6- Because the embryo is fertilised in the lab the child born by this technique may exhibit the following complications more often than a child who is conceived naturally:

-Have a lower IQ:

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

-Chance of being Autistic:

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

-Develop yet unknown medical complications:

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]

Please give your reasons:

-The likelihood of being infertile:

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

7- A child born as a result of egg donation should be told about the precise nature of their conception

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

8- A child born as a result of egg donation will have more psychological problems than naturally conceived child

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

9- Parents of a child born as a result of egg donation will not be very welcomed in the society

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

10 - Donor egg conceived children may experience overt prejudice from the wider community, relatives and friends

Strongly agree [ ] Agree [ ] Disagree [ ] Strongly Disagree [ ]
Please give your reasons:

If there is anything you will like to add that had not been mentioned regarding this topic, please mention it below:

If you are happy to be contacted again for possible follow-up research, please write your name and email address in capital letters below.

How much knowledge do you think you have about issues related to Assisted Reproductive Technologies?
Please answer on the scale below:

Not at all								**A considerable amount**	
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

If you answer is a 5 or higher, please state where you obtained this information below:

Name Email Address

Thank you for your help.

Appendix B- Consent, Information, and Debriefing Sheets for Study 1 and 2 in English and Spanish

Information sheet

Psychology Department
Middlesex University
Hendon
London NW4 4BT

Cecilia Isabel Urrutia CU084@live.mdx.ac.uk

Guatemalan's Perceptions of Assisted Reproductive Technologies (ART) and its possible consequences on the conceived child and the couple.

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

The aim of this study is to assess Guatemalan's perception towards ART and the impact it may have on the child and the couple who have a child conceived via one of the two most popularly used ART treatment options namely; In Vitro Fertilisation - IVF and conception via egg donation.
In Vitro Fertilization (IVF): Is a fertility treatment procedure in which the couple who have not achieved pregnancy by natural means will have to attend the clinic for well over two weeks to undergo a treatment in which the woman's egg is fertilized by the man's sperm in the laboratory. The resulting embryo is then transferred into the womb and approximately less than half of the cases will result in pregnancy.
Egg Donation: Is a fertility treatment procedure in which the couple who have not achieved pregnancy by natural means (particularly because of the woman's poor egg quality or age) will have to attend the clinic for well over two weeks to undergo a treatment in which a donor's egg is fertilized by the man's sperm in the laboratory. The resulting embryo is then transferred into the recipient.
As there is very little research on what the general public view about having a child by either of the two methods this research is aimed at an insight into this topic.
The research will take place at Galileo University. You will be given a basic demographic questionnaire followed by a questionnaire of 10 statements. There are no correct or incorrect answers it is simply a statement to assess public perception about the subject of conception by ART. For example, "before embarking on any of the ART techniques the couple should consider what their religion has to say about their actions". You are expected to circle/tick one of the following options: Strongly agree, Agree, Disagree, Strongly Disagree and give a couple of sentences for the reasons of your choice. The completion of the questionnaire will not take longer than 15 minutes.
You will be given a copy of this information sheet and will be asked to sign a consent form before taking part in the research.
Participation in this research is entirely voluntary. You do not have to take part if you do not want to. If you decide to take part, you may withdraw at any time during your participation without giving a reason. You may withdraw your data up until data analysis begins in 2019.

All information about you will be kept strictly confidential. Your data will be given a research code. Only the researcher and the supervisor will have access to the data. All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The Middlesex Psychology Department's Ethics Committee have reviewed this proposal.

If you have any further questions regarding your participation in this research, please contact the researcher or the supervisor using the contact details listed below.

Researcher: Cecilia Isabel Urrutia **Supervisor: Dr Bahman Baluch**
CU084@live.mdx.ac.uk b.baluch@mdx.ac.uk
Middlesex University Middlesex University
Psychology Department Psychology Department
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Informed consent

Middlesex University School of Science and Technology
Psychology Department
Written Informed Consent

Guatemalan's Perceptions of Assisted Reproductive Technologies (ART) and its possible consequences on the conceived child and the couple – 2019

Researcher's name: Cecilia Isabel Urrutia
Supervisor's name and email*:* Dr Bahman Baluch B.Baluch@mdx.ac.uk

- I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.
- I have been given contact details for the researcher in the information sheet.
- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from participating in the project at any time without any obligation to explain my reasons for doing so.
- I understand that I can ask for my data to be withdrawn from the project until data analysis begins in May 2019
- I further understand that the data I provide may be used for analysis and subsequent publication, and I provide my consent that this may occur.

If you would be willing to be contacted again at a later date for any follow up research, please tick here [ ]

__________________________ ______________________________
Print name Sign Name

Date: ___________________________

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ____________

Debriefing

Psychology Department
Middlesex University
Hendon
London NW4 4BT

Researchers name: Cecilia Isabel Urrutia
Date: April 2019

Study title: Guatemalan's Perceptions of Assisted Reproductive Technologies (ART) and its possible consequences on the conceived child and the couple.

We would like to begin by thanking you for your contribution to this study and to the research regarding egg donation in general.

The present study was designed to examine Guatemalan's perception towards ART and the impact it may have on the child and the couple who have a child conceived via one of the two most popularly used ART treatment options namely, In Vitro Fertilisation - IVF and conception via egg donation. There is very little research on this topic, particularly on the Guatemalan population. Generally, research has shown that factors such as religion, ethnicity, costs, possible consequences and participant's age and gender may have an impact on how people may regard undergoing fertility treatment via IVF or egg donation. A recent study for example by Pir Jalian (2017) has shown that Iranians are generally not supportive of a child being born by egg donation and believe that it may have an impact on the child in the society. This is in spite of the fact that having a child in a non–Western country such as Iran is the prime aim for all couples.

The questionnaires you completed will help us to have a clearer perspective on what the view is on conception by ART amongst the Guatemalan population and should provide valuable information for practitioners and couples involved in infertility treatment

Please use the contact information provided to get in touch with the researcher or the supervisor should you have any questions about this study.

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Hoja de información

Departamento de Psicología
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London NW4 4BT

Cecilia Isabel Urrutia CU084@live.mdx.ac.uk

Percepciones de las Tecnologías de Reproducción Asistida (ART) de Guatemala y sus posibles consecuencias para el niño concebido y la pareja

Esta siendo invitado a participar en una investigación para un estudio. Antes de que decida participar, es importante que entienda por qué se realiza la investigación y en qué consistirá. Tómese su tiempo para leer detenidamente la siguiente información y discútala con otros si lo desea. Por favor, pregunte si hay algo que no esté claro o si desea más información. Tómese su tiempo para decidir si desea o no participar.

El objetivo de este estudio es evaluar la percepción de los guatemaltecos con respecto a los ART y el impacto que puede tener en el niño y en la pareja que tiene un hijo concebido a través de una de las dos opciones de tratamiento con ART más utilizadas popularmente; Fertilización in vitro - IVF y concepción mediante donación de óvulos.

Fertilización in vitro (IVF): Es un procedimiento de tratamiento de fertilidad en el que la pareja que no ha logrado el embarazo por medios naturales, tendrá que asistir a la clínica durante más de dos semanas para someterse a un tratamiento en el que el esperma del hombre fecunde el óvulo de la mujer en el laboratorio. El embrión resultante se transfiere a la matriz y aproximadamente menos de la mitad de los casos dará lugar al embarazo.

Donación de óvulos: Es un procedimiento de tratamiento de fertilidad en el que la pareja que no ha logrado el embarazo por medios naturales (especialmente debido a la mala calidad o edad del óvulo de las mujeres) tendrá que asistir a la clínica durante más de dos semanas para someterse a un tratamiento en el que el óvulo del donante es fertilizado por el esperma del hombre en un laboratorio. El embrión resultante se transfiere al receptor.

Como hay muy poca investigación sobre la opinión del público en general acerca de tener un hijo por cualquiera de los dos métodos, esta investigación tiene como objetivo conocer este tema.

La investigación se llevará a cabo en la Universidad Galileo. Se le dará un cuestionario demográfico básico seguido de un cuestionario de 10 afirmaciones. No hay respuestas correctas o incorrectas, es simplemente una declaración para evaluar la percepción pública sobre el tema de la concepción por parte de ART. Por ejemplo, "antes de embarcarse en cualquiera de las técnicas ART, la pareja debe considerar lo que su religión tiene que decir sobre sus acciones". Se espera que encierre en un círculo / marque una de las siguientes opciones: Muy de acuerdo, De acuerdo, En desacuerdo, Muy en desacuerdo y dé un par de oraciones por las razones de su elección. La finalización del cuestionario no llevará más de 15 minutos.

Se le entregará una copia de esta hoja de información y se le pedirá que firme un formulario de consentimiento antes de participar en la investigación.

La participación en esta investigación es totalmente voluntaria. No es necesario que participes si no quieres. Si decide participar, puede retirarse en cualquier momento durante su participación sin dar una razón. Puede retirar sus datos hasta que el análisis de los datos comience en 2019..

Toda la información sobre usted se mantendrá estrictamente confidencial. Sus datos recibirán un código de investigación. Solo el investigador y el supervisor tendrán acceso a los datos. Todas las propuestas de investigación con participantes humanos son revisadas por un Comité de Ética antes de que puedan continuar. El Comité de Ética del Departamento de Psicología de Middlesex ha revisado esta propuesta.

Si tiene más preguntas sobre su participación en esta investigación, comuníquese con el investigador o el supervisor utilizando los datos de contacto que se enumeran a continuación.

Investigador: Cecilia Isabel Urrutia **Supervisor: Dr Bahman Baluch**
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Reunión informativa

Departamento de Psicologia
Middlesex University
Hendon
London NW4 4BT

Nombre de la investigadora: Cecilia Isabel Urrutia
Date: Abril 2019

Título del estudio: Percepciones de las tecnologías de reproducción asistida (ART) en Guatemala y sus posibles consecuencias para el niño concebido y la pareja.

Nos gustaría comenzar agradeciéndole por su contribución a este estudio y a la investigación sobre la donación de óvulos en general.

El presente estudio fue diseñado para examinar la percepción de Guatemala sobre los ART y el impacto que puede tener en el niño y en la pareja que tiene un hijo concebido a través de una de las dos opciones de tratamiento con ART más utilizadas popularmente; Fertilización in vitro - IVF y concepción mediante donación de óvulos.

Hay muy poca investigación sobre este tema, particularmente sobre la población guatemalteca. En general, las investigaciones han demostrado que factores como la religión, el origen étnico, los costos, las posibles consecuencias y la edad y el género de los participantes pueden tener un impacto en la forma en que las personas pueden considerar someterse a un tratamiento de fertilidad mediante FIV o donación de óvulos. Un estudio reciente, por ejemplo, por Pir Jalian (2017) ha demostrado que los Iraníes generalmente no apoyan que un niño comience a nacer con la donación de óvulos y creen que puede tener un impacto del niño en la sociedad. Esto es a pesar del hecho de que tener un hijo en un país no occidental como Irán es el objetivo principal de todas las parejas.

Los cuestionarios que completó nos ayudarán a tener una perspectiva más clara de lo que está en juego con la concepción de ART entre la población guatemalteca y deben proporcionar información valiosa para los profesionales y las parejas que participan en el tratamiento de la infertilidad.

Utilice la información de contacto proporcionada para ponerse en contacto con el investigador o el supervisor si tiene alguna pregunta sobre este estudio.

Investigador: Cecilia Isabel Urrutia **Supervisor: Dr Bahman Baluch**
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Formulario de consentimiento informado

Escuela de Ciencia y Tecnología de Middlesex University
Departamento de Psicología
Consentimiento Informado Por Escrito

Título de estudio y curso académico:
Percepciones de las Tecnologías de Reproducción Asistida (ART) de Guatemala y sus posibles consecuencias para el niño concebido y la pareja – 2019
Nombre del investigador: Cecilia Isabel Urrutia
Nombre y correo electrónico del supervisor: Dr Bahman Baluch B.Baluch@mdx.ac.uk

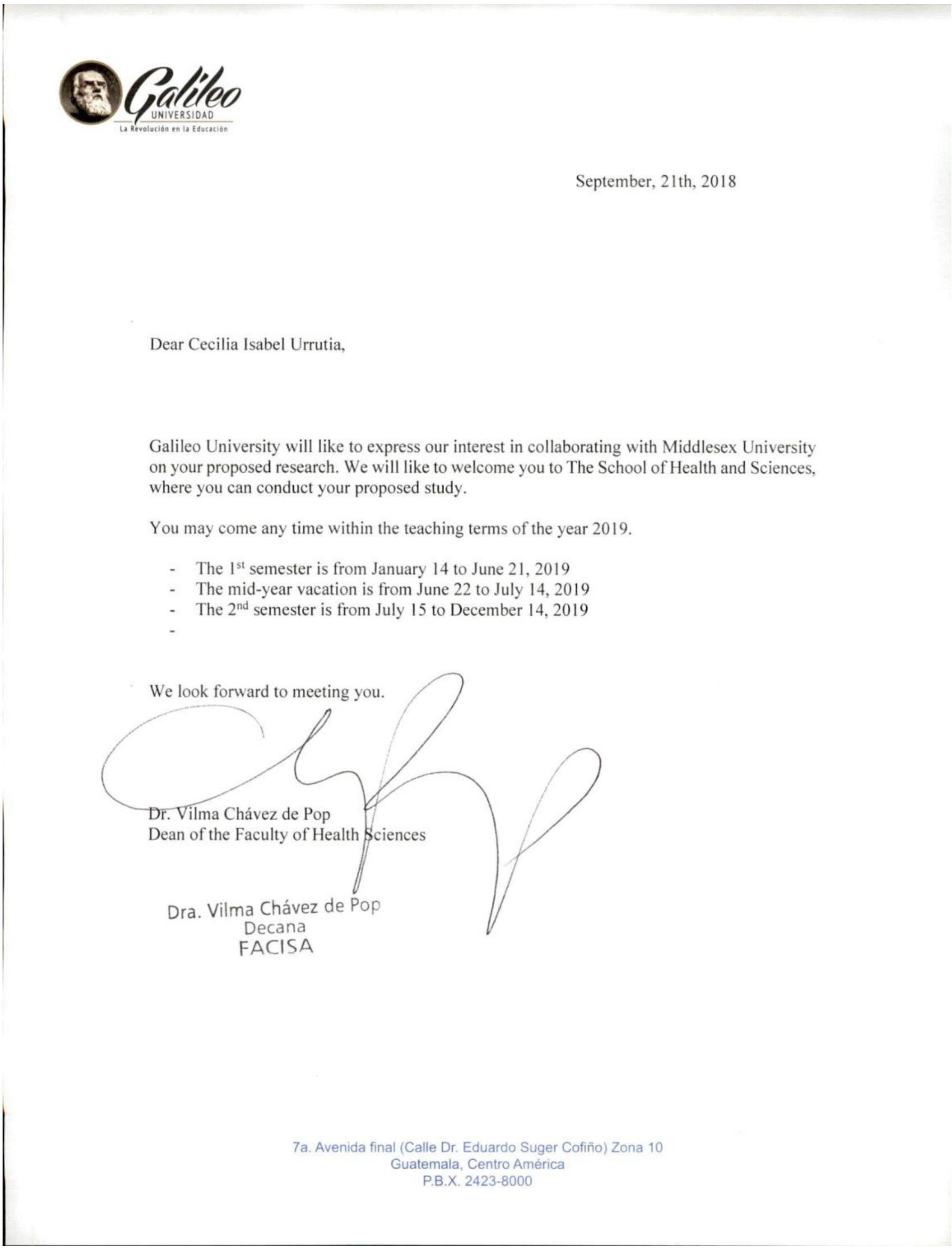
- He entendido los detalles de la investigación según lo explicado por el investigador en la hoja de información
- Me han dado los datos de contacto del investigador en la hoja de información
- Entiendo que mi participación es totalmente voluntaria, que los datos recopilados durante la investigación no serán identificables, y tengo el derecho de retirarme de participar en el proyecto en cualquier momento sin obligación de explicar mis razones para hacerlo
- Entiendo que puedo solicitar que mi información sea retirada del proyecto hasta que el análisis de datos comience en Noviembre de 2019
- Además, entiendo que los datos que proporciono se pueden usar para el análisis y la publicación posterior, como una tesis de postgrado, y dar mi consentimiento para que esto ocurra.

_______________________ _____________________
Nombre escrito Nombre firmado

Fecha:___________

Para el participante: Los datos pueden ser inspeccionados por el Presidente del panel de Ética de Psicología y el Presidente del Comité de Ética de la Facultad de Ciencias y Tecnología de la Universidad de Middlesex, si así lo requieren las auditorías institucionales sobre la corrección de los procedimientos. Aunque esto sucedería en estricta confidencialidad, marque aquí si no desea que sus datos se incluyan en las auditorías:_______.

Appendix C- Letters Granting Access to Subjects and Data Collection for Study 1 and 2



Galileo
UNIVERSIDAD
La Revolución en la Educación

September, 21th, 2018

Dear Cecilia Isabel Urrutia,

Galileo University will like to express our interest in collaborating with Middlesex University on your proposed research. We will like to welcome you to The School of Health and Sciences, where you can conduct your proposed study.

You may come any time within the teaching terms of the year 2019.

- The 1st semester is from January 14 to June 21, 2019
- The mid-year vacation is from June 22 to July 14, 2019
- The 2nd semester is from July 15 to December 14, 2019
-

We look forward to meeting you.

Dr. Vilma Chávez de Pop
Dean of the Faculty of Health Sciences

Dra. Vilma Chávez de Pop
Decana
FACISA

7a. Avenida final (Calle Dr. Eduardo Suger Cofiño) Zona 10
Guatemala, Centro América
P.B.X. 2423-8000

Letter of acceptance for research at San Carlos University in Guatemala

Licenciada Urrutia:

El señor Director M.A. Mynor Lemus conoció el oficio enviado por la Licenciada Cecilia Isabel Urrutia, ha expresado su interés en colaborar con las propuestas presentadas por la Licda. Urrutia, y que será bienvenida en la Escuela de Ciencias Psicológicas en el momento que desee.

Se espera contar con su valiosa visita.

Por cuestiones de programación le comunico que para el 2019 las actividades se realizan de la siguiente manera:

1. Inicio de actividades de 1er. semestre 15 de enero finalizan el 15 de mayo
2. Junio vacaciones de medio año
3. inicio de 2do. semestre 15 de julio y finaliza en octubre

Atentamente
Angela De León
Secretaria de Dirección

Translated to English from Spanish

Graduate Urrutia,

The Director M.A. Mynor Lemus acknowledged the official mail sent by the graduate Cecilia Isabel Urrutia, and has expressed his interest in collaborating with the proposals presented by the graduate Urrutia, he says she is welcomed in the school of psychology sciences in the moment she wishes.

We await her valuable visit.

For programming reasons I communicate the following events and how they take place for 2019:

1. Start of activities for the 1st semester 15 of January and end 15 of May
2. June vacations for the middle of the year
3. Start of activities for the 2nd semester 15 of July and end in October

Attentively,

Angela De Leon

Admissions secretary

Middlesex University London

Psychology REC

The Burroughs
Hendon
London NW4 4BT

Main Switchboard: 0208 411 5000

12/10/2018

APPLICATION NUMBER: 4884

Dear Cecilia Isabel Urrutia,

Re your application title: Guatemalan perceptions of Assisted Reproductive Technologies - Quantitative quasi experimental

Supervisor: Bahman Baluch

Thank you for submitting your application. I can confirm that your application has been given approval from the date of this letter by the Psychology REC.

Although your application has been approved, the reviewers of your application may have made some useful comments on your application. Please look at your online application again to check whether the reviewers have added any comments for you to look at.

Also, please note the following:

1. Please ensure that you contact your supervisor/research ethics committee (REC) if any changes are made to the research project which could affect your ethics approval. There is an Amendment sub-form on MORE that can be completed and submitted to your REC for further review.
2. You must notify your supervisor/REC if there is a breach in data protection management or any issues that arise that may lead to a health and safety concern or conflict of interests.
3. If you require more time to complete your research, i.e., beyond the date specified in your application, please complete the Extension sub-form on MORE and submit it your REC for review.
4. Please quote the application number in any correspondence.
5. It is important that you retain this document as evidence of research ethics approval, as it may be required for submission to external bodies (e.g., NHS, grant awarding bodies) or as part of your research report, dissemination (e.g., journal articles) and data management plan.
6. Also, please forward any other information that would be helpful in enhancing our application form and procedures - please contact MOREsupport@mdx.ac.uk to provide feedback.

Good luck with your research.

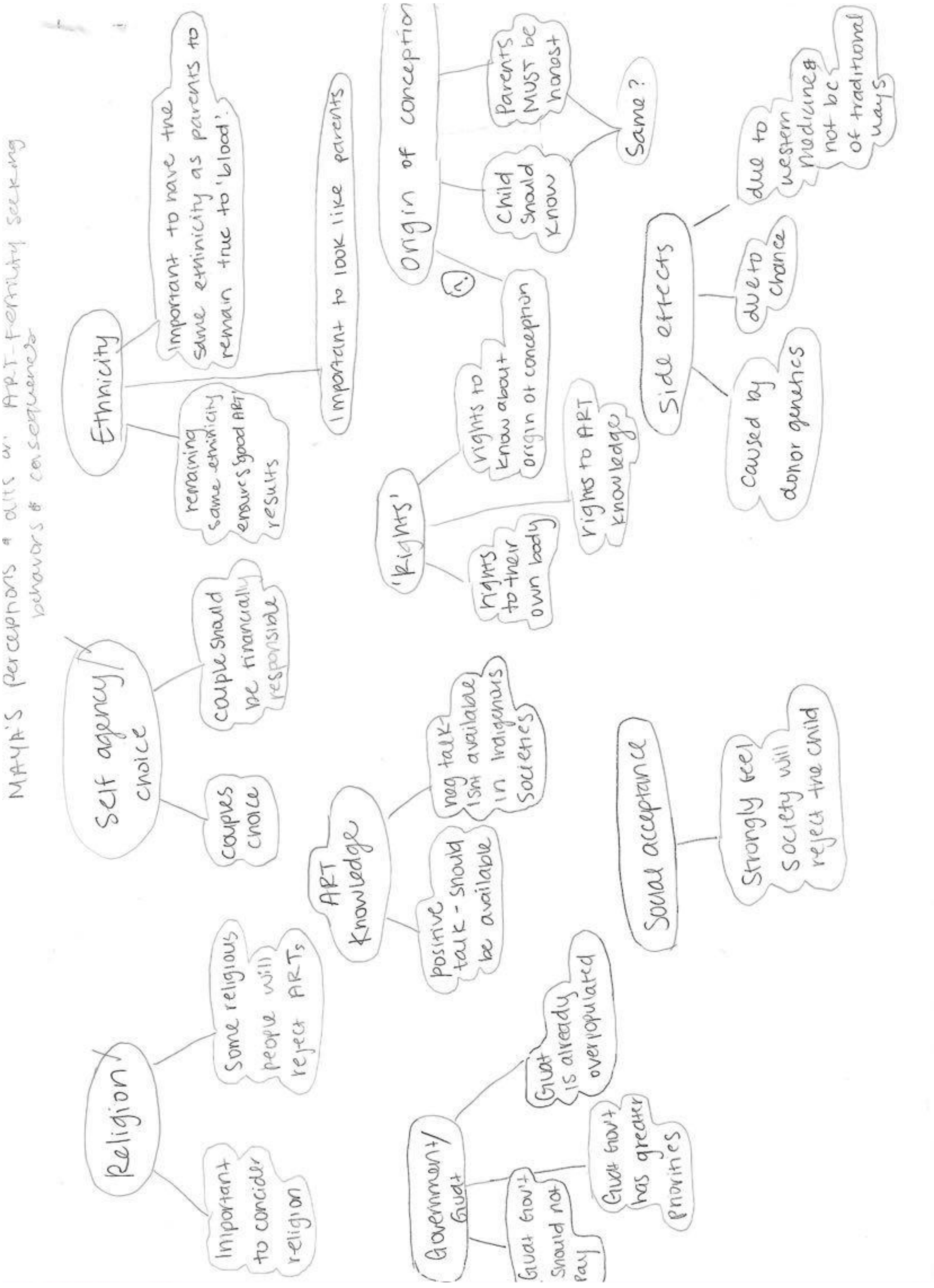
Yours sincerely,

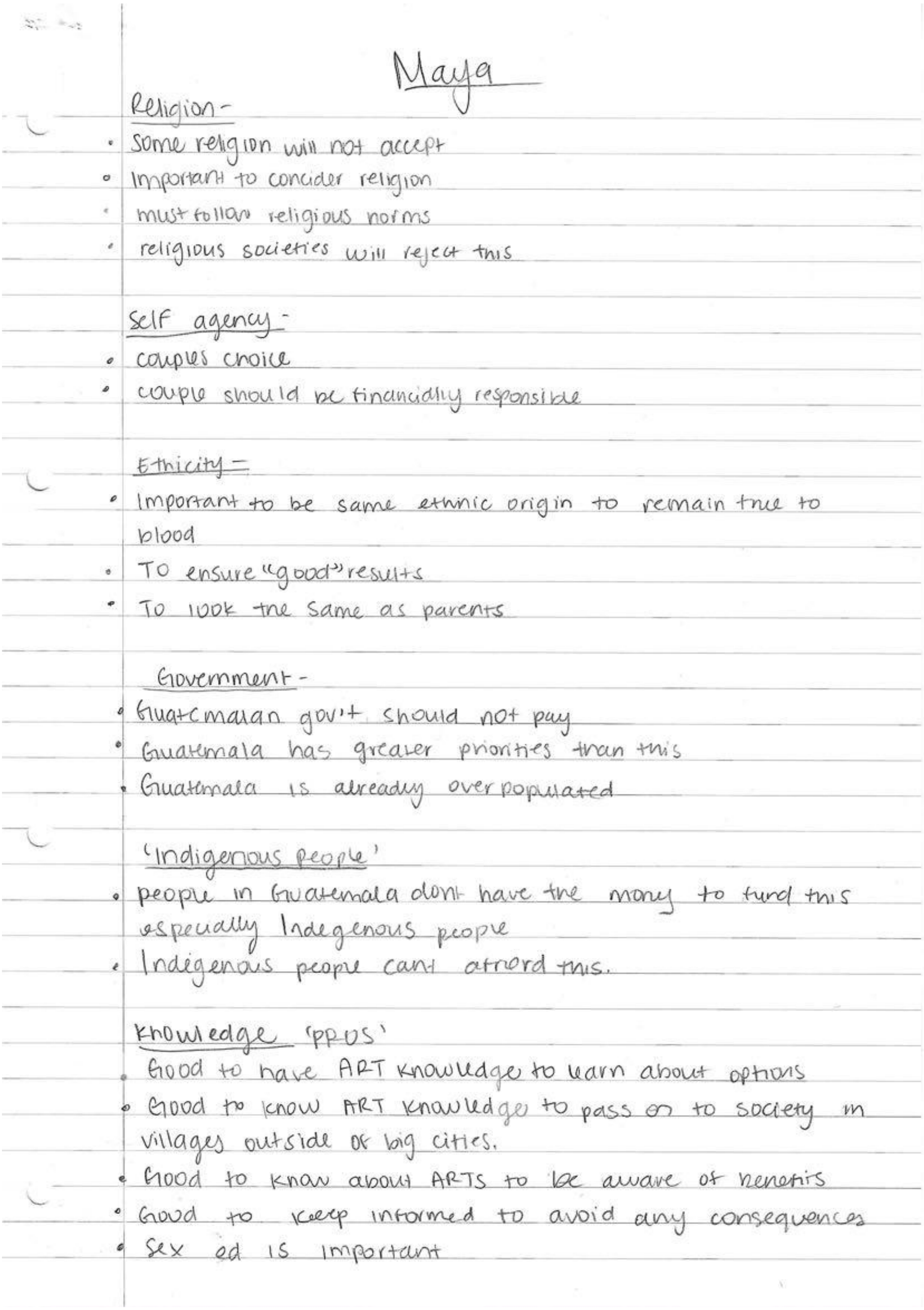
Chair

Psychology REC

Middlesex University

Appendix D- Raw Transcripts and Coding Process Sample for Study 1





Maya

Religion-

- Some religion will not accept
- Important to concider religion
- must follow religious norms
- religious societies will reject this

Self agency-

- couples choice
- couple should be financially responsible

Ethicity =

- Important to be same ethnic origin to remain true to blood
- To ensure "good" results
- To look the same as parents

Government-

- Guatemalan gov't should not pay
- Guatemala has greater priorities than this
- Guatemala is already overpopulated

'Indigenous People'

- people in Guatemala dont have the mony to fund this especially Indegenous people
- Indigenous people cant afford this.

Knowledge 'PROS'

- Good to have ART knowledge to learn about options
- Good to know ART knowledge to pass on to society in villages outside of big cities.
- Good to know about ARTS to be aware of benefits
- Good to keep informed to avoid any consequences
- Sex ed is important

Knowledge 'cons'

- The country cannot afford to fund research like this
- The country has other scientific priorities
- Indégenous communities do not have access to this

"Rights"

- couples right to choose how their baby is born
- good to have access to ART knowledge to know your 'rights'.
- couples have the "rights" to choose their babies ethnicity
- Children have the "right" to know about their nature of conception

Side effects –

- sid effects depend on donor genetics
- side effects depend on childs upbringing
- Side effects can happen due to chance
- side effects can happen because of western medicine.

nature of conception –

- The child should know
- It is important for parents to always be honest
- The child must know to avoid future consequences

Social acceptance

- society will reject the child
- Society will care
- religion will reject the child

MAYA PEOPLE

1. Before embarking on any of the ART techniques the couple should consider what their religion has to say about their actions

P

couples choice

up to parents to decide

P 1. It is the opinion of whoever wishes to make a family or have children

S

up to couples to decide

2. I think it the couples decision and they have all the right

Some religions will not accept

religion does not matter when doing good

3. The religion does not matter when doing something good

Some religions would not accept ART

4. There are religions that would see this as sin or an intrusion with God's plan

If God wanted them to be parents, they would be

5. I think they should think about it, because if God would have wanted them to be parents they would have been naturally

up to couple

P

6. Don't know

dont need permision, its personal

7. I don't think you need permission, it is something personal

P

yes to avoid religious conflict

8. If not later they will have religious conflict

The decision is as a couple

9. For one reason or another they made the decision as a couple, not everyone else's decision. they're looking to stabilize their marriage or whatever their objective is, as long as that's what they wished for

should be their personal choice

10. Strongly disagree as I think people should act autonomous and not base their actions on religion

should be clear as to why they do it as a couple

11. They must be clear why they will do it and do it by communication. Religion should not decide for them

couples choice

P

MAYA PEOPLE

Important to concider religion.
12. It is important what the bible says on the matter, it is also important what the bible states

• Important to concider religion P

free to make decisions, right
13. They are free to make decisions about their own bodies

religion does not matter
14. Religion has nothing to do with the choices of couples

PO • couples right to choose

15. One is free to chose

P • must follow church rules

must follow the church rules
16. They are under the rules of the church

17. Many religions do not agree with this

P • couple should concider religion

If couple are religious they should concider their religion
18. If the couple are devoted to their religion, they should always ask the priest or pastor about their actions

act according to values and morals, not religion
19. I think they have to be able to talk library and act according to their values that they have, not because their religion doesn't allow them

S • religion would reject this

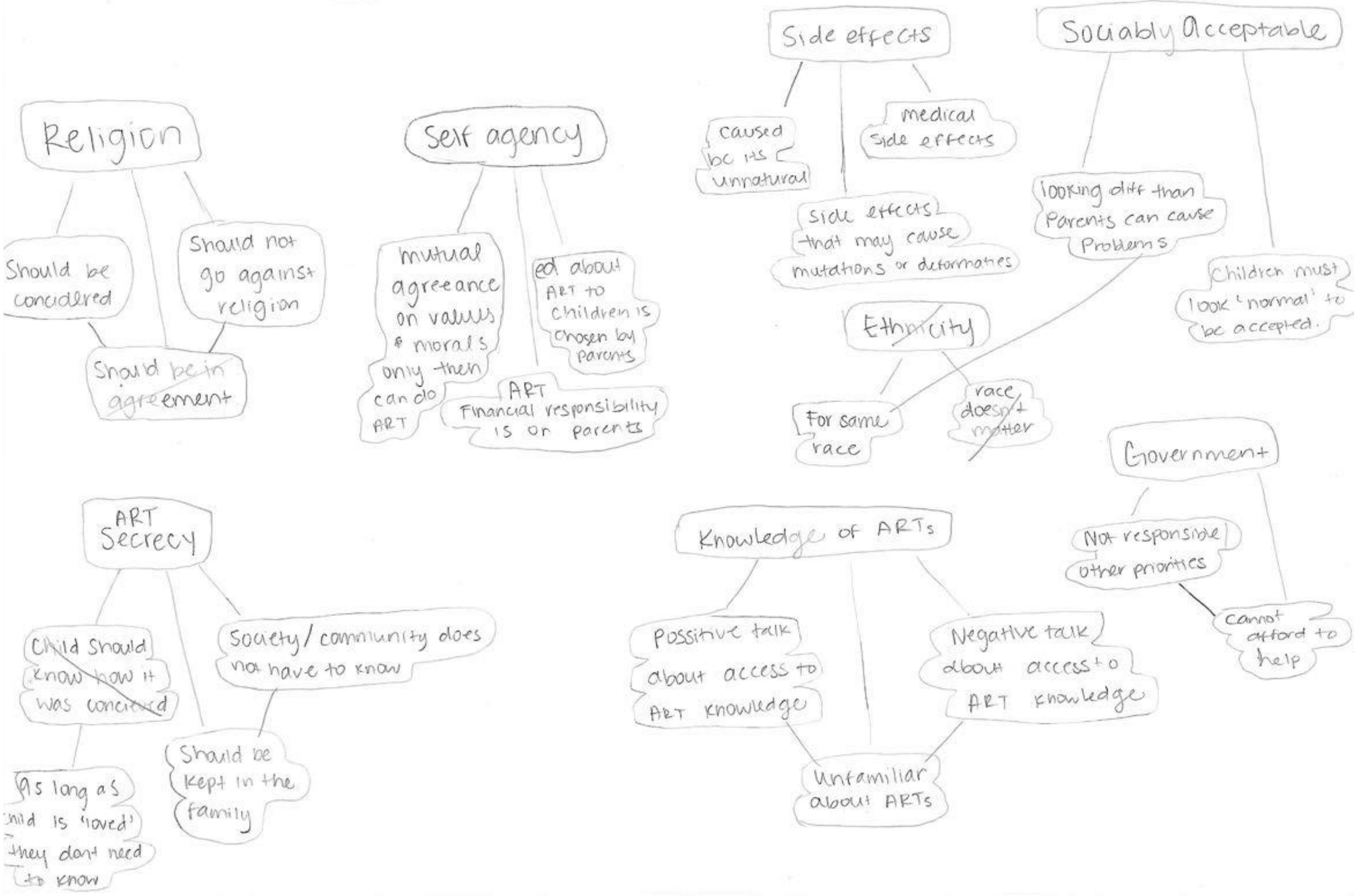
Couple can choose what it wants, couple has rights.
20. Because each couple has its rights. Guatemala is a secular country, religion and politics are different. As long as the couple has the economic means to have IVF they can do so. Only if it is a very religious couple, will religion have an effect on their actions

PO • couples right to choose

religion does not allow this
21. Religion does not permit this because they don't allow us to have a child from another person

religion doesn't matter, its couples choice
22. One can say when they want children, with who and how, religion doesn't matter

Ladino's perceptions & attitudes on ART - fertility seeking behaviours & consequences.



Ladino

Knowledge 'PROS'

- young people should know about ART
- Important to keep informed
- important to understand there are diff ways to concieve
- Information is important for future
- important to know diff options
- good to be informed about ART
- important for common knowledge
- good to know about ART to pass info down to family
- good to know bc its lacking in Guat
- ART knowledge may benefit Guat
- Important in case of consequences
- knowledge is needed to make more informed choices
- Could help children born from ART know how they were concieved

Knowledge "Cons"

- ART ed will not make a diff
- Children will not understand this concept
- only natural ways should be taught
- Not for children
- ART knowledge is not important
- ART research is not possible in developing countries
- Guat is lacking knowledge on ART
- Society doesnt understand ART
- People are ignorant to this topic
- Unfamiliar about side effects on ART
- There is no knowledge of ART in Guatemala
- Should only be taught about natural conception
- Should be taught only at specific age
- Should be taught by family only
- Sex ed must follow community rules

"looking sociably acceptable"

- If child looks diff it can lead to problems
- not looking the same might cause problems
- Same race to avoid problems w/ similarities
- would be weird if baby doesnt look like parents
- As long as child doesnt have deformities it would be accepted
- As long as the baby looks normal it will be accepted
- Society will be confused if child looks diff than parents
- child will have psych problems if it doesnt look like parents.
- If children look normal society will accept them

Ethnicity

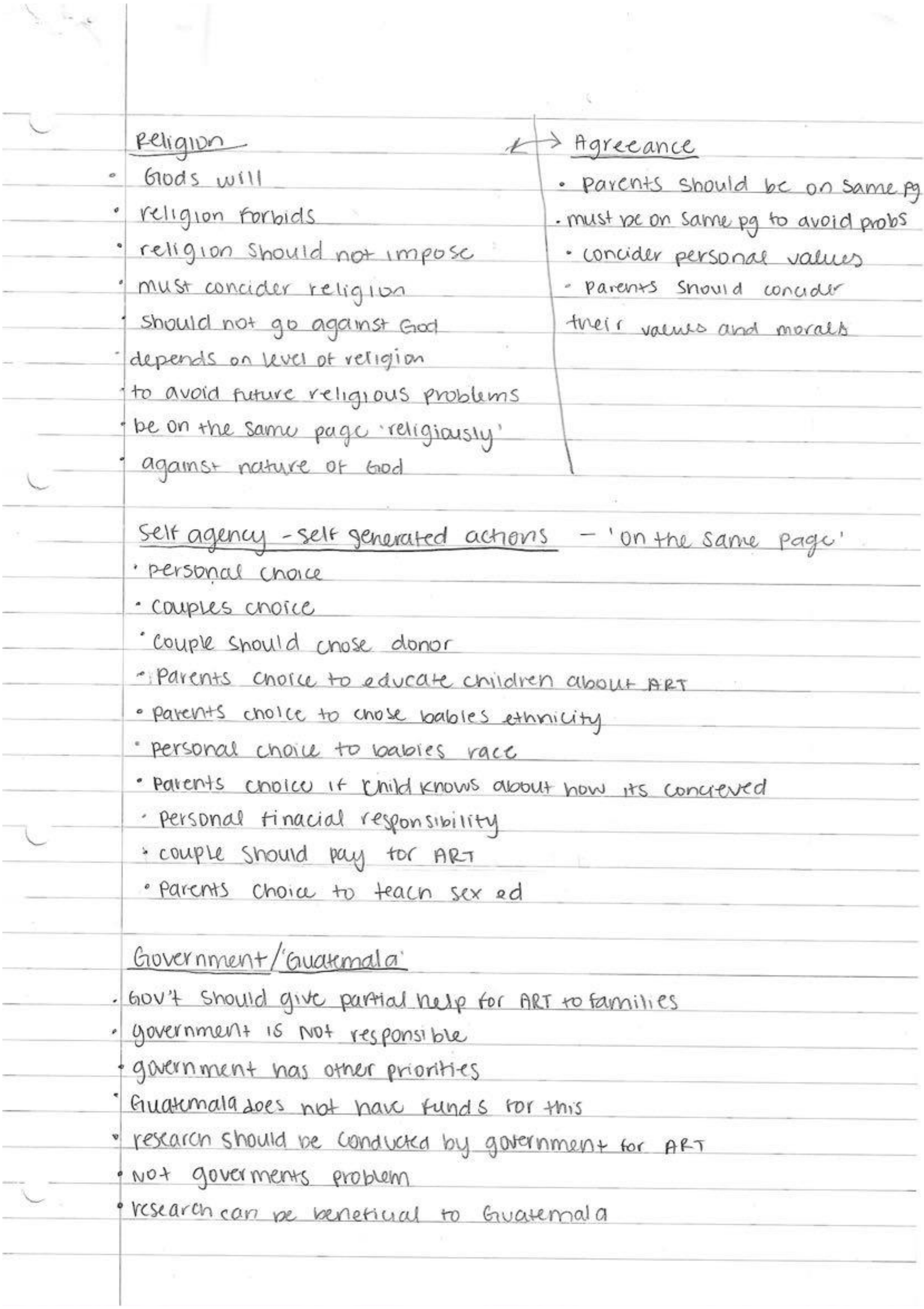
- ethnic background is not important
- Should have the same race
- race does not matter
- Parents should not have a choice in race when doing ART
- same race is irrelevant
- race is not important
- Same race = healthy baby
- Same race is important for genetics

Medical side effects

- lower IQ is irrelevant from ART
- No med consequences because of ART
- could cause gentic problems
- Side effects depend on donor
- any medical procedure can have risks
- No side effects with ART
- There could be future side effects with ART
- Could cause possible mutations
- Side effects could happen to anyone

Side effects due to ARTs being 'UNNATURAL'

- could cause deformation
- IQ could be effected bc its unnatural
- could be health risk bc its not natural



Religion

- Gods will
- religion forbids
- religion should not impose
- must concider religion
- should not go against God
- depends on level of religion
- to avoid future religious problems
- be on the same page 'religiously'
- against nature of God

Agreeance

- parents should be on same pg
- must be on same pg to avoid probs
- concider personal values
- parents should concider their values and morals

Self agency - self generated actions – 'on the same page'

- personal choice
- couples choice
- couple should chose donor
- Parents choice to educate children about ART
- parents choice to chose babies ethnicity
- personal choice to babies race
- Parents choice if child knows about how its concieved
- personal finacial responsibility
- couple should pay for ART
- Parents choice to teach sex ed

Government/'Guatemala'

- Gov't should give partial help for ART to families
- government is not responsible
- government has other priorities
- Guatemala does not have funds for this
- research should be conducted by government for ART
- not goverments problem
- research can be beneficial to Guatemala

ART 'secrecy' to child

- Child should know about its treatment
- Child should know who donors are in case of future problems
- As long as child is loved, they dont need to know
- Child may know at appropriate age
- Not important for child to know
- Child should know to normalize procedures

~ Society ~

- Society does not have to know
- It should be kept in the family
- Society would discriminate if they know
- People would reject family if they know
- In Guatemala people would need to keep this a secret
- the world doesnt have to know
- No one has to know

Sociatal acceptance of ART

- Society will not accept children from ART
- Society would accept, people dont care anymore
- Our Society would discriminate children born like this
- People would reject children and parents depending on social circle
- Guatemalan society is to blame for not accepting children from ARTs.
- as long as community doesnt know it will be accepted

'due to chance' not ART

- Psych problems can happen to anyone
- Prejudice can happen to anyone
- Side effects can happen to anyone

self agency
- self generated actions-

LADINOS

1. Before embarking on any of the ART techniques the couple should consider what their religion has to say about their actions

does not think its important
1. I don't think this is a criteria that is important

consideration of morals & ethics should be considered
2. They should consider their morals and personal ethics code

should concider religion to avoid problems
3. If they do not consider them, they could have problems as a couple

If their values & principles aren't the same. It could cause probs
4. Due to values and principles, they could get into conflict

• Considered personal values

life is made by god & men • Gods will
5. The creation of men is a divine process, but this is not a process only made by God, but by men too

• Personal choice

It is up to the couple to make this decision.
6. The couple should make this decision together, religion should not impose

If they are active in their religion they should follow what the rel. says
7. If they are active in their religion they should take in consideration the preaching's that they dictate

• Some religions do not accept ART

The person should do what feels right.
8. The person should do what they feel is right for themselves and their health

There are religions that would not accept ARTs.
9. There are religions that are very particular and do not understand what it is like to have children through ARTs

• Couples choice / personal choice

Religion should not get involved in these methods
10. Religion should not intervene in these methods

so that the religion doesn't effect the religion
11. So that it doesn't affect the participation with in the same one

• Personal choice

conunomismo
This shouldn't effect the couples desicionmaking
12. If the couple want to take action, religion should not matter

this could effect very religious people's discison
13. They could be people that would follow the holy word of God, and this effects their actions

Science & religion should work together, and it should be viewed as help from science, not viewed as impure
14. Science and religion should not be contrary to each other but should work together to provide the miracle of life, it should not be viewed as something impure but rather a biological help from science

Family matters more than religion
15. Everyone has their reasons as to why they do this, religion should not matter. Family matters more.

• Religion doesn't allow

The bible does not allow these treatments
16. The bible does not condone good things like life formation

this is the couples decision
17. This is whatever the couple wants, it is their decision

This is the person's decision
18. This is the persons decision not a religious law they must follow

• personal choice

LADINOS

• Couples decision

This is the couples decision, they will have a strong need for a family.

19. The decision is something between the couple. The yearning to form a family could be bigger than their religious norms

It is important to be in good standing religiously to make these decisions.

20. I would consider yes, it is important to be in good status in the spiritual part of things

It is an individual choice

21. Because everyone decides what to do with their own bodies

Religion shouldn't impose

Religion should not impose on having a child

22. If they truly wish to have a child and they can't, religion should not crush and destroy that illusion that could become a reality

• Personal decision

personal decision

23. It is a personal decision

Religion has motives, would be good to get more information

24. All religion has motives, and it would be good to talk more about this to have more information

• could be taboo

may be concidered taboo

25. It could be considered taboo

I do not agree, this is a good way to have children

26. I do not agree, since the couple can't have children this would be a good method to be able to have a baby

• Parents should be in agreement

Parents should agree so that the child isnt affected.

27. Both should agree so that when the baby arrives the baby can feel the love they both have for it

• Religion shouldnt impose

religion should not stop treatment

28. Because religion should not be an obstacle to start treatment

Free to make decisions

29. Everyone is free to make their own decisions

• against nature

It is not against religion

30. Because I don't see it against religion

could be considered against nature

31. Because it can be considered as something that is against nature

• personal choice

self responsibility / can make own decisions

32. Everyone is responsible for their actions

couple's decision, their wish, religion should not impose

33. It is a decision the couple should make, if it is their wish to use these techniques religion should not impose

if they wish to be a parent they should not stop themselves by the opion of others

34. If someone truly has the wish to be a parent, they should not have to stop themselves by the opinion of a third party- just because they might be inconvenienced of bothered by the method- they should not affect the decision

Couples decision

They will chose to have children this way regardless

35. Because even if religion opposes, they will still chose to have children this way

recieved help from priest.

36. I received help from a priest

Couples decision, does not have to be consulted

37. Because it is the decision of the couple and it is something that does not have to be consulted .

couples decision, religion should not intrude

38. It is a decision made by couples where religion should not intrude

Appendix E- Semi- Structured Interview Questions for Study 2 in English and Spanish

A semi-structured interview with a Guatemalan fertility key coordinator

Participant: A Guatemalan fertility coordinator

Open ended questionnaire based on analysis of results of quantitative and qualitative research

Procedure: To conduct via Zoom and recorded for further analysis.

Religion:

Part 1- Participants in my research considered religion to play a role in deciding to engage in ART treatment. To what extent did religion play a factor before, during or after any treatment? How were these issues finally resolved?

Part 2 - Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Government:

Part 1- Participants in my research considered that the government should not fund any fertility treatments as there are other priorities. To what extent were concerns linked to the funding of the treatment and whether or not the government should offer financial support towards the cost of the treatment? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Assisted Reproductive Technology (ART) and Secrecy:

Part 1 Participants in my research expressed that in general society should not know the origins and method of conception. However, it was stated that the parents should be honest regarding the method of conception. To what extent were concerns about secrecy and information regarding how a child was conceived a factor before, during or after conception? How were these issues finally resolved?

Part 2 - Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Social acceptance:

Part 1 - Participants in my research considered that society may not accept a child born via egg donation. To what extent is social acceptance a factor to consider before, during or after conception? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Side effects (medical complications):

Part 1- Participants in my research considered that there may be many unknown side effects and medical complications linked to new Assisted Reproductive Technology, which could cause medical complications for the conceived child. To what extent were medical complications a factor to consider before, during or after conception? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Self-agency:

Part 1- Participants in my research commented that the couples should be in mutual agreement to undergo treatment and they should be responsible for incurring any costs of fertility treatments. Furthermore, these participants also stated that couples should bear the financial responsibility regarding their treatment. To what extent were couples in agreement with their decisions, and were they willing to pay the bill for costs incurred before, during and after treatment?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Knowledge of Assisted Reproductive Technology:

Part 1- Participants in my research generally commented that they are not very knowledgeable about Assisted Reproductive Technologies and that there are not enough programmes available on this subject. To what extent did you see your participants having knowledge about ART before, during, or after treatment? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Ethnicity:

Part 1 - Participants in my research considered that to have fertility treatments, the couple must be of the same ethnic group. To what extent were concerns about ethnicity a factor to consider before any treatment options? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Rights:

Part 1 - Participants in my research commented that they must have access to rights pertaining to their body and the right to access knowledge about the method of their conception. To what extent were concerns about rights a factor to consider before, during and after treatment? How were these issues finally resolved? Do you think this will change due to the COVID-19 pandemic? If so, how?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Your (The coordinator's) observations:

1. Based on your experience of working with infertile patients, were there any specific points observed that are not covered in this series of questions? If so, what were they and how were they resolved? Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

2. What major changes do you anticipate in patients' needs and the future of fertility coordination/approach during the current COVID -19 pandemic in Guatemala?

3. To what extent has the COVID-19 pandemic affected both Maya and Ladino in whether they may choose traditional fertility treatments?

Una entrevista semiestructurada con un coordinador clave de fecundidad de Guatemala

Participante: Un coordinador de fertilidad Guatemalteca

Cuestionario abierto basado en el análisis de los resultados de la investigación cuantitativa y cualitativa.

Procedimiento: Realizar vía Zoom y grabar para análisis.

Religión:

Parte 1- los participantes en mi investigación consideraron que la religión importa en la decisión de participar en el tratamiento de ART. ¿Hasta qué punto la religión fue un factor antes, durante o después de cualquier tratamiento? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Crees que esto cambiará o ha cambiado debido a la pandemia de COVID-19? ¿Si es así, cómo?

Gobierno:

Parte 1- los participantes en mi investigación consideraron que el gobierno no debería financiar ningún tratamiento de fertilidad ya que hay otras prioridades. ¿Hasta qué punto las preocupaciones estaban relacionadas con la financiación del tratamiento y si el gobierno debería o no ofrecer apoyo financiero para cubrir el costo del tratamiento? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Tecnología de reproducción asistida (ART) y secretos:

Parte 1- Los participantes en mi investigación expresaron que en general la sociedad no debería conocer los orígenes y el método de concepción. Sin embargo, se afirmó que los padres deben ser honestos con respecto al método de concepción. ¿Hasta qué punto las preocupaciones sobre el secreto y la información sobre cómo se concibió un niño fueron un factor antes, durante o después de la concepción? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Cree que esto cambiará o ha cambiado debido a la pandemia de COVID-19? ¿Si es así, cómo?

Aceptación social:

Parte 1- los participantes en mi investigación consideraron que la sociedad no puede aceptar un niño nacido a través de la donación de óvulos. ¿En qué medida la aceptación social es un factor a considerar antes, durante o después de la concepción? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Efectos secundarios (complicaciones médicas):

Parte 1- los participantes en mi investigación consideraron que puede haber muchos efectos secundarios desconocidos y complicaciones médicas relacionadas con la nueva tecnología de reproducción asistida, que podrían causar complicaciones médicas para el niño concebido. ¿En qué medida las complicaciones médicas fueron un factor a considerar antes, durante o después de la concepción? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Auto-agencia:

Parte 1- los participantes en mi investigación comentaron que las parejas deben estar de mutuo acuerdo para someterse al tratamiento y deben ser responsables de incurrir en los costos de los tratamientos de fertilidad. Además, estos participantes también afirmaron que las parejas deben asumir la responsabilidad financiera con respecto a su tratamiento. ¿En qué medida las parejas estaban de acuerdo con sus decisiones y estaban dispuestas a pagar la factura de los costos incurridos antes, durante y después del tratamiento?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Conocimientos de Tecnologías de Reproducción Asistida:

Parte 1- los participantes en mi investigación generalmente comentaron que no tienen mucho conocimiento sobre las tecnologías de reproducción asistida y que no hay suficientes programas disponibles sobre este tema. ¿Hasta qué punto vio que sus participantes tenían conocimientos sobre TAR antes, durante o después del tratamiento? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Etnicidad:

Parte 1 - Los participantes en mi investigación consideraron que para tener tratamientos de fertilidad, la pareja debe ser del mismo grupo étnico. ¿Hasta qué punto las preocupaciones sobre el origen étnico fueron un factor a considerar antes de cualquier opción de tratamiento? ¿Cómo se resolvieron finalmente estos problemas?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Derechos:

Parte 1 - Los participantes en mi investigación comentaron que deben tener acceso a los derechos relacionados con su cuerpo y el derecho a acceder el conocimiento sobre el método de su concepción. ¿Hasta qué punto las preocupaciones sobre los derechos fueron un factor a considerar antes, durante y después del tratamiento? ¿Cómo se resolvieron finalmente estos problemas? ¿Crees que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Parte 2- ¿Cree que esto cambiará debido a la pandemia de COVID-19? ¿Si es así, cómo?

Sus observaciones (del coordinador):

1. Con base en su experiencia de trabajo con pacientes infértiles, ¿observó algún punto específico que no esté cubierto en esta serie de preguntas? De ser así, ¿cuáles fueron y cómo se resolvieron? ¿Crees que esto cambiará/ha cambiado debido a la pandemia de COVID-19? ¿Si es así, cómo?

2. ¿Qué cambios importantes anticipa en las necesidades de los pacientes y el futuro de la coordinación/enfoque de fertilidad durante la actual pandemia de COVID-19 en Guatemala?

3. ¿En qué medida la pandemia de COVID-19 ha afectado tanto a mayas como a ladinos en cuanto a si pueden elegir tratamientos de fertilidad tradicionales?

Appendix F- Consent, Information, and Debriefing Sheets in English and Spanish for Study 2

CONSENT FORM

Title of Project: A semi-structured interview with a Guatemalan fertility key coordinator

Name of Researcher: Cecilia Isabel Urrutia

Supervisor's name and email*: Dr Bahman Baluch* ***B.Baluch@mdx.ac.uk***

Please initial box

☐ 1

1. I confirm that I have read and understand the information sheet dated ....…………….…. for the above study. I have had the opportunity to ask questions and have been given contact details for the researcher(s)

☐ 2

2. I understand that my participation is voluntary, the data collected during the research will not be identifiable, and I am free to withdraw my consent without giving a reason

☐ 3

3. I agree that this form that bears my name and signature may be seen by a designated auditor (i.e. a Chair of the Psychology Ethics Committee or representative of the University Ethics Committee) to monitor correctness of procedure

4. I agree that my non-identifiable research data may be stored in National Archives and used anonymously by others for future research. I am assured that the confidentiality of my data will be upheld through the removal of any personal identifiers ☐ 4

5. I understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur ☐ 5

6. I understand that I can ask for my data to be withdrawn from the project until data analysis begins in November 15th ☐ 6

7. I understand that my interview may be taped and subsequently transcribed ☐ 7

8. I agree to take part in the above study ☐ 8

_____________________________ ________________ ____________________________

Name of participant Date Signature

_____________________________ ________________ ____________________________

Name of person taking consent Date Signature

(if different from researcher)

_____________________________ ________________ ____________________________

Researcher Date Signature

1 copy for participant; 1 copy for researcher

FORMULARIO DE CONSENTIMIENTO

Título del proyecto: Entrevista semiestructurada con una coordinadora clave de fertilidad guatemalteca

Nombre de la investigadora: Cecilia Isabel Urrutia

Nombre y correo electrónico del supervisor: Dr. Bahman Baluch B.Baluch@mdx.ac.uk

Por favor coloque sus iniciales en la casilla

1. Confirmo que he leído y comprendido la hoja de información fechada Noviembre 2020 para el estudio anterior. He tenido la oportunidad de hacer preguntas y se le han proporcionado los datos de contacto del investigador ___

2. Entiendo que mi participación es voluntaria, los datos recopilados durante la investigación no será identificable, y soy libre de retirar mi consentimiento sin dar una razón ___

3. Acepto que este formulario, que lleva mi nombre y firma puede ser visto por un auditor designado (es decir, un presidente del Comité de Ética de Psicología o un representante del Comité de Ética Universitaria) ___

4. Acepto que mis datos de investigación que no son identificables pueden ser archivados en los Archivos Nacionales y utilizado de forma anónima por otros para futuras investigaciones. Estoy seguro que la confidencialidad de mis datos se mantendrá mediante la eliminación de cualquier clase de identificadores ___

5. Entiendo que los datos pueden usarse para análisis y posteriores publicación, y doy mi consentimiento para que esto pueda ocurrir ___

6. Entiendo que puedo solicitar que se retiren mis datos del proyecto antes que el análisis comience en el 15 de Noviembre___

7. Entiendo que mi entrevista puede ser grabada y posteriormente transcrita___

8. Acepto participar en el estudio___

___________________________ __________________________

Nombre del participante Fecha Firma

___________________________ __________________________

Nombre de la persona que toma el consentimiento Fecha Firma

(si es diferente del investigador)

___________________________ __________________________

Investigador Fecha Firma

1 copia para participante; 1 copia para investigador.

MIDDLESEX UNIVERSITY

Participant Information Sheet (PIS)

More Than Minimal Risk or High Risk Projects

(Must be used with a Consent Form that is signed by participant and retained by the researcher)

Participant ID Code:…………………………………………

This sheet is to be given to participants only for research projects/studies classified as More than Minimal Risk or High Risk. This includes projects that involve: the collection of any type of personal data; voice recordings; focus groups; experiments/observation studies, vulnerable groups (e.g. anyone under 18 years old, adults with cognitive impairment etc) and sensitive topics (anything deeply personal and distressing, taboo, intrusive, stigmatising, sexual in nature, illegal and potentially dangerous, harmful to national security etc). A different "Participant Information with Consent Sheet" (PICS) must be used for Minimal Risk projects/studies.

SECTION 1

1. Project/Study title: A semi-structured interview with a Guatemalan fertility key coordinator

2. Invitation paragraph

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 and discuss it with others 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.

Thank you for reading this.

3. What is the purpose of the study?

The present study is designed to examine the experiences of a Guatemalan fertility key coordinator with couples seeking infertility treatments in relation to findings of the public perception on ART in Guatemala.

4. Why have I been chosen?

It is important that we assess as many participants as possible, and you have indicated that you are interested in taking part in this study. To take part of this study you must be a key coordinator in the infertility field, aged 18 or over, and speak English or Spanish. You have been chosen to take part in this study because of your valuable experiences and valuable knowledge with fertility treatments in Guatemala.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do decide to withdraw from the study then please inform the researcher as soon as possible, and they will facilitate your withdrawal. If, for any reason, you wish to withdraw your data please contact the researcher within a month of your participation. After this date it may not be possible to withdraw your individual data as the results may have already been published. However, as all data are anonymised, your individual data will not be identifiable in any way.

6. What will I have to do?

You will be asked to answer questions during an online video chat interview which will take approximately 45 minutes. There are no known risks in participating in this project. However, this cannot be guaranteed. The information we get from this study may help us help practitioners and those involved in fertility treatments in giving the best advice to their patients in the pursuit of achieving their goals.

Personal data (e.g. your name, email address, voice or any data that can identify you) will NOT be collected by this study and your confidentiality will be protected

Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the committee. This means that the designated member can request to see signed consent forms. However, if this is the case your signed consent form will only be accessed by the designated auditor or member of the audit team.

7. Will I have to provide any bodily samples (i.e. blood/saliva/urine)?

No.

8. What are the possible disadvantages and risks of taking part?

There are no known risks in participating in this project.

Appropriate risk assessments for all procedures have been conducted, and will be followed throughout the duration of the study.

9. What are the possible benefits of taking part?

We hope that participating in the study will help you. However, this cannot be guaranteed. It is hoped that practitioners and those involved in fertility treatments benefit from the results of the present study in giving the best advice to their patients in the pursuit of achieving their goals.

10. Will my taking part in this study be kept confidential?

The research team has put a number of procedures in place to protect the confidentiality of participants. You will be allocated a participant code that will always be used to identify any data you provide. Your name or other personal details will not be associated with your data, for example, the consent form that you sign will be kept separate from your data. All paper records will be stored in a locked filing cabinet, accessible only to the research team, and all electronic data will be stored on a password protected computer. All information you provide will be treated in accordance with the UK Data Protection Act.

11. What will happen to the results of the research study?

The results of the research study will be used as part of a Doctoral Thesis. The results may also be presented at conferences or in journal articles. However, the data will only be used by members of the research team and at no point will your personal information or data be revealed.

12. Who has reviewed the study?

The study has received full ethical clearance from the Research ethics committee who reviewed the study. The committee is the Research ethics committee who reviewed the study. The committee is the Middlesex University Ethics committee.

13. Contact for further information

If you require further information, have any questions or would like to withdraw your data then please contact:

Cecilia Isabell Urrutia cu084@live.mdx.ac.uk

Supervisor: Dr. Bahman Baluch B.Baluch@mdx.ac.uk

Middlesex University Middlesex University

Psychology Department Psychology Department

+44 (0)20 8411 5375

Thank you for agreeing to take part in this study. You (the participant) should keep this “Participant Information with Consent” sheet since it contains important information and the research teams contact details.

SECTION 2

Middlesex University Guide to Research Privacy Notices

Privacy notices need to be presented whenever data is collected and should be understandable and accessible. Privacy notices must explain the type and source of data that will be processed. They will also set out the processing purpose, data retention schedules and data sharing. Privacy notices must include details of the subject’s rights and who the subject can complain to.

The following example may be used and completed for your research purposes.

Middlesex University Privacy Notice for Research Participants

The General Data Protection Regulation (GDPR) protects the rights of individuals by setting out certain rules as to what organisation can and cannot do with information about people. A key element to this is the principle to process individuals’ data lawfully and fairly. This means we need to provide information on how we process personal data.

The University takes its obligation under the GDPR very seriously and will always ensure personal data is collected, handled, stored and shared in a secure manner. The University’s Data Protection Policy can be accessed here: https://www.mdx.ac.uk/__data/assets/pdf_file/0023/471326/Data-Protection-Policy-GPS4-v2.4.pdf.

The following statements will outline what personal data we collect, how we use it and who we share it with. It will also provide guidance on your individual rights and how to make a complaint to the Information Commissioner’s Officer (ICO), the regulator for data protection in the UK.

Why are we collecting your personal data?

As a university we undertake research as part of our function and in our capacity as a teaching and research institution to advance education and learning. The specific purpose for data collection on this occasion is to gather qualitative data to validate findings from previous studies in hopes to help practitioners and those involved in infertility treatment benefit from the results of the present study in giving the best advice to their patients in the pursuit of achieving their goals..

The legal basis for processing your personal data under GDPR on this occasion is Article 6(1a) consent of the data subject.

Transferring data outside Europe

In the majority of instances your data will be processed by Middlesex University researchers only or in collaboration with researchers at other UK or European institutions so will stay inside the EU and be protected by the requirements of the GDPR.

In any instances in which your data might be used as part of a collaboration with researchers based outside the EU all the necessary safeguards that are required under the GDPR for transferring data outside of the EU will be put in place. You will be informed if this is relevant for the specific study you are a participant of.

Your rights under data protection

Under the GDPR and the DPA you have the following rights:

- to obtain access to, and copies of, the personal data that we hold about you;
- to require that we cease processing your personal data if the processing is causing you damage or distress;
- to require us to correct the personal data we hold about you if it is incorrect;
- to require us to erase your personal data;
- to require us to restrict our data processing activities;
- to receive from us the personal data we hold about you which you have provided to us, in a reasonable format specified by you, including for the purpose of you transmitting that personal data to another data controller;
- to object, on grounds relating to your particular situation, to any of our particular processing activities where you feel this has a disproportionate impact on your rights.

Where Personal Information is processed as part of a research project, the extent to which these rights apply varies under the GDPR and the DPA. In particular, your rights to access, change, or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may not be able to remove the information that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. The Participant Information Sheet will detail up to what point in the study data can be withdrawn.

If you submit a data protection rights request to the University, you will be informed of the decision within one month. If it is considered necessary to refuse to comply with any of your data protection rights, you also have the right to complain about our decision to the UK supervisory authority for data protection, the Information Commissioner’s Office.

None of the above precludes your right to withdraw consent from participating in the research study at any time.

Collecting and using personal data

Data will be collected by conducting a video chat interview online via Skype that will take approximately 45 minutes. The Participant will not be asked any personal information other than age to assure participant is over 18.

Data sharing

Your information will usually be shared within the research team conducting the project you are participating in, mainly so that they can identify you as a participant and contact you about the research project.

Responsible members of the University may also be given access to personal data used in a research project for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your records. All of these people have a duty to keep your information, as a research participant, strictly confidential.

If we are working with other organisations and information is shared about you, we will inform you in the Participant Information Sheet. Information shared will be on a ‘need to know’ basis relative to achieving the research project’s objectives, and with all appropriate safeguards in place to ensure the security of your information.

Storage and security

The University takes a robust approach to protecting the information it holds with dedicated storage areas for research data with controlled access.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of University information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Training is provided to new staff joining the University and existing staff have training and expert advice available if needed.

Retention

Under the GDPR and DPA personal data collected for research purposes can be kept indefinitely, providing there is no impact to you outside the parameters of the study you have consented to take part in.

Having stated the above, the length of time for which we keep your data will depend on a number of factors including the importance of the data, the funding requirements, the nature of the study, and the requirements of the publisher. Details will be given in the information sheet for each project.

Contact us

The Principal Investigator leading this research is Cecilia Isabel Urrutia

Middlesex University Middlesex University

Psychology Department Psychology Department

+44 (0)20 8411 5375

The University’s official contact details are:

Data Protection Officer

Middlesex University

The Burroughs

London

NW4 4BT

Tel: +44 (0)20 8411 5555

Email: dpaofficer@mdx.ac.uk

Thank you for agreeing to take part in this study. You (the participant) should keep this “Participant Information with Consent” sheet since it contains important information, and the research teams contact details

MIDDLESEX UNIVERSITY

Hoja de información del participante (PIS)

Proyectos de riesgo más que mínimo o alto

(Debe usarse con un formulario de consentimiento firmado por el participante y retenido por el investigador)

Código de identificación del participante:……………………………………………….

Esta hoja se debe entregar a los participantes solo para proyectos de investigación / estudios clasificados como Riesgo más que mínimo o Riesgo alto. Esto incluye proyectos que involucran: la recolección de cualquier tipo de datos personales; grabaciones de voz; grupos de enfoque; experimentos / estudios de observación, grupos vulnerables (por ejemplo, cualquier menor de 18 años, adultos con deterioro cognitivo, etc.) y temas delicados (cualquier cosa profundamente personal y angustiosa, tabú, intrusiva, estigmatízate, de naturaleza sexual, ilegal y potencialmente peligrosa, dañina para la seguridad nacional etc). Se debe utilizar una “Hoja de información del participante con consentimiento” (PICS) diferente para los proyectos / estudios de riesgo mínimo.

SECCIÓN 1

1. Título del proyecto / estudio: Una entrevista semiestructurada con un coordinador clave de fertilidad de Guatemala

2. Párrafo de invitación

Se le invita a participar en un estudio de investigación. Antes de tomar una decisión, es importante que comprenda por qué se está realizando la investigación y qué implicará. Tómese el tiempo para leer detenidamente la siguiente información y discútala con otras personas si lo desea. Pregúntenos si hay algo que no esté claro o si desea más información. Tómese su tiempo para decidir si desea participar o no. Gracias por leer esto.

3. ¿Cuál es el propósito del estudio?

El presente estudio está diseñado para examinar las experiencias de un coordinador clave de fertilidad guatemalteco con parejas que buscan tratamientos de infertilidad en relación con los hallazgos de la percepción pública sobre el TAR en Guatemala.

4. ¿Por qué me han elegido?

Es importante que evaluemos a tantos participantes como sea posible, y usted ha indicado que está interesado en participar en este estudio. Para participar en este estudio debes ser un coordinador clave en el campo de la infertilidad, tener 18 años o más y hablar inglés o español. Ha sido elegida para participar en este estudio debido a sus valiosas experiencias y valiosos conocimientos con los tratamientos de fertilidad en Guatemala.

5. ¿Tengo que participar?

Depende de usted decidir si participa o no. Si decide participar, se le entregará esta hoja de información para que la guarde y se le pedirá que firme un formulario de consentimiento. Si decide participar, aún puede retirarse en cualquier momento y sin dar una razón. Si decide retirarse del estudio, informe al investigador lo antes posible y ellos facilitarán su retirada. Si, por cualquier motivo, desea retirar sus datos, comuníquese con el investigador dentro de un mes de su participación. Después de esta fecha, es posible que no sea posible retirar sus datos individuales, ya que es posible que los resultados ya se hayan publicado. Sin embargo, como todos los datos son anónimos, sus datos individuales no serán identificables de ninguna manera.

6. ¿Qué tendré que hacer?

Se le pedirá que responda preguntas durante una entrevista de video chat en línea que tomará aproximadamente 45 minutos. No se conocen riesgos al participar en este proyecto. Sin embargo, esto no se puede garantizar. La información que obtenemos de este estudio puede ayudarnos a ayudar a los médicos y a los involucrados en los tratamientos de fertilidad a brindar el mejor consejo a sus pacientes en la búsqueda de sus objetivos.

Los datos personales (por ejemplo, su nombre, dirección de correo electrónico, voz o cualquier dato que pueda identificarlo) NO serán recopilados por este estudio y su confidencialidad estará protegida

Tenga en cuenta que a fin de garantizar la garantía de calidad y la equidad, un miembro designado del comité puede seleccionar este proyecto para su auditoría. Esto significa que el miembro designado puede solicitar ver formularios de consentimiento firmados. Sin embargo, si este es el caso, solo el auditor designado o el miembro del equipo de auditoría accederá a su formulario de consentimiento firmado.

7. ¿Tendré que proporcionar muestras corporales (es decir, sangre / saliva / orina)?

No.

8. ¿Cuáles son las posibles desventajas y riesgos de participar?

No se conocen riesgos al participar en este proyecto.

Se han realizado evaluaciones de riesgo apropiadas para todos los procedimientos y se seguirán durante la duración del estudio.

9. ¿Cuáles son los posibles beneficios de participar?

Esperamos que participar en el estudio le ayude. Sin embargo, esto no se puede garantizar. Se espera que los médicos y los involucrados en los tratamientos de fertilidad se beneficien de los resultados del presente estudio al brindar el mejor asesoramiento a sus pacientes en la búsqueda de sus objetivos.

10. ¿Se mantendrá la confidencialidad de mi participación en este estudio?

El equipo de investigación ha implementado una serie de procedimientos para proteger la confidencialidad de los participantes. Se le asignará un código de participante que siempre se utilizará para identificar cualquier dato que proporcione. Su nombre u otros datos personales no se asociarán con sus datos, por ejemplo, el formulario de consentimiento que firme se mantendrá separado de sus datos. Todos los registros en papel se almacenarán en un archivador cerrado con llave, accesible solo para el equipo de investigación, y todos los datos electrónicos se almacenarán en una computadora protegida con contraseña. Toda la información que proporcione será tratada de acuerdo con la Ley de Protección de Datos del Reino Unido.

11. ¿Qué pasará con los resultados del estudio de investigación?

Los resultados del estudio de investigación se utilizarán como parte de una Tesis Doctoral. Los resultados también pueden presentarse en conferencias o en artículos de revistas. Sin embargo, los datos solo serán utilizados por miembros del equipo de investigación y en ningún momento se revelarán sus datos o información personal.

12. ¿Quién ha revisado el estudio?

El estudio ha recibido la autorización ética completa del comité de ética de la investigación que revisó el estudio. El comité es el comité de ética de la investigación que revisó el estudio. El comité es el comité de ética de la Universidad de Middlesex.

13. Póngase en contacto para obtener más información

Si necesita más información, tiene alguna pregunta o desea retirar sus datos, comuníquese con:

Cecilia Isabel Urrutia cu084@live.mdx.ac.uk

Supervisor: Dr. Bahman Baluch B.Baluch@mdx.ac.uk
Universidad de Middlesex Universidad de Middlesex
Departamento de Psicología Departamento de Psicología
+44 (0) 20 8411 5375

Gracias por aceptar participar en este estudio. Usted (el participante) debe conservar esta hoja de "Información del participante con consentimiento", ya que contiene información importante y los datos de contacto de los equipos de investigación.

SECCIÓN 2

Guía de la Universidad de Middlesex para investigar avisos de privacidad

Los avisos de privacidad deben presentarse siempre que se recopilen datos y deben ser comprensibles y accesibles. Los avisos de privacidad deben explicar el tipo y la fuente de datos que se procesarán. También establecerán el propósito del procesamiento, los programas de retención de datos y el intercambio de datos. Los avisos de privacidad deben incluir detalles de los derechos del sujeto y ante quién puede presentar una queja.

El siguiente ejemplo se puede utilizar y completar para sus fines de investigación.

Aviso de privacidad de la Universidad de Middlesex para participantes en la investigación

El Reglamento general de protección de datos (GDPR) protege los derechos de las personas al establecer ciertas reglas sobre lo que la organización puede y no puede hacer con la información sobre las personas. Un elemento clave para esto es el principio de procesar los datos de las personas de manera legal y justa. Esto significa que debemos proporcionar información sobre cómo procesamos los datos personales.

La Universidad se toma muy en serio su obligación en virtud del GDPR y siempre se asegurará de que los datos personales se recopilen, manejen, almacenen y compartan de manera segura. Puede acceder a la Política de protección de datos de la universidad aquí: https://www.mdx.ac.uk/__data/assets/pdf_file/0023/471326/Data-Protection-Policy-GPS4-v2.4.pdf.

Las siguientes declaraciones describen qué datos personales recopilamos, cómo los usamos y con quién los compartimos. También proporcionará orientación sobre sus derechos individuales y cómo presentar una queja ante el Oficial del Comisionado de Información (ICO), el regulador de protección de datos en el Reino Unido.

¿Por qué recopilamos sus datos personales?

Como universidad, emprendemos la investigación como parte de nuestra función y en nuestra capacidad como institución de enseñanza e investigación para promover la educación y el aprendizaje. El propósito específico de la recopilación de datos en esta ocasión es recopilar datos cualitativos para validar los hallazgos de estudios anteriores con la esperanza de ayudar a los profesionales y a los involucrados en el tratamiento de la infertilidad a beneficiarse de los resultados del presente estudio para brindar el mejor consejo a sus pacientes en la búsqueda. de lograr sus objetivos ..

La base legal para procesar sus datos personales bajo GDPR en esta ocasión es el consentimiento del artículo 6 (1a) del interesado.

Transferencia de datos fuera de Europa

En la mayoría de los casos, sus datos serán procesados solo por investigadores de la Universidad de Middlesex o en colaboración con investigadores de otras instituciones del Reino Unido o Europa, por lo que permanecerán dentro de la UE y estarán protegidos por los requisitos del GDPR.

En cualquier caso en el que sus datos puedan ser utilizados como parte de una colaboración con investigadores fuera de la UE, se implementarán todas las salvaguardas necesarias que se requieren en virtud del RGPD para transferir datos fuera de la UE. Se le informará si esto es relevante para el estudio específico del que participa.

Sus derechos bajo la protección de datos

Según el RGPD y la DPA, tiene los siguientes derechos:

- para obtener acceso y copias de los datos personales que tenemos sobre usted;
- solicitar que dejemos de procesar sus datos personales si el procesamiento le está causando daños o angustia;
- para solicitarnos que corrijamos los datos personales que tenemos sobre usted si son incorrectos;
- para solicitarnos que eliminemos sus datos personales;
- para exigirnos que restrinjamos nuestras actividades de procesamiento de datos;
- recibir de nosotros los datos personales que tenemos sobre usted y que nos ha proporcionado, en un formato razonable especificado por usted, incluso con el fin de transmitir esos datos personales a otro controlador de datos;

- oponerse, por motivos relacionados con su situación particular, a cualquiera de nuestras actividades de procesamiento particulares cuando crea que esto tiene un impacto desproporcionado en sus derechos.

Cuando la información personal se procesa como parte de un proyecto de investigación, la medida en que se aplican estos derechos varía según el RGPD y la DPA. En particular, sus derechos para acceder, cambiar o mover su información pueden ser limitados, ya que necesitamos administrar su información de formas específicas para que la investigación sea confiable y precisa. Si se retira del estudio, es posible que no podamos eliminar la información que ya hemos obtenido. Para salvaguardar sus derechos, utilizaremos la mínima información de identificación personal posible. La Hoja de información del participante detallará hasta qué punto del estudio se pueden retirar los datos.

Si presenta una solicitud de derechos de protección de datos a la Universidad, se le informará de la decisión en el plazo de un mes. Si se considera necesario negarse a cumplir con cualquiera de sus derechos de protección de datos, también tiene derecho a presentar una queja sobre nuestra decisión ante la autoridad supervisora de protección de datos del Reino Unido, la Oficina del Comisionado de Información.

Nada de lo anterior impide su derecho a retirar su consentimiento para participar en el estudio de investigación en cualquier momento.

Recopilación y uso de datos personales

Los datos se recopilarán mediante la realización de una entrevista de video chat en línea a través de Skype que tomará aproximadamente 45 minutos. No se le pedirá al participante ninguna información personal que no sea la edad para asegurar que el participante sea mayor de 18 años.

Compartir datos

Por lo general, su información se compartirá con el equipo de investigación que lleva a cabo el proyecto en el que participa, principalmente para que puedan identificarlo como participante y comunicarse con usted sobre el proyecto de investigación.

Los miembros responsables de la Universidad también pueden tener acceso a los datos personales utilizados en un proyecto de investigación con fines de seguimiento y / o para realizar una auditoría del estudio para asegurarse de que la investigación cumple con la normativa aplicable. Las personas de las autoridades reguladoras (personas que comprueban que estamos realizando el estudio correctamente) pueden requerir acceso a sus registros. Todas estas personas tienen el deber de mantener su información, como participante de la investigación, estrictamente confidencial.

Si estamos trabajando con otras organizaciones y se comparte información sobre usted, le informaremos en la Hoja de información del participante. La información compartida se hará sobre la base de la "necesidad de saber" en relación con el logro de los objetivos del proyecto de investigación y con todas las salvaguardias adecuadas para garantizar la seguridad de su información.

Almacenamiento y seguridad

La Universidad adopta un enfoque sólido para proteger la información que contiene con áreas de almacenamiento dedicadas para datos de investigación con acceso controlado.

Junto a estas medidas técnicas, existen políticas y procesos integrales y efectivos para garantizar que los usuarios y administradores de la información de la Universidad sean conscientes de sus obligaciones y responsabilidades con respecto a los datos a los que tienen acceso. De forma predeterminada, las personas solo tienen acceso a la información que necesitan para realizar sus funciones. Se brinda capacitación al personal nuevo que ingresa a la Universidad y el personal existente tiene capacitación y asesoramiento experto disponible si es necesario.

Retención

Según el RGPD y la DPA, los datos personales recopilados con fines de investigación pueden conservarse indefinidamente, siempre que no haya ningún impacto para usted fuera de los parámetros del estudio en el que ha dado su consentimiento para participar.

Habiendo dicho lo anterior, el período de tiempo durante el cual conservamos sus datos dependerá de una serie de factores, incluida la importancia de los datos, los requisitos de financiación, la naturaleza del estudio y los requisitos del editor. Los detalles se darán en la hoja de información de cada proyecto.

Contáctenos

La Investigadora Principal que lidera esta investigación es Cecilia Isabel Urrutia

Universidad de Middlesex Universidad de Middlesex

Departamento de Psicología Departamento de Psicología

+44 (0) 20 8411 5375

Los datos de contacto oficiales de la Universidad son:

Delegado de protección de datos
Universidad de Middlesex
Los Burroughs
Londres
NW4 4BT
Tel: +44 (0) 20 8411 5555
Correo electrónico: dpaofficer@mdx.ac.uk

Gracias por aceptar participar en este estudio. Usted (el participante) debe conservar esta hoja de "Información del participante con consentimiento", ya que contiene información importante y los datos de contacto de los equipos de investigación.

Debriefing

Psychology Department
Middlesex University
Hendon
London NW4 4BT

Researchers name: Cecilia Isabel Urrutia
Date: November 2020

Study title: A Semi-structured interview with a Guatemalan fertility treatment key coordinator

The present study was designed to examine the experiences of a Guatemalan fertility key coordinator with couples seeking infertility treatments in relation to findings of the public perception on ART in Guatemala.

There is very little research on this topic, particularly on the Guatemalan population. Generally research has shown that factors such as religion, ethnicity, costs, possible consequences and participant's age and gender may have an impact on how people may regard undergoing fertility treatment via IVF or egg donation. A recent study for example by Pir Jalian (2017) has shown that Iranians are generally not supportive of a child being born by egg donation and believe that it may have an impact on the child in the society. This is in spite of the fact that having a child in a non–Western country such as Iran is the prime aim for all couples.

The interview you complete will help us have a clearer perspective on what the view on is on ART amongst the Guatemalan population, and should provide valuable information for practitioners and couples involved in infertility treatment.

Please use the contact information provided to get in touch with the researcher or the supervisor should you have any questions about this study.

Researcher: Cecilia Isabel Urrutia
CU084@live.mdx.ac.uk
Middlesex University
Psychology Department

Supervisor: Dr Bahman Baluch
b.baluch@mdx.ac.uk
Middlesex University
Psychology Department
+44 (0)20 8411 5375

Reunión informativa

Departamento de Psicologia
Middlesex University
Hendon
London NW4 4BT

Nombre de la investigadora: Cecilia Isabel Urrutia
Date: Noviembre 2020

Título del estudio: Una entrevista semiestructurada con un coordinador clave de tratamiento de fertilidad de Guatemala

El presente estudio fue diseñado para examinar las experiencias de un coordinador guatemalteco 'clave' de fertilidad, con parejas que buscan tratamientos de infertilidad en relación con los hallazgos de la percepción pública sobre los tratamientos de infertilidad en Guatemala.

Existe muy poca investigaciones sobre este tema, particularmente sobre la población Guatemalteca. En general, la investigación ha demostrado que factores como la religión, el origen étnico, los costos, las posibles consecuencias, la edad y el género de los participantes pueden tener un impacto en cómo las personas pueden considerar someterse a un tratamiento de fertilidad mediante IVF o donación de óvulos. Un estudio reciente, por ejemplo, de Pir Jalian (2017) ha demostrado que los Iraníes generalmente no apoyan que un niño nazca mediante la donación de óvulos y creen que puede tener un impacto en el niño en la sociedad. Esto a pesar del hecho de que tener un hijo en un país no occidental como Irán es el objetivo principal de todas las parejas.

La entrevista que complete nos ayudará a tener una perspectiva más clara de cuál es la opinión sobre tratamientos de infertilidad entre la población guatemalteca y debería proporcionar información valiosa para los médicos y las parejas involucradas en el tratamiento de la infertilidad.

Utilice la información de contacto proporcionada para ponerse en contacto con el investigador o el supervisor si tiene alguna pregunta sobre este estudio.

Researcher: Cecilia Isabel Urrutia
CU084@live.mdx.ac.uk
Middlesex University
Psychology Department

Supervisor: Dr Bahman Baluch
b.baluch@mdx.ac.uk
Middlesex University
Psychology Department
+44 (0)20 8411 5375

Appendix G- Letter Granting Access to Subjects and Data Collection for Study 2

Subject: Re: Att: Licda. Gabriela Meléndez entrevista para estudio doctoral

Hola Cecilia!

Con gusto te puedo apoyar virtualmente, disculpa la demora en mi respuesta, hemos estado ocupadas con trasladar toda nuestra formación a la modalidad virtual.

Cuando quieras podemos agendar una reunión para la entrevista conmigo o con las estudiantes, o una grupal o con un doctor. Quedo pendiente.

Saludos,

Gabriela

Gabriela Meléndez Peláez
Directora / Asociación Corazón del Agua
Directora y Coordinadora Académica "Técnico Universitario en Partería Profesional con Enfoque Intercultural" Asociación Corazón del Agua / Universidad Galileo
Tel: Oficina: 22302523, Personal: (502) 49060836

****

TRANSLATED:

Hello Cecilia!

I can gladly support you virtually, sorry for the delay in my response, we have been busy with moving all our training to virtual mode.

Whenever you want we can schedule a meeting for an interview with me or with the students, or a group one or a doctor. I will wait for your response.

Regards,
Gabriela

Middlesex University London

Psychology REC

The Burroughs
Hendon
London NW4 4BT

Main Switchboard: 0208 411 5000

06/10/2020

APPLICATION NUMBER: 14246

Dear Cecilia Isabel Urrutia and all collaborators/co-investigators

Re your application title: A semi-structured interview with a Guatemalan fertility key coordinator

Supervisor: Bahman Baluch

Co-investigators/collaborators:

Thank you for submitting your application. I can confirm that your application has been given APPROVAL from the date of this letter by the Psychology REC.

The following documents have been reviewed and approved as part of this research ethics application:

Document Type	File Name	Date	Version
GDPR Declaration	Data Protection Declaration Form 2019	20/05/2020	1
Data Protection Checklist	Data Protection Checklist Form V2	20/05/2020	1
Materials	Interview Questions A semi-structured interview with a Guatemalan fertility key coordinator	01/10/2020	1
Materials	Interview questions SPANISH Una entrevista semiestructurada con una coordinadora clave de fertilidad guatemalteca	01/10/2020	1
Aims, objectives and hypotheses	Research proposal A semi-structured interview with a Guatemalan fertility key coordinator	01/10/2020	1
Participant Information Sheet	Participant Information Sheet 2020 for A semi-structured interview with a Guatemalan fertility key coordinator	01/10/2020	1
Participant Information Sheet	Consent Form 2020 for A semi-structured interview with a Guatemalan fertility key coordinator	01/10/2020	1
Debriefing Sheet	Debriefing 2020 A semi-structured interview with a Guatemalan fertility key coordinator	01/10/2020	1
Methods and data	Email approval Maya A semi-structured interview with a Guatemalan fertility key coordinator	01/10/2020	1

Although your application has been approved, the reviewers of your application may have made some useful comments on your application. Please look at your online application again to check whether the reviewers have added any comments for you to look at.

Also, please note the following:

1. Please ensure that you contact your supervisor/research ethics committee (REC) if any changes are made to the research project which could affect your ethics approval. There is an Amendment sub-form on MORE that can be completed and submitted to your REC for further review.

2. You must notify your supervisor/REC if there is a breach in data protection management or any issues that arise that may lead to a health and safety concern or conflict of interests.

3. If you require more time to complete your research, i.e., beyond the date specified in your application, please complete the Extension sub-form on MORE and submit it your REC for review.

4. Please quote the application number in any correspondence.

5. It is important that you retain this document as evidence of research ethics approval, as it may be required for submission to external bodies (e.g., NHS, grant awarding bodies) or as part of your research report, dissemination (e.g., journal articles) and data management plan.

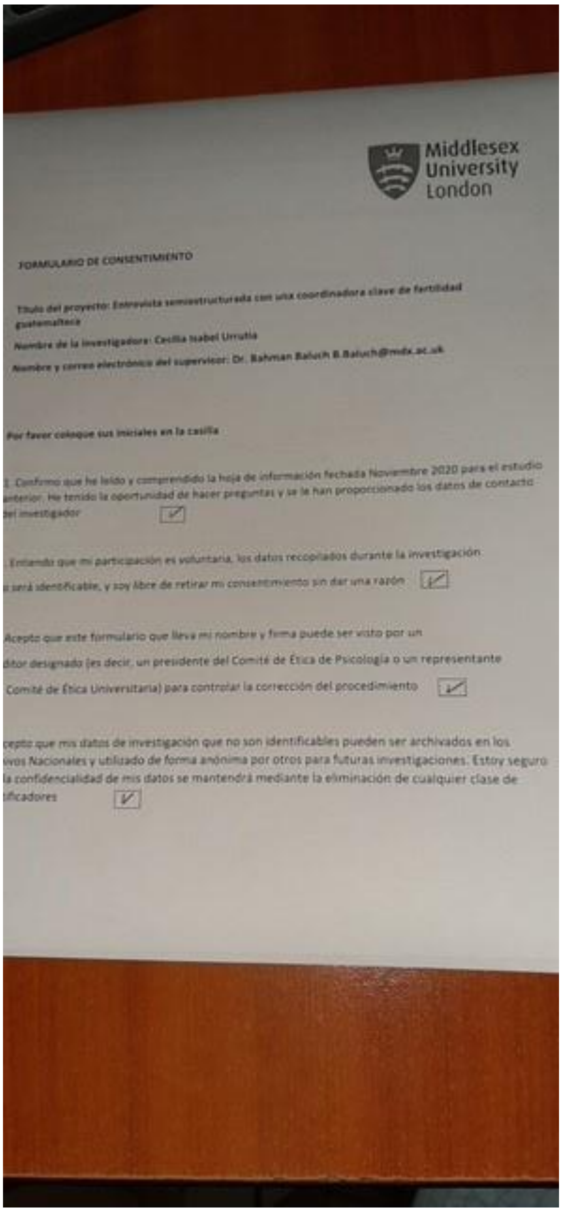
6. Also, please forward any other information that would be helpful in enhancing our application form and procedures - please contact MOREsupport@mdx.ac.uk to provide feedback.

Good luck with your research.

Yours sincerely

Chair

Psychology REC



Middlesex
University
London

FORMULARIO DE CONSENTIMIENTO

Título del proyecto: Entrevista semiestructurada con una coordinadora clave de fertilidad guatemalteca

Nombre de la investigadora: Cecilia Isabel Urrutia

Nombre y correo electrónico del supervisor: Dr. Bahman Baluch B.Baluch@mdx.ac.uk

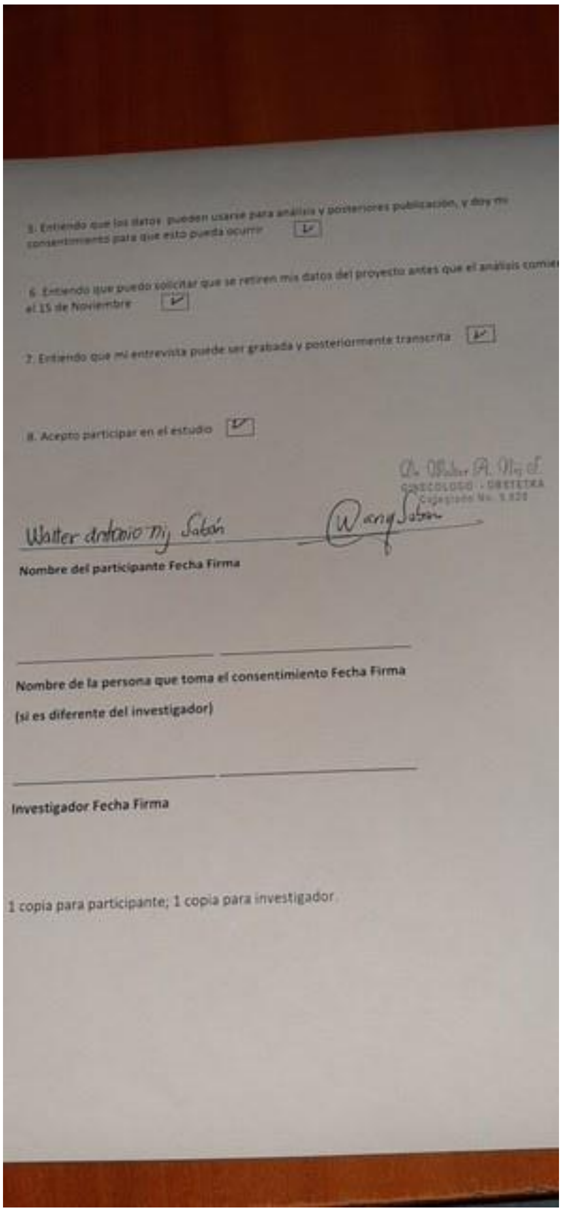
Por favor coloque sus iniciales en la casilla

1. Confirmo que he leído y comprendido la hoja de información fechada Noviembre 2020 para el estudio anterior. He tenido la oportunidad de hacer preguntas y se le han proporcionado los datos de contacto del investigador ☑

. Entiendo que mi participación es voluntaria, los datos recopilados durante la investigación o será identificable, y soy libre de retirar mi consentimiento sin dar una razón ☑

Acepto que este formulario que lleva mi nombre y firma puede ser visto por un ditor designado (es decir, un presidente del Comité de Ética de Psicología o un representante Comité de Ética Universitaria) para controlar la corrección del procedimiento ☑

cepto que mis datos de investigación que no son identificables pueden ser archivados en los ivos Nacionales y utilizado de forma anónima por otros para futuras investigaciones. Estoy seguro la confidencialidad de mis datos se mantendrá mediante la eliminación de cualquier clase de ificadores ☑



5. Entiendo que los datos pueden usarse para análisis y posteriores publicación, y doy mi consentimiento para que esto pueda ocurrir ☑

6. Entiendo que puedo solicitar que se retiren mis datos del proyecto antes que el análisis comie
el 15 de Noviembre ☑

7. Entiendo que mi entrevista puede ser grabada y posteriormente transcrita ☑

8. Acepto participar en el estudio ☑

GINECOLOGO - OBSTETRA
Colegiado No. 5.820

Walter antonio Mij Sabán

Nombre del participante Fecha Firma

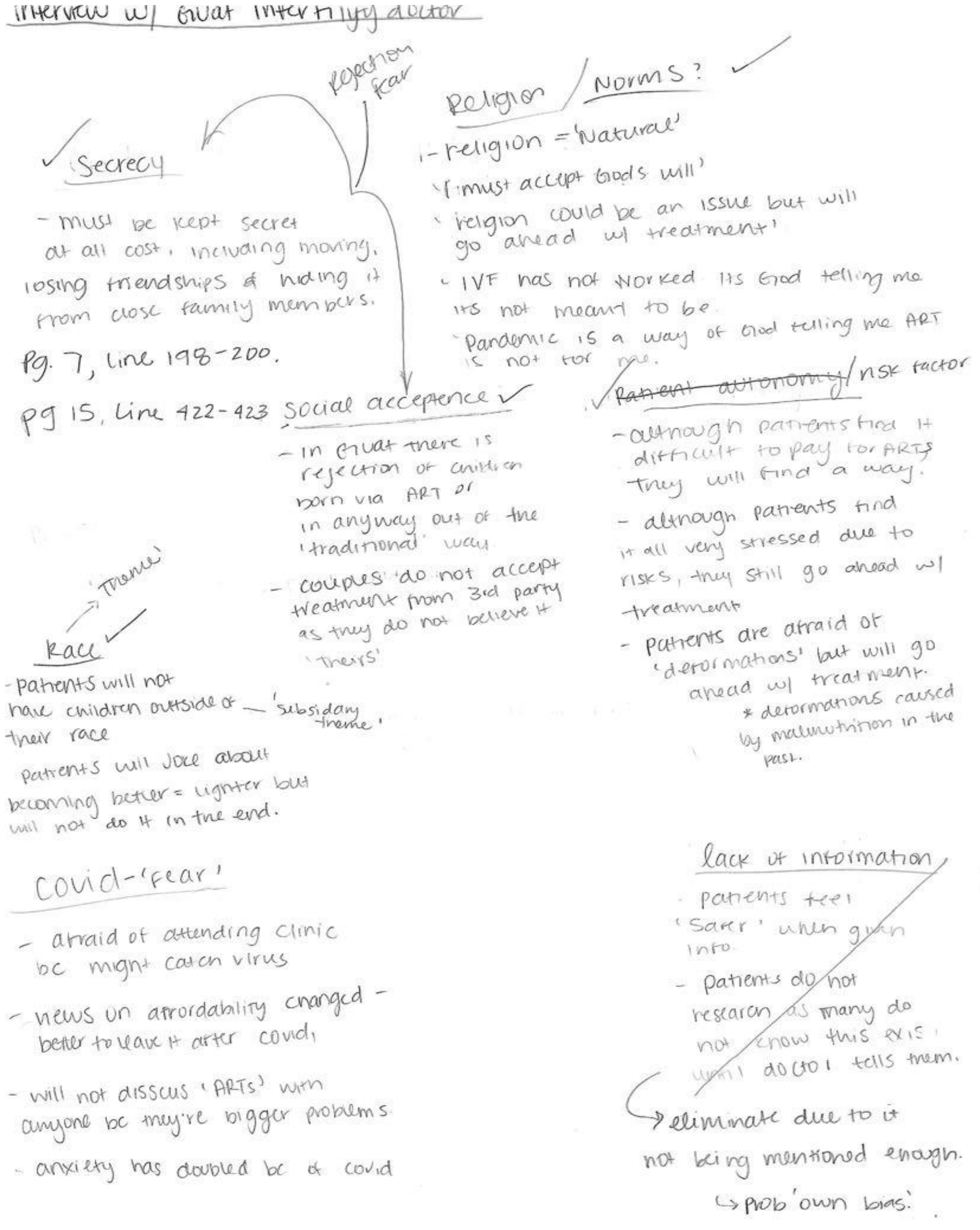
Nombre de la persona que toma el consentimiento Fecha Firma

(si es diferente del investigador)

Investigador Fecha Firma

1 copia para participante; 1 copia para investigador.

Appendix H Raw Transcripts and Coding Process Sample for Study 2



Interview w/ Gvat infertility doctor

rejection fear

✓ Secrecy

- must be kept secret at all cost, including moving, losing friendships & hiding it from close family members.

Pg. 7, Line 198-200.

Pg 15, Line 422-423

Religion / Norms? ✓

- religion = 'Natural'
- 'I must accept God's will'
- 'religion could be an issue but will go ahead w/ treatment'
- 'IVF has not worked its God telling me its not meant to be.
- 'Pandemic is a way of God telling me ART is not for me.

Social accepetence ✓

- In Gvat there is rejection of children born via ART or in anyway out of the 'traditional' way
- couples 'do not accept treatment from 3rd party as they do not believe it 'theirs'

✓ ~~Patient autonomy~~/risk factor

- although patients find it difficult to pay for ARTS they will find a way.
- although patients find it all very stressed due to risks, they still go ahead w/ treatment
- patients are afraid of 'deformations' but will go ahead w/ treatment.
  - * deformations caused by malnutrition in the past.

'Theme'

Race ✓

- patients will not have children outside of their race — 'subsidary theme'

patients will joke about becoming better = lighter but will not do it in the end.

Covid-'fear'

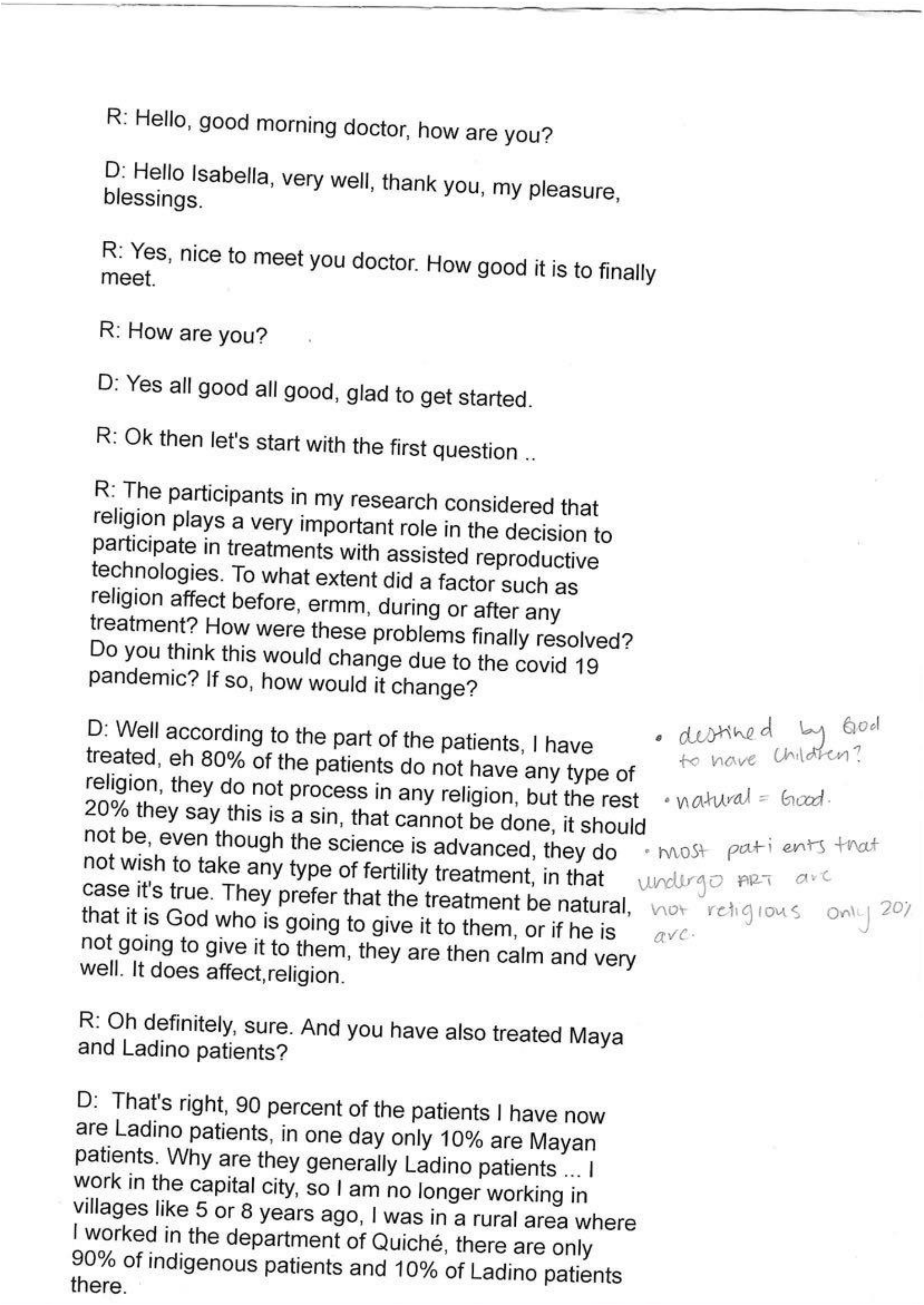
- afraid of attending clinic bc might catch virus
- news on affordability changed - better to leave it after covid,
- will not disscus 'ARTs' with anyone bc they're bigger problems.
- anxiety has doubled bc of covid

lack of information

- ~~patients feel 'safer' when given info.~~
- ~~patients do not research as many do not know this exis until doctor tells them.~~

→ eliminate due to it not being mentioned enough.

↳ prob 'own bias.'



R: Hello, good morning doctor, how are you?

D: Hello Isabella, very well, thank you, my pleasure, blessings.

R: Yes, nice to meet you doctor. How good it is to finally meet.

R: How are you?

D: Yes all good all good, glad to get started.

R: Ok then let's start with the first question ..

R: The participants in my research considered that religion plays a very important role in the decision to participate in treatments with assisted reproductive technologies. To what extent did a factor such as religion affect before, ermm, during or after any treatment? How were these problems finally resolved? Do you think this would change due to the covid 19 pandemic? If so, how would it change?

D: Well according to the part of the patients, I have treated, eh 80% of the patients do not have any type of religion, they do not process in any religion, but the rest 20% they say this is a sin, that cannot be done, it should not be, even though the science is advanced, they do not wish to take any type of fertility treatment, in that case it's true. They prefer that the treatment be natural, that it is God who is going to give it to them, or if he is not going to give it to them, they are then calm and very well. It does affect,religion.

- destined by God to have children?
- natural = Good.
- most patients that undergo ART are not religious only 20% are.

R: Oh definitely, sure. And you have also treated Maya and Ladino patients?

D: That's right, 90 percent of the patients I have now are Ladino patients, in one day only 10% are Mayan patients. Why are they generally Ladino patients ... I work in the capital city, so I am no longer working in villages like 5 or 8 years ago, I was in a rural area where I worked in the department of Quiché, there are only 90% of indigenous patients and 10% of Ladino patients there.

R: Ahh okay.

R: And would you say that a Mayan patient and a Ladino patient, when talking about religion, it's important to them?

D: The majority of Ladino patients consider religion very important, now the indigenous patients consider that it is not a sin, it is simply not allowed in their community. They have their own methods.

ART = Sin 4 Ladino
ART = Not allowed w/ Maya, they have their own traditional methods.

R: Okay, now, when there are those religious conversations between a couple and with you, how have you seen that these problems get solved?

D: Generally, in the case of ladino patients, they make the decision to have some type of fertility treatment, in the end they decide both without pressure from the doctor, without pressure from the consultant or psychologist in the case, they make their decision, seeing the pros and cons of that decision of a medical treatment, and in the end, they make their decision to do it.

→ make sure its informed decision?
→ doctor bias to make sure I know this!

R: Okay and now you think that this is going to change during or after, because of the pandemic? And... and ..

D: Yes ...

R: Please continue...

D: No, forgive me. Continue, continue...

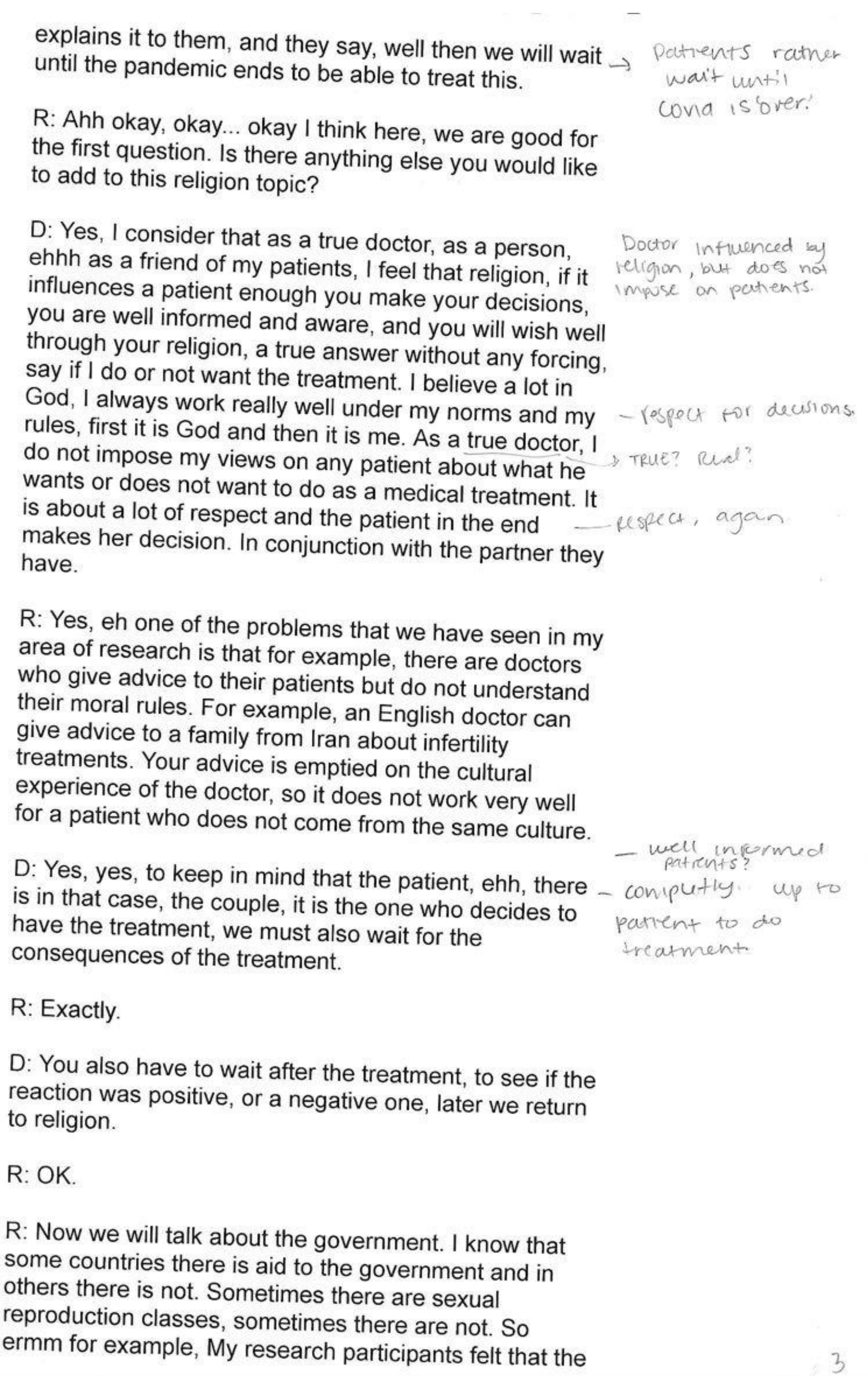
R: Was going to say, do you think this would change due to the covid 19 pandemic? That is to have the treatment and if there are problems with religion. Do you think that the pandemic would affect this?

D: Yes, generally in the pandemic, the whole world came to change, right? Covid-19 gave us a 360 degree turn to commerce, ehh what is ermm companies, and health also came to change. We as doctors are giving priority to patients with covid 19. In fact, every patient who arrives is requested a test 24-48 hours in advance. In Guatemala, the cheapest would be the swab, right? So, some patients do not want to do it, just imagine and see on television, what a swab is like, when one

– people are reluctant to come in bc of COVID.

Afraid of testing?

– Imagine? Linked to what?



explains it to them, and they say, well then we will wait until the pandemic ends to be able to treat this.

→ Patients rather wait until Covid is 'over.'

R: Ahh okay, okay... okay I think here, we are good for the first question. Is there anything else you would like to add to this religion topic?

D: Yes, I consider that as a true doctor, as a person, ehhh as a friend of my patients, I feel that religion, if it influences a patient enough you make your decisions, you are well informed and aware, and you will wish well through your religion, a true answer without any forcing, say if I do or not want the treatment. I believe a lot in God, I always work really well under my norms and my rules, first it is God and then it is me. As a true doctor, I do not impose my views on any patient about what he wants or does not want to do as a medical treatment. It is about a lot of respect and the patient in the end makes her decision. In conjunction with the partner they have.

Doctor influenced by religion, but does not impose on patients.

— respect for decisions.

→ TRUE? Real?

— respect, again

R: Yes, eh one of the problems that we have seen in my area of research is that for example, there are doctors who give advice to their patients but do not understand their moral rules. For example, an English doctor can give advice to a family from Iran about infertility treatments. Your advice is emptied on the cultural experience of the doctor, so it does not work very well for a patient who does not come from the same culture.

— well informed patients?

D: Yes, yes, to keep in mind that the patient, ehh, there is in that case, the couple, it is the one who decides to have the treatment, we must also wait for the consequences of the treatment.

— completely up to patient to do treatment

R: Exactly.

D: You also have to wait after the treatment, to see if the reaction was positive, or a negative one, later we return to religion.

R: OK.

R: Now we will talk about the government. I know that some countries there is aid to the government and in others there is not. Sometimes there are sexual reproduction classes, sometimes there are not. So ermm for example, My research participants felt that the

3

Appendix I- Semi- Structured Interview Questions for Study 3

A semi-structured interview with a UK fertility key coordinator case study

Participant: A UK fertility coordinator

Open ended questionnaire based on analysis of results of quantitative and qualitative research

Procedure: To conduct via Zoom and recorded for further analysis.

Religion:

Part 1- Participants in my research considered religion to play a role in deciding to engage in ART treatment. To what extent did religion play a factor before, during or after any treatment? How were these issues finally resolved?

Part 2 - Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Government:

Part 1- Participants in my research considered that the government should not fund any fertility treatments as there are other priorities. To what extent were concerns linked to the funding of the treatment and whether or not the government should offer financial support towards the cost of the treatment? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Assisted Reproductive Technology (ART) and Secrecy:

Part 1- Participants in my research expressed that in general society should not know the origins and method of conception. However, it was stated that the parents should be honest regarding the method of conception. To what extent were concerns about secrecy and information regarding how a child was conceived a factor before, during or after conception? How were these issues finally resolved?

Part 2 - Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Social acceptance:

Part 1 - Participants in my research considered that society may not accept a child born via egg donation. To what extent is social acceptance a factor to consider before, during or after conception? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Side effects (medical complications):

Part 1- Participants in my research considered that there may be many unknown side effects and medical complications linked to new Assisted Reproductive Technology, which could cause medical complications for the conceived child. To what extent were medical complications a factor to consider before, during or after conception? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Self-agency:

Part 1- Participants in my research commented that the couples should be in mutual agreement to undergo treatment and they should be responsible for incurring any costs of fertility treatments. Furthermore, these participants also stated that couples should bear the financial responsibility regarding their treatment. To what extent were couples in agreement with their decisions, and were they willing to pay the bill for costs incurred before, during and after treatment?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Knowledge of Assisted Reproductive Technology:

Part 1- Participants in my research generally commented that they are not very knowledgeable about Assisted Reproductive Technologies and that there are not enough programmes available on this subject. To what extent did you see your participants having knowledge about ART before, during, or after treatment? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Ethnicity:

Part 1 - Participants in my research considered that to have fertility treatments, the couple must be of the same ethnic group. To what extent were concerns about ethnicity a factor to consider before any treatment options? How were these issues finally resolved?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Rights:

Part 1 - Participants in my research commented that they must have access to rights pertaining to their body and the right to access knowledge about the method of their conception. To what extent were concerns about rights a factor to consider before, during and after treatment? How were these issues finally resolved? Do you think this will change due to the COVID-19 pandemic? If so, how?

Part 2- Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

Your (The coordinator's) observations:

1. Based on your experience of working with infertile patients, were there any specific points observed that are not covered in this series of questions? If so, what were they and how were they resolved? Do you think this will/has changed due to the COVID-19 pandemic? If so, how?

2. What major changes do you anticipate in patients' needs and the future of fertility coordination/approach during the current COVID -19 pandemic in the UK?

3. To what extent has the COVID-19 pandemic affected UK patients in whether they may choose traditional fertility treatments?

Appendix J- Consent, Information, and Debriefing Sheets for study 3

Middlesex University London

CONSENT FORM

Title of Project: A semi-structured interview with a UK fertility key coordinator

Name of Researcher: Cecilia Isabel Urrutia

Supervisor's name and email: Dr Bahman Baluch B. Baluch@mdx.ac.uk

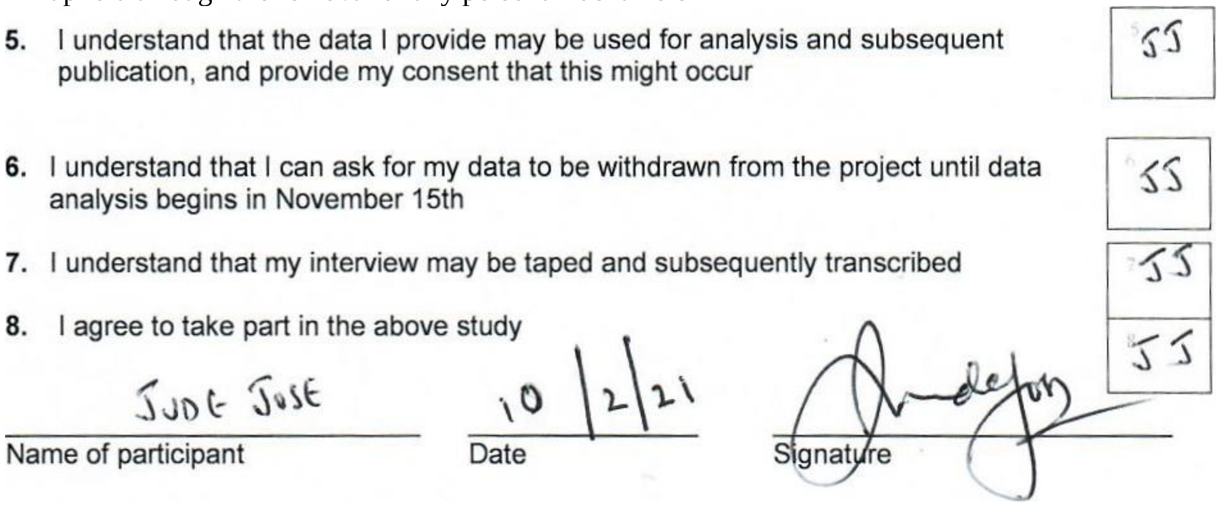
Please initial box

1. I confirm that I have read and understand the information sheet dated ………………………………. for the above study. I have had the opportunity to ask JJ

   questions and have been given contact details for the researcher(s) JJ

2. I understand that my participation is voluntary, the data collected during the research will not be identifiable, and I am free to withdraw my consent without giving a reason JJ
3. I agree that this form that bears my name and signature may be seen by a designated auditor (i.e. a Chair of the Psychology Ethics Committee or representative of the University Ethics Committee) to monitor correctness of procedure

4. I agree that my non-identifiable research data may be stored in National Archives and used anonymously by others for future research. I am assured that the confidentiality of my data will be upheld through the removal of any personal identifiers



5. I understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur JJ

6. I understand that I can ask for my data to be withdrawn from the project until data analysis begins in November 15th JJ

7. I understand that my interview may be taped and subsequently transcribed JJ

8. I agree to take part in the above study JJ

JUDE JOSE
Name of participant

10/2/21
Date

Signature

Name of person taking consent Date Signature

(if different from researcher)

Researcher Date Signature

Participant Information Sheet (PIS)

More Than Minimal Risk or High Risk Projects

(Must be used with a Consent Form that is signed by participant and retained by the researcher)

Participant ID Code:……………………………………………

SECTION 1

1. Project/Study title: A semi-structured interview with a UK fertility key coordinator

2. Invitation paragraph

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 and discuss it with others 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.

Thank you for reading this.

3. What is the purpose of the study?

The present study is designed to examine the experiences of a UK fertility key coordinator with couples seeking infertility treatments in relation to findings of the public perception on ART in Guatemala.

4. Why have I been chosen?

It is important that we assess as many participants as possible, and you have indicated that you are interested in taking part in this study. To take part of this study you must be a key coordinator in the infertility field, aged 18 or over, and speak English or Spanish. You have been chosen to take part in this study because of your valuable experiences and valuable knowledge with fertility treatments in the UK.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do decide to withdraw from the study then please inform the researcher as soon as possible, and they will facilitate your withdrawal. If, for any reason, you wish to withdraw your data please contact the researcher within a month of your participation. After this date it may not be possible to withdraw your individual data as the results may have already been published. However, as all data are anonymised, your individual data will not be identifiable in any way.

6. What will I have to do?

You will be asked to answer questions during an online video chat interview which will take approximately 45 minutes. There are no known risks in participating in this project. However, this cannot be guaranteed. The information we get from this study may help us help practitioners and those involved in fertility treatments in giving the best advice to their patients in the pursuit of achieving their goals.

Personal data (*e.g. your name, email address, voice or any data that can identify you*) will NOT be collected by this study and your confidentiality will be protected

Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the committee. This means that the designated member can request to see signed consent forms. However, if this is the case your signed consent form will only be accessed by the designated auditor or member of the audit team.

7. Will I have to provide any bodily samples (i.e. blood/saliva/urine)? No.

8. What are the possible disadvantages and risks of taking part? There are no known risks in participating in this project.

Appropriate risk assessments for all procedures have been conducted, and will be followed throughout the duration of the study.

9. What are the possible benefits of taking part?

We hope that participating in the study will help you. However, this cannot be guaranteed. It is hoped that practitioners and those involved in fertility treatments benefit from the results of the present study in giving the best advice to their patients in the pursuit of achieving their goals.

10. Will my taking part in this study be kept confidential?

The research team has put a number of procedures in place to protect the confidentiality of participants. You will be allocated a participant code that will always be used to identify any data you provide. Your name or other personal details will not be associated with your data, for example, the consent form that you sign will be kept separate from your data. All paper records will be stored in a locked filing cabinet, accessible only to the research team, and all electronic data will be stored on a password protected computer. All information you provide will be treated in accordance with the UK Data Protection Act.

11. What will happen to the results of the research study?

The results of the research study will be used as part of a Doctoral Thesis. The results may also be presented at conferences or in journal articles. However, the data will only be used by members of the research team and at no point will your personal information or data be revealed.

12. Who has reviewed the study?

The study has received full ethical clearance from the Research ethics committee who reviewed the study. The committee is the Research ethics committee who reviewed the study. The committee is the Middlesex University Ethics committee.

13. Contact for further information

If you require further information, have any questions or would like to withdraw your data then please contact:

Cecilia Isabell Urrutia cu084@live.mdx.ac.uk

Supervisor: Dr. Bahman Baluch B.Baluch@mdx.ac.uk
Middlesex University Middlesex University
Psychology Department Psychology Department
+44 (0)20 8411 5375

Thank you for agreeing to take part in this study. You (the participant) should keep this “Participant Information with Consent” sheet since it contains important information and the research teams contact details.

SECTION 2

Middlesex University Guide to Research Privacy Notices

Privacy notices need to be presented whenever data is collected and should be understandable and accessible. Privacy notices must explain the type and source of data that will be processed. They will also set out the processing purpose, data retention schedules and data sharing. Privacy notices must include details of the subject’s rights and who the subject can complain to.

The following example may be used and completed for your research purposes.

Middlesex University Privacy Notice for Research Participants

The General Data Protection Regulation (GDPR) protects the rights of individuals by setting out certain rules as to what organisation can and cannot do with information about people. A key element to this is the principle to process individuals’ data lawfully and fairly. This means we need to provide information on how we process personal data.

The University takes its obligation under the GDPR very seriously and will always ensure personal data is collected, handled, stored and shared in a secure manner. The University’s Data Protection Policy can be accessed here: https://www.mdx.ac.uk/__data/assets/pdf_file/0023/471326/Data-Protection-Policy-GPS4v2.4.pdf.

The following statements will outline what personal data we collect, how we use it and who we share it with. It will also provide guidance on your individual rights and how to make a complaint to the Information Commissioner’s Officer (ICO), the regulator for data protection in the UK.

Why are we collecting your personal data?

As a university we undertake research as part of our function and in our capacity as a teaching and research institution to advance education and learning. The specific purpose for data collection on this occasion is to gather qualitative data to validate findings from previous studies in hopes to help practitioners and those involved in infertility treatment benefit from the results of the present study in giving the best advice to their patients in the pursuit of achieving their goals..

The legal basis for processing your personal data under GDPR on this occasion is Article 6(1a) consent of the data subject.

Transferring data outside Europe

In the majority of instances your data will be processed by Middlesex University researchers only or in collaboration with researchers at other UK or European institutions so will stay inside the EU and be protected by the requirements of the GDPR.

In any instances in which your data might be used as part of a collaboration with researchers based outside the EU all the necessary safeguards that are required under the GDPR for transferring data outside of the EU will be put in place. You will be informed if this is relevant for the specific study you are a participant of.

Your rights under data protection

Under the GDPR and the DPA you have the following rights:

- to obtain access to, and copies of, the personal data that we hold about you;
- to require that we cease processing your personal data if the processing is causing you damage or distress;
- to require us to correct the personal data we hold about you if it is incorrect;
- to require us to erase your personal data;
- to require us to restrict our data processing activities;
- to receive from us the personal data we hold about you which you have provided to us, in a reasonable format specified by you, including for the purpose of you transmitting that personal data to another data controller;
- to object, on grounds relating to your particular situation, to any of our particular processing activities where you feel this has a disproportionate impact on your rights.

Where Personal Information is processed as part of a research project, the extent to which these rights apply varies under the GDPR and the DPA. In particular, your rights to access, change, or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may not be able to remove the information that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. The Participant Information Sheet will detail up to what point in the study data can be withdrawn.

If you submit a data protection rights request to the University, you will be informed of the decision within one month. If it is considered necessary to refuse to comply with any of your data protection rights, you also have the right to complain about our decision to the UK supervisory authority for data protection, the Information Commissioner’s Office.

None of the above precludes your right to withdraw consent from participating in the research study at any time.

Collecting and using personal data

Data will be collected by conducting a video chat interview online via Skype that will take approximately 45 minutes. The Participant will not be asked any personal information other than age to assure participant is over 18.

Data sharing

Your information will usually be shared within the research team conducting the project you are participating in, mainly so that they can identify you as a participant and contact you about the research project.

Responsible members of the University may also be given access to personal data used in a research project for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your records. All of these people have a duty to keep your information, as a

research participant, strictly confidential.

If we are working with other organisations and information is shared about you, we will inform you in the Participant Information Sheet. Information shared will be on a 'need to know' basis relative to achieving the research project's objectives, and with all appropriate safeguards in place to ensure the security of your information.

Storage and security

The University takes a robust approach to protecting the information it holds with dedicated storage areas for research data with controlled access.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of University information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Training is provided to new staff joining the University and existing staff have training and expert advice available if needed.

Retention

Under the GDPR and DPA personal data collected for research purposes can be kept indefinitely, providing there is no impact to you outside the parameters of the study you have consented to take part in.

Having stated the above, the length of time for which we keep your data will depend on a number of factors including the importance of the data, the funding requirements, the nature of the study, and the requirements of the publisher. Details will be given in the information sheet for each project.

Contact us

The Principal Investigator leading this research is Cecilia Isabel Urrutia

Middlesex University Middlesex University
Psychology Department Psychology Department
+44 (0)20 8411 5375
The University's official contact details are:

Data Protection Officer
Middlesex University
The Burroughs
London
NW4 4BT

Tel: +44 (0)20 8411 5555
Email: dpaofficer@mdx.ac.uk

Thank you for agreeing to take part in this study. You (the participant) should keep this “Participant Information with Consent” sheet since it contains important information, and the research teams contact details.

Debriefing

Psychology Department
Middlesex University
Hendon
London NW4 4BT

Researchers name:
Cecilia Isabel Urrutia
Date: February 2021

Study title: **A Semi-structured interview with a UK fertility treatment key coordinator**

The present study was designed to examine the experiences of a UK fertility key coordinator with couples seeking infertility treatments in relation to findings of the public perception on ART in Guatemala.

There is very little research on this topic, particularly on the Guatemalan population. Generally, research has shown that factors such as religion, ethnicity, costs, possible consequences and participant's age and gender may have an impact on how people may regard undergoing fertility treatment via IVF or egg donation. A recent study for example by Pir Jalian (2017) has shown that Iranians are generally not supportive of a child being born by egg donation and believe that it may have an impact on the child in the society. This is in spite of the fact that having a child in a non–Western country such as Iran is the prime aim for all couples.

The interview you complete will help us have a clearer perspective on what the view on is on ART amongst the Guatemalan population compared to the UK and should provide valuable information for practitioners and couples involved in infertility treatment.

Please use the contact information provided to get in touch with the researcher or the supervisor should you have any questions about this study.

Researcher: Cecilia Isabel Urrutia **Supervisor: Dr Bahman Baluch**

CU084@live.mdx.ac.uk b.baluch@mdx.ac.uk

Middlesex University
Psychology Department

Middlesex University
Psychology Department
+44 (0)20 8411 5375

Appendix K- Letter Granting Access to Subjects and Data Collection for Study 3

Email from participant no.2

Dear XXX,

Thank you for your speedy reply!

I will put Feb 3rd into my diary and will contact you nearer the time to touch bases.

Thank you again for your help.

BW

Cecilia Isabella

From: XXX
Sent: 10 December 2020 15:36
To: Cecilia Isabel Urrutia <CU084@live.mdx.ac.uk>
Subject: RE: Doctoral Student requesting interview with consultants undertaking management of Infertility

Dear Cecilia,

I am available on Wednesday the 3rd of February in the afternoon.

Best wishes,

XXX

From: Cecilia Isabel Urrutia [mailto:CU084@live.mdx.ac.uk]
Sent: 10 December 2020 12:32
To: xxxx
Subject: RE: Doctoral Student requesting interview with consultants undertaking management of Infertility

Dear XXX,

Thank you very much for agreeing to help with the next step of my thesis. I am looking to get started on this part of the research sometime in late January/early February.

Meanwhile perhaps you can let me know what availability you might have in late January/early February, and we can reconnect in the new year?

Thank you again for agreeing to help. It’s very appreciated!

Best wishes,

Cecilia Isabella

From: xxxx
Sent: 10 December 2020 11:18
To: CHAKRABARTI, Sanhita (NHS BEDFORDSHIRE CCG) <sanhita.chakrabarti@nhs.net>; ghaly.hanna@mkuh.nhs.uk; Liliana Grosu <Liliana.grosu@bedfordhospital.nhs.uk>
Cc: Cecilia Isabel Urrutia <CU084@live.mdx.ac.uk>

Subject: RE: Doctoral Student requesting interview with consultants undertaking management of Infertility

Dear Sanhita,

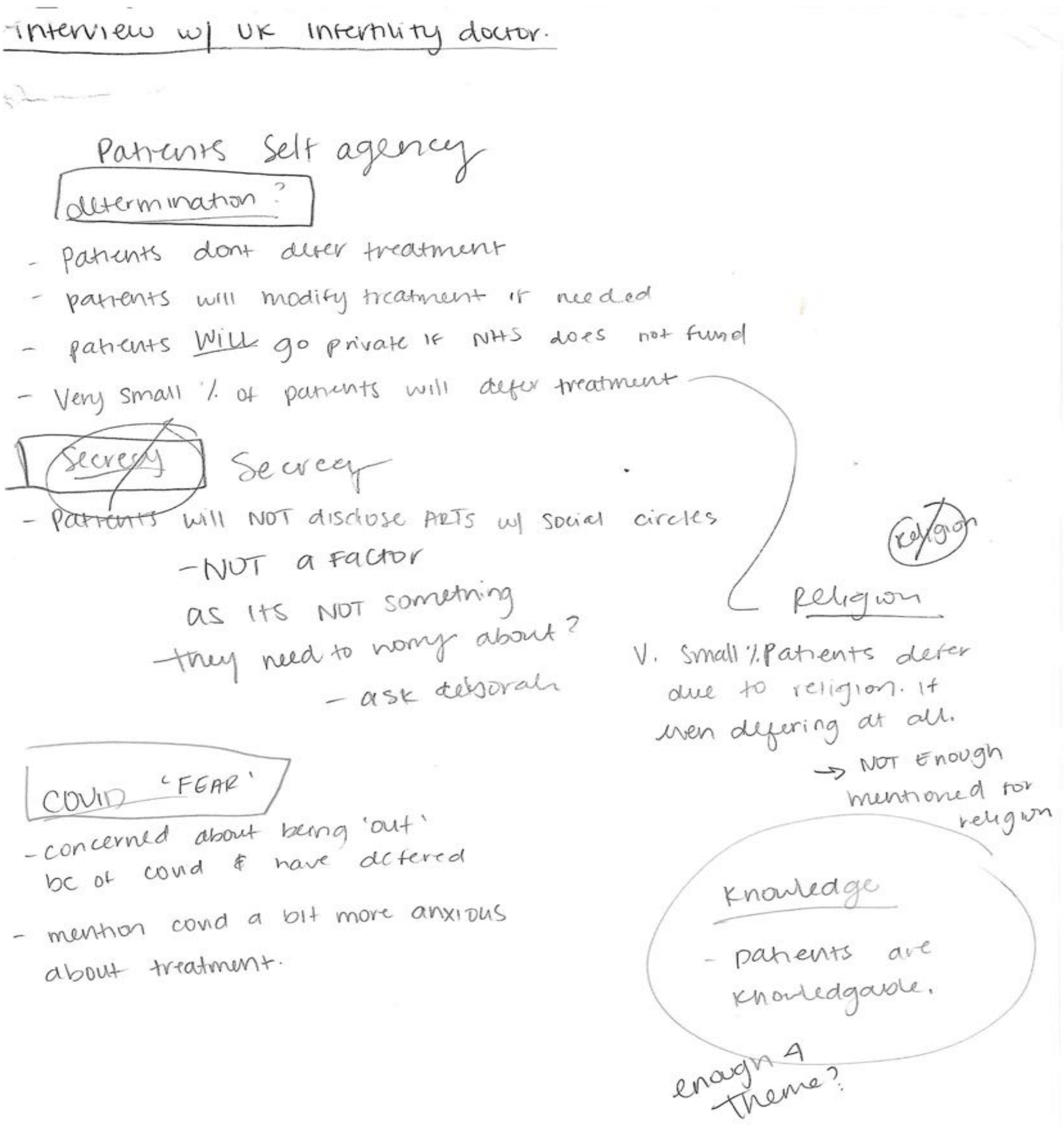
That is absolutely fine. We have a dedicated satellite IVF centre linked with Bourn hall Clinic.

Please advise her to get I touch with me.

Thanks,

XXX

Appendix L- Raw Transcripts and Coding Process Sample for Study 3



Interview w/ UK infertility doctor.

Patients Self agency

determination ?

- Patients dont defer treatment
- patients will modify treatment if needed
- patients WILL go private if NHS does not fund
- Very small % of patients will defer treatment

~~Secrecy~~ Secrecy

- Patients will NOT disclose ARTS w/ social circles
  - NOT a factor as its NOT something they need to worry about?
    - ask deborah

~~religion~~

Religion

V. Small % Patients defer due to religion. If even defering at all.

→ NOT Enough mentioned for religion

COVID 'FEAR'

- concerned about being 'out' bc of covid & have defered
- mention covid a bit more anxious about treatment.

Knowledge

- patients are Knowledgable.

enough 4 Theme?

R: Yes hello doctor can you hear me ok?

D: Yes hello Cecilia Isabella Urrutia is that correct?

R: Hahaha yes that is correct. Perfect.

D: Ok can you hear me ok?

R: Yes it seems to be working.

D: so how long is this going to take? → worried about time?

R: it will take about 45 minutes to an hour if that's ok?

D: oh yes that's ok.

R: Ok perfect So Let's Begin.

D: before we begin I have a question is Guatemala it Catholic country? Doc. interested in Religion?

R: yes Guatemala is a Catholic and Protestant country.

D: So do the Catholics do IVF there?

R: Yes they do IVF there however there is a bit of a stigma attached to it.

D: ok and you want to know if my patients have the same perception as the people you have studied in Guatemala but their perceptions in the UK is that correct?

R: yes that is correct after I want to see what patients in the UK think about undergoing infertility treatment in your experience.

D: ok let's get started.

R: Brilliant so the first question is participants in my research considered religion to play a role in The sailing to engage in a r t treatment to what extent the religion player Factor before during or after any treatment how are these issues family resolved do you think this will change due to the covid-19 pandemic if so how?

→ Majority of people dont alter treatment

D: Okay, umm in my opinion, I do not have many patients that defer their treatment due to the religious views however I do have minority of patients that have rejected the treatment due to religious reasons, or want to modify the treatment. For example based on the religion that they follow they do not want any of their embryos to be destroyed. So we have to tailor according to her needs. However majority of the women do not defer treatment due to religious reasons. I have to say that in my practice we have a huge religious diversity. There are very few people that do not want to go into IVF due to religious reasons.

— Patients will get modified treatment if needed

└ most Patients go for IVF in the end.

R: Right okay. Do you think this has changed due to the pandemic of covid-19 and if so how?

D: No I do not believe there has been any change to treatment due to religious reasons There is no effect.

→ modify treatments / regulation's about embryos

R: Okay, perfect. Would you like to add anything else about this topic of religion?

very Small percent of PPl reject due to religion

D: What I'm trying to say is that there is an extremely small percentage of patients that reject IVF due to religion Or religious reasons. We do try our best to tailor the requirements to compliment the religious views if needed.

R: Okay thank you. So we'll move on to question number two then. Participants in my research considered that the government should not fund any fertility treatment as there are other priorities now to what extent were there concerns relating to the funding of the treatment and whether or not the government should offer financial support towards the cost of the treatment? How are these issues finally resolved and do you think this will change due to the covid-19 pandemic? If so how?

Funding is not up to clinic but up to NHS

D: So yes in United Kingdom unlike other places, Every treatment is under the public sector in the NHS, very little treatment is in the private sector. However there is private work going on. Now the government is not willing to offerFree funding for all patients who require IVF, Different sectors have to meet different criteria, And this depends on the area we call it commissioning groups. If these areas meet the criteria they will get free funding However the number of cycles they get really depends on the Commissioning Group.

R: Right...

although gov funds IVF it is a lottery to get it paid for.

D: So there is no real Consistency it all has to do with the area They Call It the Postcode Lottery. As it depends on where you live, Depending on where you live is if you get a free cycle Some areas do not fund IVF at all. So there has been a national growing weed for every women to get one IVF cycle free. one cycle free for women who are waiting on IVF. But that does not come true because the different commissioning groups do not agree on that. So currently depending on where you live You have to meet the specific criteria from the commissioning groups in that area Depending on where you live you're entitled to 1 to 3 Cycles depending on the Commissioning Group in that area. And if you don't meet the criteria the only other option is to go for IVF privately.

→ although people might not get it funded, PPl will still go for treatment privately.

R: Oh okay..

D: Okay? Now, they can appeal The decision not to fund them because They don't meet the criteria but most of the time the appeal will be denied and they will have to go private.

R: I see, okay. And will people usually do that, will they go private?

D: Yeah yeah they go private.

R: Right, okay. And have you seen any changes to this due to the covid-19 pandemic?

→ yes as more patients will go private not enough NHS funds.

D: There has been many changes because when the government financial status declines, They can say that they will not fund any Cycles or even say they will not fund IVF. So only time will say.

R: Okay thank you. Will you like to add anything to this topic here?

D: No.

R: Okay, so moving on to my third question, participants in my research expressed that in general, society should not know the origins and methods of conception however it was

2