



#### **Abstract**

Infertility is a highly prevalent reproductive health condition in Sub-Saharan Africa, which often has a devastating impact on the people concerned. In Ghana, a country where childbearing is greatly valued and childlessness is stigmatized, the infertility rate is around 15%. The study was carried out to explore how childless couples in Accra, Ghana perceive and respond to the innovative Walking Egg fertility treatment, introduced by the Association of Childless Couples of Ghana. This more affordable technology responds to the rising demand for ARTs, a consequence of the suffering and stigmatization of childless couples. The research was based upon anthropological literature, thirty-one in-depth interviews, a focus group discussion and several ethnographic observations. Using Weiss' cultural construction of illness (1988) as an anthropological lens through which to look at childlessness and the response to infertility treatment, this thesis explores how Ghanaian couples ascribe meaning to their childlessness, how this subsequently influences their help-seeking behavior and finally situates their response to tWE. Using a concept of Rayna Rapp (1998), it is argued that Ghanaian childless couples – confronted with a new technology and obliged to regain their moral position towards this technology – may become moral and even double pioneers in their quest for parenthood. Moreover, it is put forward that Rapp's concept of (moral) pioneering may be incorporated into Weiss' cultural model of illness as each new form of treatment or technology has its pioneers.

**Key words:** Ghana, infertility, childlessness, ARTs, help-seeking behavior, moral pioneers, the Walking Egg, fertility treatment.

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#### 1. Introduction

This study is part of a broader comparative research project carried out in Kenya and Ghana, entitled "Involuntary Childlessness, 'Low Cost' IVF and Fertility Associations in Ghana and Kenya: Enhancing Knowledge and Awareness". This multidisciplinary research is funded by Share-Net International. It has a quantitative part – carried out by two child development and education master's (CDE) students – and a qualitative part – carried out by four medical anthropology and sociology (MAS) master's students – of the University of Amsterdam. Infertility is a highly prevalent reproductive health condition in Sub-Saharan Africa, which often has a devastating impact on the people concerned. Yet, thus far it has received scant attention from policy makers, non-governmental organizations (NGOs) or donors. The goal of the overall project is to increase knowledge and awareness about infertility and childlessness among these stakeholders and to generate insight into the impact of two currently undertaken activities – the introduction of more affordable in-vitro fertilization (IVF) as introduced by the Walking Egg (tWE) and the establishment of patient organizations – to address infertility in Ghana and Kenya. Insights gained from the overall project are implemented to improve infertility interventions in Ghana, Kenya and other countries in the global South<sup>1</sup>.

Within the context of this broader project, my thesis focused on Ghana, a country I subsequently visited with the intention of studying a specific novel fertility treatment: the Walking Egg treatment. My objective was to find an answer to the following question: 'How do childless couples in Ghana perceive and respond to the Walking Egg fertility treatment?' Field research revealed that local perception and response to any fertility treatment is an intricate affair shaped by diverse social, cultural, religious, economic and political factors; and any analysis must be situated within a framework that can handle this complexity.

As a result, this thesis provides contextualized insights for locally appropriate implementation of this treatment. It presents a theoretical framework which extends Weiss' cultural constructivist model (Weiss 1988), the three empirical chapters which map onto the elements of this framework, finally culminating in a chapter focused on the Walking Egg treatment. The empirical chapters explore how Ghanaian couples experience infertility and ascribe meaning to their childlessness, how this subsequently influences their treatment seeking behavior and finally situating their response to tWE within this context.

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<sup>&</sup>lt;sup>1</sup> Retrieved from research proposal 'Involuntary Childlessness, 'Low-Cost' IVF and Fertility Associations in Ghana and Kenya: Enhancing Knowledge and Awareness'.

Following this introduction, the second chapter provides background and context for infertility, infertility care and assisted reproductive technologies (ARTs) in resource-poor areas and embeds the study within current debates. The context of Ghana as a nation is discussed, and subsequently information about the Association of Childless Couples of Ghana (ACCOG), the fertility center and the Walking Egg project is provided. Finally, the research aims and relevance of this study are reviewed.

Building on this background the third chapter develops and presents the theoretical framework for this research. It includes relevant anthropological theories and concepts. First of all, I will discuss Weiss' conceptual framework since the structure of this thesis is partly inspired by his work. In addition, I will approach infertility as a social construct. I then elaborate on Kleinman's Explanatory Model (1980), as one of the components of Weiss' framework, to analyze the beliefs couples hold about their childlessness and the personal and social meaning they attach to infertility. Subsequently I explain Lock and Kaufert's notions on 'pragmatic behavior' in order to understand how childless couples react to medical technology and how they make decisions in the biomedical field. Finally I elaborate on the concept of 'moral pioneers', as developed by Rapp (1998), in order to use this concept in addition to Weiss' conceptual framework.

Chapter four presents my field methodology. I conducted my fieldwork from February to April 2016 at a fertility center in Madina, Ghana, recently set up by the local Pentecost Hospital in collaboration with ACCOG. Patients travel from all over Ghana to visit this center. Recently, ACCOG introduced a new form of in-vitro fertilization (IVF) at this fertility center. This more affordable and accessible IVF treatment is developed by 'The Walking Egg' (tWE), an NGO based in Belgium. This treatment is referred to as 'tWE-IVF'. Together with Evelien Oomen (student MAS) I was responsible for the ethnographic part, while Margot Visser (student CDE) took responsibility for the quantitative data. First I will review the ethnographic study site. Then I will discuss the different forms of data collection – observation, interview and focus group discussion – and describe the data analysis. Finally I will discuss the ethical considerations, my positionality and the limitations of the study.

In chapters five, six and seven I present the empirical data I collected. To fully understand local perceptions and choices I will first elaborate on the meaning of infertility and childlessness within the Ghanaian context in the fifth chapter. I will show how the meaning childless couples ascribe to their infertility emerges in four different domains: the personal, family, societal and religious domain. Subsequently, I will discuss the treatment-seeking behavior engendered by the strong desire for a child in chapter six. The several factors

influencing this same behavior, such as perceived causes of infertility, access and availability of fertility care, advice given by family and community members, religious beliefs and gender influence will also be highlighted. The information given in these chapters adds to and reaffirms existing insights on infertility and help-seeking in Ghanaian contexts with greater attention paid to the religious aspect than may be encountered in previous research on this subject. These two empirical chapters will provide an insight into the circumstances that led the childless couples into the uncharted territory of ARTs.

Chapter seven delves into tWE and argues that childless couples who are confronted with tWE treatment could be seen as 'double' pioneers (based upon Rapp's concept of moral pioneer). Confronted with tWE-IVF, couples have to regain their moral position in relation to this new technology and decide whether or not to use it. Therefore, this chapter looks into how couples perceive tWE treatment and how they become (moral) pioneers. I will describe three different moments of this 'pioneering' of childless couples. First I will describe their point of view and decision-making with respect to ARTs in general, then their moral position regarding third party involvement and finally their positionality towards tWE-IVF. I argue that this concept can be added as a new component to Weiss' framework.

To conclude, in chapter eight I will summarize the major findings of this study, make some recommendations and answer my research question.

## 2. Infertility and Assisted Reproductive Technology in Context

In order to contextualize my research, I provide an overview of, and background information about infertility, ARTs and the context in which this study is carried out. First, the concept of infertility and its meaning will be explored. Next, information on infertility care and the globalization of ARTs will be analyzed. Subsequently, literature on infertility and ARTs in the Ghanaian context will be reviewed. Then I will provide information about the Association of Childless Couples of Ghana and the Pentecost Hospital's Fertility Center, where I conducted my research. Thereafter, a description will be given of The Walking Egg project which introduced more affordable and accessible IVF to Ghana. Lastly the research aims and relevance of this study are discussed.

#### 2.1 Infertility

Infertility is an important global public health issue, affecting more than 15% of all couples of reproductive age globally<sup>2</sup>. According to the World Health Organization, more than 180 million couples in developing countries suffer from primary or secondary infertility<sup>3</sup>. There are major differences in the definitions of and the approach to infertility, which will be clarified in the theoretical framework. Within this thesis, 'infertility' is defined as the 'inability to conceive after 12 months of regular unprotected intercourse by couples that have the intent to become pregnant' (Greil et al. 2011:736). In the biomedical context, this is also called 'primary infertility'. 'Secondary infertility' refers to couples who have been able to conceive (but did not necessarily experience giving birth) at least once, and experience infertility afterwards<sup>4</sup>.

Infertility can be caused by many different factors. From a biomedical perspective, infertility is caused by physical 'defects' due to male factors (30%), female factors (30%) or a combination of both (30%). The remaining 10% falls into the category of unexplained factors (Vayena et al. 2002:22). In most cases, male infertility is caused by a diminished sperm production, resulting in a no sperm-count or a low-sperm count (Irvine & Cawood 1996:273). Common causes of female infertility are ovulation disorders, blocked fallopian tubes, uterine fibroids or the consequences of an unsafe abortion (Vayena et al. 2002:22).

<sup>&</sup>lt;sup>2</sup> Website: http://www.who.int/bulletin/volumes/88/12/10-011210/en/ (10-11-2015).

<sup>&</sup>lt;sup>3</sup> National, Regional, and Global Trends in Infertility Prevalence Since 1990: A Systematic Analysis of 277 Health Surveys - collaboration with WHO in 2004.

<sup>&</sup>lt;sup>4</sup> Website: https://www.nlm.nih.gov/medlineplus/ency/article/001191.htm (17-01-2016).

However, these are the biomedical explanations of infertility. In several non-western parts of the world, the cause of infertility is considered to be supernatural. A study into the social meaning of infertility and childbearing in Ghana, for example, revealed that some Ghanaians see infertility as a condition brought on by supernatural causes, such as bewitchment, or by disobedience to social norms (Tabong and Adongo 2013). It is important to pay attention to both the biological and the social explanation in order to understand how couples experience infertility and give meaning to their childlessness.

The experience of infertility can be interpreted as a 'disruption of life' (Becker 1994). Becker states that in all cultures, 'the life cycle is structured by expectations about each phase of life, and meaning is assigned to specific life events and the roles that accompany them' (1994:383). However, 'when expectations about the course of life are not met [...] people experience inner chaos and disruption of the fabric of their lives. Such disruptions represent loss of the future' (ibid.). There is a sense of being deprived of one's future. The consequences of childlessness are very varied and context specific, including for example: social insecurity, increase in sexually transmitted diseases or marital instability.

#### 2.2 Infertility care and ARTs in developing countries

Worldwide, many different forms of infertility care have emerged as a response to unwanted infertility. Within the broad field of infertility care, this section will focus on assisted reproductive technologies (ARTs). ARTs encompass 'a wide range of techniques designed primarily to aid couples unable to conceive without medical assistance' (Akande 2012:8). They involve several types of medical treatment such as intrauterine insemination (IUI)<sup>5</sup>, in vitro fertilization (IVF)<sup>6</sup> and intracytoplasmic sperm injection (ICSI)<sup>7</sup>. The past 30 years there has been a rapid evolution of ARTs which have, according to Inhorn and Birenbaum-Carmeli, 'evoked a variety of social, cultural, legal and ethical responses' (2008:178).<sup>8</sup>

According to Simpson and Hampshire, the provision of ARTs have gone through several phases. In their first phase – between 1980 and 1990 – extra-corporeal conception became available (mainly) in the private sector to a relatively small number of people in Europe,

<sup>5</sup> IUI is a technique whereby sperm (male partner's or donor's) are injected directly into the uterus, sometimes preceded by sperm sorting for sex selection.

<sup>&</sup>lt;sup>6</sup> IVF is a technique whereby sperm and eggs are fertilized outside the body, after which the embryo is transferred to the uterus.

<sup>&</sup>lt;sup>7</sup> ICSI is a variant of IVF that overcomes male infertility by micromanipulation and injection of "weak" sperm directly into oocytes under a high-powered microscope.

<sup>&</sup>lt;sup>8</sup> I would like to stress that there is a rich body of ART scholarship; but due to lack of space in this study I will only give a small glimpse of the (anthropological) debates surrounding ARTs.

the Middle East and North America (Simpson & Hampshire 2015:2). The second phase of ARTs – since the late 1990s – refers to the spread of IVF across the globe while the techniques for the greatest part were still available only to elites. Recently, the delivery of ARTs is spreading beyond the private sector in both first and third world settings (ibid.: 3). Here, the authors refer to ARTs as being in their third phase: 'an extension of access and availability that further integrates ARTs into infertility treatment across the globe' (ibid.: 3). New ART clinics are opening in countries where this would have been previously unthought-of.

Despite the fact that the majority of couples dealing with infertility are residents of developing countries, the provision of infertility medical services in developing countries is either unavailable or very costly (Ombelet et al. 2008:605). Infertility in developing countries is underestimated and neglected by both local governments and international non-profit organizations (Ombelet et al. 2010). Infertility care and the implementing of ARTs are not considered a priority because of: 'the widespread belief that infertility is not a pressing problem in poor developing countries where fatal and contagious diseases remain uncontrolled' and 'because infertility as such is not directly life-threatening' (ibid.: 108). However, these arguments completely neglect the devastating psychological, social, personal and economic burden of being childless in most poor societies (ibid.).

The provision of ARTs in poor resource settings is the controversial subject of many debates. I will briefly describe three of the current debates most relevant to this thesis, hoping to provide an insight into the socio-cultural issues and obstacles that infertility care has to battle in resources-poor countries.

The first debate about the globalization of ARTs in developing countries concerns population growth (Gerrits 2010, Ombelet et al. 2010). This argument of overpopulation is used: 'in countries where overpopulation poses a demographic problem, infertility management should not be supported by the government' (Ombelet 2011:258). The implementation of ARTs is not considered a priority in countries struggling to decrease their fertility rate and hardly able to meet the health needs of the population. Consequently, there is a lack of interest for infertility care and ARTs from both the public health sector and NGO's in resource-poor areas. This focus on population control complicates the introduction of ARTs in developing countries.

The second debate involving ARTs stems from the moral discussions about the use of third-party material (donor sperm, eggs and embryos) and surrogate bodies. According to Gerrits, (ethical) regulation of ARTs in many resource-poor countries 'is still non-existent and constitutes an enormous challenge for the authorities in charge' (2015:102). The use of third-party material raises a mass of questions and concerns; governments, churches and other

authorities exerting societal influence will have to re-establish their position towards the implementation of ARTs and donor gamete. The introduction of ARTs and third party material is not, per definition, welcomed everywhere. These technologies often have to compete with traditional perceptions about procreation – 'the sanctity of the marital relationship and the sanctity of the embryo' (Dutney 2007:174) – where conception should only take place between husband and wife.

Finally, a frequently used argument in the debate surrounding ARTs is one concerning the scarcity of health resources and the limited budget available for fertility care; it is 'hard to justify expensive fertility treatment in settings with few resources and more important challenges to deal with' (Ombelet 2011:259). It is debated whether the use of costly techniques can be justified in countries where poverty is still an important issue (ibid.). The financial burden of ARTs is often greater in non-Western countries because their government and NGO budgets are limited (Inhorn Birenbaum-Carmeli 2008:179). Infertility care is rarely funded by the state or health insurance. Moreover, infertility services in developing countries are often only available in the capital or in a few large cities and travel expenses and accommodation increase the total costs of treatment for rural patients (Gerrits 2012:3). However, these high costs have led to the development of low-cost fertility treatments, on which I will elaborate later.

#### 2.3 Infertility and ARTs in Ghana

For the purpose of this study, it is important to provide some information about the Ghanaian context. This section offers an insight into the socio-cultural perceptions of Ghanaians, giving particular reference to men and women with infertility problems.

Ghana, officially called the Republic of Ghana, is located in West Africa (see appendix 1 for map of Ghana) and achieved independence from the United Kingdom in 1957, the first sub-Saharan African nation that gained its freedom from European colonialization (Heaton & Darkwah 2011:1578). Ghana has a population of approximately 27 million with a life expectancy of 61 years and is considered a low-middle-income country. There is great ethnic, linguistic and religious diversity, encompassing ethnic groups such as the Akan, who constitute almost half of the population, including the Ashanti people; the Mole-Dagbon, Ewe and Ga-Dangme. Although English is the official language and also the lingua franca, Ghana is a

<sup>10</sup> Website: http://www.indexmundi.com/ghana/ethnic\_groups.html (10-07-2016).

<sup>&</sup>lt;sup>9</sup> Website: http://data.worldbank.org/country/ghana (08-07-2016).

multilingual country, each ethnic group speaking its own language. It is a highly religious country, 96% of the population<sup>11</sup> considering themselves to be religious (Hiadzi 2014:8). Ghana is mostly a Christian country (Evangelic/Pentecostal, Protestant, Catholic and other Christian beliefs) with Islam also holding influence (Addai, Opoku-Agyeman & Ghartey 2011). In some areas, traditional (indigenous) African beliefs are also practiced (ibid.).

In their article about religion and trust in Ghana, Addai et al. state that studies from Ghana have established that religion strongly informs behaviors, including reproductive health decisions, use of reproductive services and sexual behavior (2011:996). Therefore, it is of great importance to analyze the religious context – which I will do in chapter five – as high levels of religiosity may influence the couples' response to infertility.

Beside religion, experiences of infertility are influenced by other socio-cultural aspects. According to Nana Yaw Osei (Chief Executive Officer of ACCOG) 'the joy of couples is to have children after marriage since 'voluntary childlessness' cannot be found in the dictionary of people in Ghana' (Osei 2014:18). This statement shows an important characteristic of traditional Ghanaian society: pronatalism (Nukunya 2003), which embodies 'the belief that a person's social value is linked to procreation' (Parry 2005:337). The ultimate purpose of marriage is to procreate because children are seen as 'a means of perpetuating the family lineage' (Alhassan et al. 2014:4). Hörbst and Gerrits state that normative mainstream culture in Ghana demands that a couple procreates, 'in order to be socially accepted and respected as complete human beings' (2016:6). Children are highly valued because they give worth and meaning to marriage, and 'marriage and family are highly valued religious and societal aspects' (ibid.). Besides status identity, children are also seen as a form of economic security in old age in Ghana (Donkor 2008:23). When children are not conceived as desired, a married couple will often experience a wide range of emotions: grief, disappointment, anger, helplessness and guilt.

Since children are highly valued for social, cultural and economic reasons, infertility can have a devastating impact on the couples concerned and often creates enormous problems for them (Alhassan et al. 2014:4). According to the Ghana Statistical Service (2009), the infertility rate in Ghana is around 15%, which has consequences on different levels. At societal level, childless men and women may suffer from stigmatization and social exclusion (Donkor & Sandall 2007). At community level, childless couples may experience pressure from family or are denied participation in certain rituals (Hiadzi 2015). Furthermore, as childless couples do not have children to take care of them, their social and economic security might be affected on

<sup>&</sup>lt;sup>11</sup> The Global Index for Religiosity and Atheism (2012) placed Ghana at the top of the 'Most religious countries in the world'

a personal level (Donkor 2008:23). Additionally, gender plays an important role in the blaming process, since women are often held responsible for the absence of children (Donkor 2008:22). The above insights were also shared by my respondents, in this thesis I will discuss the impact infertility had on my respondents.

The socio-cultural importance of children in combination with the high infertility rate in Ghana lead to 'a high demand not only for fertility treatments in the so-called traditional and religious health-care systems, but also for biomedical interventions' (Hörbst & Gerrits 2016:7). The high value placed on fertility in Ghana co-created the space for ART clinics (ibid.). As a consequence, Ghana is (together with Nigeria and South-Africa) an IVF leader in sub-Saharan Africa (Inhorn & Patrizio 2015:8). The first IVF baby was born in 1995, and since then the number of IVF clinics in Ghana is growing (Gerrits 2016:33). Recent research has shown that fourteen fertility clinics in Ghana – mostly located in or near the capital – are known to offer ARTs (IUI, IVF, ICSI) (Hörbst & Gerrits 2016:7). The clinics offering these high-tech treatments are all private and the public health sector is not involved in the provision of ARTs. Patients have to pay these expensive treatments (around 2500 euros per IVF cycle <sup>12</sup>) themselves since there are no national funds covering these expenses (ibid.). To date, there are no ART legislation or professional regulations for the use of ARTs in Ghana (ibid.).

#### 2.4 ACCOG and The Pentecost Hospital's Fertility Center

The Association of Childless Couples of Ghana (ACCOG) – the first Ghanaian support group for people facing infertility – is a non-faith-based NGO which supports those living with infertility in Ghana and beyond. The association was established and registered in July 2012 (Osei 2014:100) by Nana Yaw Osei: the chief executive officer (CEO) who also performs the role of fertility counselor. The name of this association is chosen with the intention to remove the stigma on infertility in Ghana and to encourage freedom of discussion about childlessness. ACCOG seeks to 'provide a platform for childless couples to enjoy the benefits of marriage while facilitating their access to other options of having children' (Osei 2014:99). According to Osei the association 'also provides counselling and other support services to those divorced as a result of childlessness to enable them to cope with their situation' (ibid.: 99). ACCOG's mission, objectives and activities are presented in Table I (Osei 2014:100):

 $<sup>^{12}</sup>$  This price does not include examinations, hospitalization, medicines and other costs.

**Table I.** — ACCOG: The Association of Childless Couples of Ghana.

#### **MISSION**

To support members in their quest to have a happy family

#### **OBJECTIVES**

- · To eliminate/decrease the stigma associated with childlessness.
- To build mutual understanding between couples for a life free of violence.
- To provide persons interested in Assisted Reproductive Technologies (ART) with counselling and /or assistance for the treatment.
- To empower members, especially women, economically and provide them with training and education (Adult Literacy Education).
- To encourage members to consider adoption as an alternative.

#### **ACTIVITIES**

ACCOG has four main areas/programmes:

- · Advocacy and Public Education
- · Counselling and Reproductive Healthcare Services
- Economic Empowerment
- · Adult Literacy Education

ACCOG is a member of International Consumer Support for Infertility (iCSi), a network of patient associations from more than 40 countries across the world. Their vision is to 'empower patients to become full partners in ART health care and public policy by building effective relationships with providers, governments and media worldwide'. ACCOG tries to realize this vision in Ghana by creating public awareness of infertility and ARTs. So far, ACCOG interacted with more than 400 childless couples and individuals (Osei 2014:101).

Currently, one of the main aims of ACCOG is to increase affordable and accessible ARTs in the country. Nana Yaw Osei was determined to introduce the more affordable tWE method in Ghana, which will be discussed below. To offer fertility treatment to their members, the association encouraged the Pentecost Hospital in Madina to set up a private fertility clinic on its compound. Both the Pentecost Hospital's Fertility Center and ACCOG receive funding from the hospital, which in turn is financed by the Ghanaian government. Apart from the funding of the hospital, ACCOG has not been able to secure any funds for its activities (Osei 2014:101) as infertility is not on the national agenda.

The fertility center staff is provided by the main hospital. Presently, Dr Attoh, the medical administrator and medical doctor, runs the center, together with Dr Lartey, the medical doctor. The center has its own laboratory where a biomedical scientist and an embryologist carry out tests and do the analysis. New clients are welcomed by the secretary. Two nurses are present to assist new clients and inform them about the procedure. A cleaner is employed on a daily basis.

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<sup>&</sup>lt;sup>13</sup> Website: http://www.icsicommunity.org/ (08-08-16).





Reception/waiting room

The Pentecost Hospital's Fertility Center

### 2.5 The Walking Egg project

According to Nana there is an urgent need for accessible and affordable high quality infertility care due to the severe economic and socio-cultural consequences of infertility and childlessness in Ghana (Osei 2014). Even though ACCOG has signed an agreement with some fertility hospitals to get reduced prices for its members, the key factor withholding infertile couples from treatment remains a financial one (ibid.: 19). According to Inhorn and Patrizio, the high cost of IVF and the lack of IVF clinics has inspired clinician-led efforts to bring low-cost IVF (LCIVF) to resource-poor areas (2015:2). This recent development in the field of ARTs has been called 'a reproductive justice movement, driven by the goal of helping the world's infertile, most of whom are located in resource-poor settings' (ibid.: 20). Likewise, ACCOG is involved in the introduction of more affordable and accessible IVF in Ghana.

In order to introduce LCIVF in Ghana, ACCOG recently started a collaboration with a Belgian based non-profit organization: 'the Walking Egg' (tWE) (Ombelet 2011). The main goal of this project is to 'raise global awareness surrounding childlessness, and to make infertility care in all its aspects universally available and accessible for a much larger part of the population' (Ombelet 2013:162). In his article Prof. Dr. Ombelet, gynecologist and cofounder of tWE, explains the benefits of this new simplified IVF method, referred to as 'tWE-IVF' in this thesis: 'With this new system, specifically designed for low resource settings, we can avoid the high costs of medical gases, complex incubation equipment and infrastructure typical of IVF laboratories in high resource settings' (2013:165). The price of tWE-IVF in Ghana, including all expenses, is estimated to be around 1000–1500 Euros per IVF cycle, less than half the price of traditional IVF in Ghana (Gerrits 2016:37). This new laboratory method

has recently been tested in Belgium (Van Blerkom et al. 2014), resulting in forty births.<sup>14</sup> Unfortunately, despite these encouraging results in Belgium, the first batch of treatments in Ghana<sup>15</sup> did not result in a single pregnancy. This is striking because the fertilization rate of the collected eggs was excellent (more than 90%). Experts of the Walking Egg and the Fertility Center suggest that there was – for an unknown reason – a very poor response to Tamoxiphene, the medication that stimulates the ovarian function.<sup>16</sup> The women that took part in the first batch were offered to participate in the second batch free of charge (which would take place after my fieldwork period), while the Walking Egg team and the Ghanaian team are investigating the cause of the earlier failure and attempting to increase the success rate.

The failure of the first tWE-IVF batch is not the only challenge the Walking Egg faced when introducing the method in Ghana. The new method is interwoven in a debate of skepticism, suspicion and fear of competition. To start with, it took Dr. Van Blerkom<sup>17</sup>, who developed the simplified culture system, a year to convince the Belgian medical ethics authority that the method was worth trying in humans: 'it's so simple that some people don't believe it', he explains.<sup>18</sup> But not only critics are skeptical about the simplification of the treatment; commercial and western fertility clinics in particular are not keen on the Walking Egg project either. There is a lot of opposition and people lobby from different sides to stop the new development<sup>19</sup>. According to Dr Attoh, this is explained by the fact that the project compels the conventional IVF treatment centers to reduce their fees: 'their business will be suffering and they would do anything for us not to succeed'. And lack of knowledge about the method, combined with the fear of competition, – according to him – has led the conventional clinics to spread discouraging rumors, alleging that tWE-IVF is only an experiment and clients are used as guinea-pigs; that the program will fail; and that treatment may be accompanied by heavy complications.<sup>20</sup>

The decisions made and actions undertaken by the childless couples in the current study,

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<sup>&</sup>lt;sup>14</sup> Website: http://www.pickabrain.fr/2016/06/how-a-team-of-belgian-doctors-is-bringing-cheap-ivf-to-the-world/ (08-08-16)

<sup>&</sup>lt;sup>15</sup> From November 18<sup>th</sup> till November 30<sup>th</sup>, an international Walking Egg expert team visited the Pentecost Fertility Centre where a first cohort of about 20 patients was treated with tWE-IVF-method.

<sup>&</sup>lt;sup>16</sup> Website: http://www.thewalkingegg.com/content/first-mission-pentecost-fertility-center (08-08-16)

<sup>&</sup>lt;sup>17</sup> Jonathan van Blerkom is a professor in the department of molecular, cellular and developmental biology at the University of Colorado, the IVF Laboratory Director at Colorado Reproductive Endocrinology in Denver and a member of the Board of Directors of the Walking Egg Foundation.

<sup>&</sup>lt;sup>18</sup> Website: http://www.theverge.com/2014/6/10/5793872/a-low-tech-breakthrough-could-put-in-vitro-fertilization-in-reach-for (08-08-16)

<sup>&</sup>lt;sup>19</sup> Video 'The Walking Egg in Africa (Ghana)', a production of Tamara Swing with the support of The Belgian Development Cooperation. https://www.youtube.com/watch?v=oqJRbL4D2Gg (08-08-16)

<sup>&</sup>lt;sup>20</sup> It is imperative that positive results are attained in the near future to dispel these concerns.

set out in the empirical chapters, should be interpreted in the light of the debate and concerns described above.

#### 2.6 Research aims and relevance

This research was motivated by the introduction of the Walking Egg initiative in Ghana. The first phase of this project was monitored by interviewing the childless couples who pursue medical interventions – in particular tWE-IVF – to achieve parenthood. I have paid special attention to the socio-cultural context in which the meaning of childlessness is shaped because it strongly affects the way people explain, experience and deal with infertility. It clarifies why these childless couples, eagerly looking for a solution, – at a certain moment – have decided to use modern reproductive technologies. There is relatively little sociological or anthropological research on the adoption of ARTs in an African context. According to Bochow, 'studies relating to the social acceptability of ARTs in African societies are still very limited' (2015:136), and so this study hopes to make a significant contribution to the literature concerning this topic. It will give an insight into personal experiences of infertility treatment and the ethical and moral considerations about these technologies by the couples involved. Furthermore, I will show how, in their turn, these technologies impact the search for a solution. Finally, by providing an insight into the meaning and implications of childlessness in Ghana, this thesis intends to put infertility on the international reproductive health care agenda.

#### 3. Theoretical Framework

To define the perception of and response to infertility treatment by childless couples, this chapter will discuss relevant anthropological theories regarding the construction of illness and help-seeking behavior.

First of all, Weiss' conceptual framework will be discussed. This model reveals the complex relationship between the various components that affect the perception of, and the response to illness. I will build upon this framework to show that these are also the components of infertility and to interpret the complexity of the way infertility is socially constructed within a particular cultural context. In this thesis I will elaborate on infertility as a social construct. Subsequently, Kleinman's explanatory model, as part of Weiss' framework, will be explained in order to explore how couples experience and interpret their childlessness. Next, Lock and Kaufert's notions on pragmatic behavior will be discussed to better understand treatment-seeking behavior. Finally, the concept of 'moral pioneers' will be described, a term introduced by Rayna Rapp to describe women who had to choose whether or not to terminate their pregnancies, based on the results of amniocentesis. Above theories and concepts inform the analysis of my data.

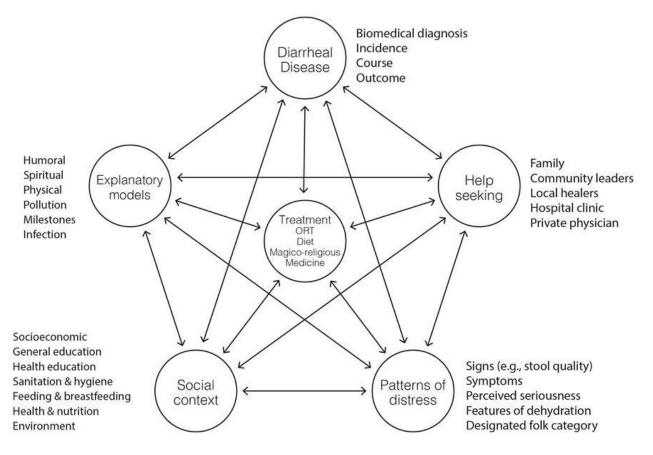
#### 3.1 Weiss' cultural model of illness

In his article about diarrheal illness-related beliefs and practices, Weiss (1988) provides a conceptual framework to show the cultural construction of diarrheal disease. According to Weiss, the framework is based on several concepts developed by medical anthropologists, including 'patterns of distress', 'explanatory models', 'patterns of help-seeking' and 'specific treatments' (ibid.). Patterns of distress – based on notions of Nichter – refer to 'the constellation of symptoms that people complain about and the ways they experience the effects of illness' (Weiss 1988:6). Explanatory models, developed by Kleinman, 'characterize the meaning people attribute to illness as they try to explain it' (ibid.: 6). Patterns of help-seeking show diverse types of help-seeking behavior, from both modern and traditional sources.

Each set of variables shown in the model is related to the others. Together they characterize the 'cultural construction of illness'. According to Weiss, each component represents an aspect of the 'complex relationship between a disease and the cultural context in which it occurs' (ibid.: 7). The several determinants of the experience of illness are interrelated and form what Dunn refers to as a 'causal web' (Dunn & Janes 1986).

I will make use of Weiss' conceptual framework because it shows how the cultural context 'determines perceptions of illness and how people respond to it' (Weiss 1988:6) and visualizes how many factors influence this construction of illness. The focus is mainly on the social context, explanatory models, help-seeking behavior and treatment.<sup>21</sup> I am not the first one in using Weiss' model in the context of infertility: in their article on social and cultural aspects of infertility in Africa, Gerrits and Hardon (2001) created a framework that was inspired by Weiss' conceptual framework. It provides a comprehensive overview of cultural, social and economic aspects relevant to infertility. The authors show how cultural, social and economic factors influence the way people explain, experience, perceive and deal with infertility.

The social context and explanatory models will be covered in chapter 5. Chapter 6 is focused on the help-seeking component and chapter 7 will discuss the treatment aspect of Weiss' model.



Cultural construction of diarrheal illness: interrelationship of social factors, illness experience, help seeking and outcome

Source: Weiss (1988:6)

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<sup>&</sup>lt;sup>21</sup> I only came to the decision to implement this model during the analysis of my data and the process of writing. The fieldwork therefore does not include data on patterns of distress.

#### 3.2 Infertility as social construct

In spite of the attention paid to infertility by a multiple of disciplines and sectors, including research organizations and those in the private and public sector, there are major differences between the diverse definitions of infertility, the social framing of this issue, and the recommendations for action. Whether infertility is characterized as a disease or a social condition, for example, has implications for policy and practice (Van Zandvoort, De Koning, & Gerrits 2001; Greil et al. 2011). The line between fertility and infertility is often blurred (Greil & McQuillan 2010:1), depending on the definitions employed and on the socio-cultural context in which it is experienced and interpreted (Greil et al. 2011:740).

Within the scope of this research infertility is approached as a social construct. Many authors confirm that 'an adequate social scientific approach to infertility needs to recognize that infertility is a socially constructed phenomenon' (Greil & McQuillan 2010:12). This approach emphasizes the importance of the socio-cultural context – such as gender ideology, access to care, family structure, ethnic identity and social class – in shaping the lived experience of infertility (Greil et al 2011:740).

Infertility is a phenomenon with far-reaching psychological, social and economic consequences; the nature of these consequences, however, is dependent on each particular socio-cultural context (Greil et al. 2011:742). Therefore 'infertility is best understood as a socially constructed process whereby individuals come to regard their inability to have children as a problem or not, to define the nature of the issue, and to construct appropriate courses of action' (ibid., 737). This means, for instance, that couples will speak of infertility when not conceiving within 12 months. At the same time, couples that are classified as infertile within the biomedical discourse might not identify as infertile due to a lacking desire for children.

### 3.3 Kleinman's Explanatory model

Weiss' cultural model of diarrheal illness is based on the ideas of anthropologist and psychiatrist Arthur Kleinman regarding the 'cultural construction of illness' (1980). As may be seen in Weiss' model, one of the components is the 'explanatory model', which 'reveals how people make sense of their illness and provides a framework whereby social science researchers and healthcare providers engage with participants/patients in comprehensively understanding their lived illness experience'.<sup>23</sup>

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<sup>&</sup>lt;sup>23</sup> Website: https://medanth.wikispaces.com/Explanatory+Model (01-07-2016).

According to Kleinman, neither health nor ill-health can be fully understood from a biomedical viewpoint only. Their biological implications should be linked to their social and cultural framing and significance. Accordingly, Kleinman proposed an explanatory model for socially and culturally contextualizing illness and health. The model investigates social realities and associated discourses and explanations of sickness, all of which are culturally shaped and influence how individuals experience disease.

Explanatory models, such as Kleinman's, are used to explain how people view their illness; its cause, how it affects them, and what will make them feel better. Patients, researchers and clinicians are guided by different explanatory models which emphasize different dimensions of these issues. Thus, medical decision-making is placed in a cultural context. The models also serve to emphasize the importance of examining health and health-seeking behaviors.

I will make use of Kleinman's model to analyze the explanatory accounts given by the couples in this study, their perceptions of childlessness as well as the personal and social meaning they attach to infertility. In this way, the explanatory model will provide insight into how childless couples experience and interpret their affliction.

Kleinman makes a distinction between the patient's explanatory model – described above – and the physician's explanatory model, whose perspective is mainly through a biomedical lens. I will make use of this distinction in order to show how couples slowly admit certain aspects of the physician's biomedical model into their own non-biomedical model.

#### 3.4 Lock and Kaufert on 'Pragmatic behavior'

In order to understand how childless couples react to medical technology and how they make decisions in the biomedical field, I will draw upon Lock and Kaufert's notions on pragmatic behavior. Contrary to the assumption that women take a passive, suspicious or resistant attitude towards technological interventions, Lock and Kaufert argue that 'women's relationships with technology are usually grounded in existing habits of pragmatism' (1998:2). 'Pragmatic Women and Body Politics' is a collection of essays which aims to 'illustrate the complexity of women's responses to the process of medicalization' (Lock & Kaufert 1998:2).

According to the authors, women have learnt, by circumstance, how to employ the tools available to them pragmatically. They show that 'if the *apparent* benefits outweigh the costs to themselves, and if technology serves their own ends, then most women will avail themselves of what is offered' (ibid.: 2). This means that 'individual behavior and responses are not

determined by dominant ideologies', but are influenced by pragmatic thinking and the weighing of a range of (personal) costs and benefits.

In empirical chapter six and seven I will elaborate further on the above and will refer to the concept of pragmatism to demonstrate how it guides all stages of the (moral) journey, traveled by the couples in this study. I will argue that these couples take a strategic pragmatic approach when interacting with fertility technologies.

#### 3.5 'Moral pioneers' by Rayna Rapp

Rayna Rapp is an American feminist researcher and health activist who observed that the dominant voices in the discourse on reproductive technology in public literature were predominantly those of white, male and highly educated professionals:

'In 1983, when I began to investigate the social impact and cultural meaning of amniocentesis (and related prenatal diagnostic technologies), the voices of experts in medicine, bioethics, health planning, and law dominated the published literature. These experts were mostly male, overwhelmingly white, and highly professional. As a feminist researcher and health activist, and as a woman trying to understand the complex consequences of having used amniocentesis in my own pregnancies, I thought I could help to wrest the discourse on new reproductive technologies from the hands of medical experts, turning it over to the women who used, might use, or might refuse to use them.' (Rapp 1998:46)

Here, Rapp accurately reflects the position I myself take in this thesis: that it is of great importance to focus and reflect on the (moral) position of childless couples considering this new, more affordable technology. Since they are the ones undergoing the treatment, their voice should be heard in scientific literature. To be able to reflect on the new, more affordable IVF treatment it is essential to take into account how couples react to this technological development after a long period of childlessness; and how they respond to its benefits and disadvantages.

In her article about the social impact and cultural meaning of prenatal diagnosis in the United States, Rapp states that this biomedical technology 'provides a context in which every pregnant woman is interpolated into the role of moral philosopher' (1998:46). She explains how these women can be seen as 'experts capable of analyzing its burdens and benefits and casting a rather different light on contests for meaning and rationality' (1998:48). Rapp calls these

women "moral pioneers" because they are 'operating at the intersection of reproductive technology, genetic discourses, and gender relations as they refract and enact other forms of social hierarchy' (1998:68). She states:

'I came to think of the women who submitted to the discipline of a new reproductive technology in order to reap its biomedical benefits as moral pioneers. At once conscripts to techno-scientific regimes of quality control and normalization, and explorers of the ethical territory its presence produces, contemporary pregnant women have become our moral philosophers of the private' (1999:306).

According to Rapp, pregnant women and their husbands become moral pioneers when they are confronted with the dilemma of making a decision about whether to carry on the pregnancy or to terminate it, forced to judge the quality of their own fetuses. Since the couples interviewed for this study were also confronted with a new reproductive technology and therefore had to regain their moral position – and consequently make a decision in 'a highly charged moral area' (Williams et al. 2005:1991) –, I argue that this definition similarly applies to my research group. Where Rapp's research group had to make a decision about what constitutes an acceptable human life, my research group has to decide what constitutes an acceptable way to conceive.

# 4. Methodology

This chapter provides insight into the methodology of this study and its ethnographic design, including the ethical considerations, my positionality and its limitations. Together with my Dutch research colleagues, Evelien Oomen and Margot Visser, I spent ten weeks in Accra, Ghana conducting fieldwork. As described before, Evelien and I carried out the qualitative part of the research project whilst Margot was responsible for the quantitative part. During the period of data gathering, we collaborated with three graduate students from the University of Ghana: Charles Yajalin, Deborah Baiden and Esther Abedu. They functioned as research assistants<sup>24</sup> throughout the whole process and as translators<sup>25</sup> during some of the interviews.

First of all, I will describe the study site and how we gained access to it. I will then elaborate on the different research methods I employed in order to collect the data and also how it was analyzed. Thereafter, as previously mentioned, I will describe the ethical considerations and lastly will reflect on my positionality and the limitations of this study.

### 4.1 Study site and gaining access

The main research site was the Pentecost Hospital's Fertility Center in Madina, Accra. The recently opened center was next to the main hospital and consists of two separated parts. The front side is divided into three parts: the doctor's office, ACCOG's office and the reception/waiting room. The treatments are carried out at the rear side of the center, which can only be entered in the presence of staff because of fingerprint screening at the door. The treatment area consists of a laboratory, the office of the embryologists, a room for sperm collection, two changing rooms, a recovery room and sanitary facilities. The majority of the recruited participants of this study were clients at the Pentecost Hospital's Fertility Center. In addition, we interviewed staff members of the clinic. Access to the fertility center was gained through collaboration with ACCOG's fertility counselor Nana Yaw Osei who can be considered our 'gatekeeper'26. Although the fertility center was our primary research site, data was also obtained during observations outside the clinic at places such as churches, markets and also our neighborhood.

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<sup>&</sup>lt;sup>24</sup> Some of the tasks were: assisting in recruiting participants, making phone calls and taking notes.

<sup>&</sup>lt;sup>25</sup> Some of the study participants were not fluent in English, therefore the Ghanaian students helped with translating local languages to English and vice versa.

<sup>&</sup>lt;sup>26</sup> In anthropology, a 'gatekeeper' refers to one who 'opens a door' to the research field, giving access to resources difficult to attain otherwise.

#### 4.2 Data collection

The data upon which this thesis is based were gathered through ethnographic observations and informal conversations, in-depth interviews and a focus group discussion.

#### 4.2.1 Ethnographic observations and informal conversations

The first anthropological research method I have used is 'ethnographic observation' of a social setting. This method describes the collection of information through all the sensory pathways – gustatory, auditory, olfactory, tactile and visual – to 'take in stimuli from all sources of the cultural environment in which they are studying' (Whitehead 2005:11). The whole body becomes a data-collecting instrument to gather stimuli that 'might have meaning for the members of the community, or that provides insight regarding their lifeways' (Ibid.: 11). Observations were carried out in the waiting room, during group counselling sessions and appointments with doctors. These provided insight into the daily activities of the clinic and client-staff interactions. Since I do not have a medical background, I was unable take an active role in clinical activities.

The observations, however, were not limited to the territory of the fertility center. To obtain a deeper understanding of Ghanaian life I participated as much as I could in daily social activities with the aim of acquiring a deeper understanding of social stratification. In the local neighborhood where Evelien, Margot and I were staying, we were the only Western residents. We tried to integrate as much as possible, by purchasing bicycles and cycling to work every day, like many other Ghanaians. We used local transport such as the *tro-tro* and we bought our food at local stands in our street. These undertakings created room for informal conversations with street sellers, neighbors, taxi-drivers and many others in which I consciously tried to turn the subject to, for example but not exclusively, the meaning of children in Ghanaian society. We also went to various church ceremonies and attended the 'one week celebration of the death' of the mother of an acquaintance of ours.

#### 4.2.2 In-depth interviews

We used different methods in order to recruit participants for the interviews, based on convenience sampling which depended on the presence of women and men at the clinic in the period of the research and their willingness to participate in our study. One of our strategies was to attend ACCOG's group counseling sessions to get in contact and interact with couples.

<sup>&</sup>lt;sup>27</sup> This ceremony takes place one week after someone's death to announce the dates of the funeral and the burial.

Nana introduced us to the clients and explained (both in English and Twi) the purpose of our presence. After briefly introducing ourselves we asked the couples to leave their phone numbers if they wished to participate in the study. Two days later we called the couples together with the research assistants to make an appointment for an interview. Another method was recruiting couples at the clinic who were having appointments. This was especially convenient during the execution of the second tWE-IVF batch, because there were many women coming to the center for checkups and minor surgeries. Since there were so many clients present, the waiting time was quite long and Nana suggested that the women could participate in the interview while waiting. Our third recruiting method was through the questionnaire where participants could leave their contacts if they were willing to participate in the qualitative study as well. After calling them we asked when their next appointment at the clinic was and tried to schedule the interview the same day.

Using the methods described above, Evelien and I conducted thirty-one interviews, each lasting approximately one hour. Interviewing thirty-seven clients in total, we spoke to twenty-five individuals and six couples. We conducted the majority of the interviews (23) together; Evelien did three interviews by herself and I did four interviews by myself. We also conducted four interviews with seven staff members at the clinic and an interview with five female teachers outside Accra. All the interviews were recorded and almost all of them were transcribed.

During the interviews we addressed various topics concerning among others, their reproductive history and their experiences with ACCOG, infertility related stigma and ARTs (see appendix 3 for topic list and interview questions). When the participants were 'sharing their story' with me, I tried to avoid suggestive questions. At times when participants did not understand certain questions, I was required to explain further, which could have resulted in influencing their replies. Moreover, in the case of translation, I had no influence on the translations of my research questions and was dependent on the interpretation of the research assistant.

Since women often came to the clinic without their husbands, more women than men are present in this study: nine men and twenty-eight women. Our sample includes clients from different parts of Ghana: Accra, Volta Region, Kumasi, Cape Coast, Kwahu, the Northern region but mainly from urban areas. The participants ranged from twenty-four to fifty-three years of age, with an average of thirty-eight. Their educational level is quite diverse: approximately one third had primary education only or no formal education at all; one third had completed secondary school or a vocational program; and one third had attained a university degree. In consequence, their professions, social class and status vary greatly, including, among

others, a hairdresser, a teacher, an architect, an IT technician. The duration of their infertility was often equal to the duration of their marriage, varying from one to eighteen years, with an average of eight years. None of the participants had a child with their current partner that was genetically related to both mother and father (for more details of the participants see appendix 4).

#### 4.2.3 Focus group discussion (FGD)

The last method we have used is a focus group discussion which is characterized by 'the interaction between the moderator and the group, as well as the interaction between group members' (Wong 2008:256). As a gatekeeper, Nana helped us to recruit eight clients – four couples – for the FGD. Evelien led the first part and I led the second part of the discussion. Our 'list of statements' and 'case studies' functioned as a starting point for discussion between the participants. In the course of the FGD, various viewpoints on childlessness and infertility were discovered by addressing topics related, among other, to stigma, sharing concerns, religion and the position of the Ghanaian government (the program of the FGD can be find in appendix 5).

#### 4.3 Data analysis

After collecting data, the researcher is faced with the task of analysis. During our stay in Accra, Evelien and I transcribed the interviews and worked out the memos and field notes of informal conversations and observations on a daily basis. Data analysis had already commenced in the field by the critical and reflective reading of the data and discussing it together in order to trace gaps in our findings and to link it to theory, summarizing it in two interim fieldwork reports.

Back from the field, the transcribed interviews were analyzed based upon four steps for the thematic analysis of interview data suggested by Green et al (2007): immersion in the data (during the process of transcribing and critical reading); coding (developed from the empirical data); categorizing (dividing codes into categories); and generation of themes (highlighting overarching themes).

#### 4.4 Ethical considerations

This research project has been approved by the Amsterdam Institute for Social Science Research (AISSR) and has received a Ghanaian research permit by the Noguchi Memorial Institute for Medical Research (NMIMR). However, having ethical clearance from both institutions does not mean that we were not faced with any ethical dilemmas in the daily conduct of our research.

In order to protect participant's rights we followed several guidelines. At the beginning of each interview, participants were informed about the ethical principles. We provided a letter about the aim and procedure of the study and when necessary we explained it verbally in further detail (see appendix 6). When still willing to participate, we kindly asked them to sign the informed consent letter. Lastly, we asked permission to record the interview. Some of the participants initially rejected the use of a voice recorder, but after explaining the procedure in detail everyone gave their consent. Participation was voluntary and had no consequences for their relationship with ACCOG or any effect on their treatment. Data obtained is treated highly confidential and will be destroyed within five years. Participants were able to skip any question that caused discomfort and were allowed to quit the interview at any given time.

During the interviews we had to take into account that talking about a sensitive topic like infertility can create discomfort. Women sometimes became emotional while sharing their experiences about childlessness. During these moments I tried to comfort them and remind them of the option to stop the interview. Talking about these issues did not just affect them negatively. More than once, participants expressed their gratitude and indicated that they felt relieved to talk about childlessness without judgement. However, not all clients were willing or able to participate when asked; sometimes this was due to the language barrier (in the absence of the translators) and at times because they were not interested or did not want to discuss their situation.

As mentioned before, I conducted both individual and couple interviews. I was aware of the possible disadvantages of interviewing couples together: 'partners for various reasons might restrain each other from expressing themselves', 'interviewees might actually be reluctant to openly share their ideas when interviewed together with their partner' and – according to Morris (2001) – 'the potential of stirring up antagonisms and conflicts of interests' (Gerrits & Hardon n.d.).

In order to ensure participants would not experience any negative social consequences as a result of this study, in this thesis I protect their anonymity by using pseudonyms and withholding identifying details. However, I decided to mention the official names of ACCOG and the Walking Egg project since they are unique in their field and therefore are traceable. This also applies to the fertility clinic, Nana Yaw Osei, and Dr Attoh and Dr Gordon, with their consent.

When observing during group counselling sessions for example, I did not ask the men

and women at the fertility center to fill in an informed consent letter. I was identifiable as a researcher as I did not hide my pen and notebook. Moreover, to secure their anonymity I will not refer to observations that can be traced back to individuals.

### 4.5 Positionality and limitations of the study

According to Wilkinson 'thinking about our positionality and explicitly discussing it in our writing is considered important in ethnographic research as it is an acknowledgement of the subjectivity of all interpretations and helps to fully contextualize our findings for the reader' (2013:134). Therefore it is of great importance to reflect on my positionality, since it influenced how participants composed themselves around me and it affected my interpretation of their stories. Introducing myself as a medical anthropologist often made participants think I was a medical expert. When they asked specific medical questions related to infertility I emphasized the fact that I am not medically trained and advised them to ask one of the doctors. Subsequently, I assumed the sensitivity of the topic and my position as a young Western female student could create distance between myself and the participants and question their trust in me. However, being a researcher and thus not allowed to share their stories, seemed to provide an element of trust. We were challenged to reflect on our positionality due to cultural differences and also due to Nana having multiple roles as gatekeeper, key informant and landlord, for which we are very grateful. As a young Dutch woman, trained to be autonomous, I attach great value to my independence and prefer to take matters into my own hands. However, on occasion this caused friction between us and Nana as he wanted to help us out by taking full responsibility when we asked him for his advice.

In regard to research limits, I want to state that all research methods have their disadvantages. It turned out to be difficult to make appointments with participants, as they often arrived one or more hours later than agreed (sometimes due to traffic). Going to the clinic without appointment and hoping for potential participants sometimes payed off, but in many cases there were almost no clients with fertility issues. We also had to take into account that some participants did not want to be interviewed because – as they told us – they were anxiously waiting to have their procedure. Although these disadvantages hindered the recruiting process, our perseverance yielded a quite satisfactory sample.

Moreover, this study has some practical limits, such as the comparatively brief, tenweek research period. As a consequence, we were not able to conduct follow-up interviews with the respondents to attain full data saturation. However, we managed to achieve saturation on certain subjects, such as religion for example. Another practical limit was the language barrier, since not all participants were fluent in English. Although we worked together with research assistants who translated local languages to English and vice versa, some parts always get lost in translation. Also interviews held in English posed difficult at times due to difference between our Dutch and their Ghanaian accent.

Finally, I am aware of the fact that my sample is not a representative of all the clients at the clinic, let alone for the whole childless population in Ghana. Since we interviewed more women than men, the sample represents more childless women than men. Furthermore, the sample only includes childless couples who are actively seeking a medical solution and have the means to access these treatments. As addressed in the context chapter, infertility in Ghana at times leads to separation and divorce. Our sample is therefore biased as we almost exclusively interviewed couples, or individuals belonging to couples, that despite their childlessness decided to stay together.

# 5. The meaning of infertility in Ghana

### 5.1 Ethnographic vignette: 'Here is our last hope'

This is the story of Charles (39 years) and Patience (34 years): a childless couple married for fifteen years. They live in the Ashanti region, the third largest and most populated region of Ghana. Both of them belong to the Akan ethnic group. Charles grew up with his parents and his two sisters until his mother and father separated when he was seven years old. He stayed with his mother but when he turned eleven, his father came to take care of him. Two years later his father died; whereupon he moved in with another family member. When Charles grew older he decided to become a pastor and obtained his theological diplomas and certificates. His wife Patience – who was much less vocal in our interview because her English was not as fluent – grew up in a big family in the same village. She was the last-born in a family of twelve children. Six of her siblings have passed away, and now she has only one brother and four sisters left. Patience was trained as a hairdresser but at the moment she is a trader and has her own small boutique.

A year after their marriage in 2001, Charles and Patience, then 25 and 20 years old, came to realize that they could not conceive. A long emotional journey began. They started visiting many herbalists and Patience took herbal medicines to enhance her fertility. However, none of the herbs and brews took effect and the couple remained childless. In their search for fertility treatment, they never visited a traditional healer because, as Charles explains, their problem would 'come in the dark through the spiritual'. It is a step that, they feel, would be in conflict with their faith in Christ. After several years of childlessness they started visiting 'hospital after hospital' and running 'test after test' in Kumasi, Cape Coast and Accra. The test results showed that Charles had a low sperm count and Patience had problems with her tubes, so both were put on hormonal fertility treatment. The treatment cost a great deal of money and was at times very painful for Patience, 'but since we are determined...' Charles explains, 'because we want to get a child, we have to go through'.

Being childless for fifteen years has been a battle for the couple every single day. I can hear the sadness in his voice when Charles tells me that 'it's a different thing here in Africa' when you do not have a child. 'You hear a lot of words, people will take you for granted, they see you as inferior, you are not important. Even sometimes if they see a little progress or blessing in your life they may say 'Monngyae no' [in Twi meaning 'leave him alone'] because you don't have a child. So we are suffering'. Their position as a pastor and pastor's wife makes

it particularly difficult for them. 'Sometimes people may look down upon you' because God has called him, but has not blessed them with children.

It is difficult for his wife to deal with the childlessness as well. Charles explains that it is their custom that 'as a pastor's wife, when somebody gives birth and they are coming to name the child in the church, she has to hold the baby'. She is always cradling infants, which is heartbreaking when you are not able to conceive yourself. 'Before the congregation she'll be smiling and pretend to be nice, but when we go home she cries', Charles tells me. 'Then she'll be asking herself why it's not her, why is she not the one having a baby'. When Charles sees his wife crying, it makes him lonely inside but he tries to comfort her. 'I see her going through some tears. That pains me'.

Despite their adversities they try to encourage themselves 'we know that truly life is not all about giving birth'. Charles describes how he learned that 'our happiness in marriage is not based upon the child that we can produce' during the group counseling session led by counselor Nana. They keep on praying; 'And also I know that, with God and time, we can have it too'. God also encourages them to continue and 'to go for the medical aspect', Charles explains.

Their position in church, however, is not the only source of pressure. The families from either side have not been very supportive during the whole process. 'Thank God, we are not living with our families. [...] it doesn't give them so much room to talk about us because we are not staying with them', Charles says. Still, his mother often asks if there is any improvement yet and if the couple still attends hospitals. Charles and Patience try to keep their family members out of their personal life 'because otherwise they will be pressuring you'.

Besides family pressure Charles and Patience also experience societal pressure. Charles gives an example: 'They say that you're inferior, you are hopeless, what are you living for? [...] The person [at the market] insults you: where do you need the money for? You don't have a child to take care after'. One time somebody came to deliver money to his wife 'and the person threw the money, bam! "Take your money, take your money and use it go and buy a child...!" This is one of the reasons why the couple does not consider adoption as an option. Firstly, because the community will know that the child is adopted, which will cause a lot of issues. People will say that 'you've gone to buy a child' which is extremely humiliating. Secondly, because they are afraid that they will miss a certain connection raising an unknown child. Besides that, the couple strongly believes that one day they will conceive. Nevertheless, adoption within the family and foster care are more tolerated. Therefore, Charles and Patience decided some months ago to take three foster children into their care and into their home: two boys (13 and 20 years old) and one girl (18 years old).

Since June 2015 Charles and Patience visit the fertility center in Madina and in November 2015 the couple took part in the first tWE-IVF batch, but dramatically neither they themselves, nor any of the other twenty-four couples conceived. 'Here is our last hope' says Charles quietly, referring to the tWE treatment. 'We believe in God that after all this process... if we are not able to achieve our goal, we have to come to understand that maybe we are not destined to have [a child], so we'll stop it. But we have all the courage and also hope that by this IVF we're going to achieve, that God's with us'.

Like countless other married couples in Ghana, Charles and Patience have been struggling with their fertility for many years. The vignette above illustrates different aspects of the experience of being childless. Many childless couples that wish to become parents ask themselves 'why us?' as in the case of Charles and Patience. This question is often the start of a long and emotional journey for those struggling with infertility: a search for meaning and understanding. This chapter shows which motivations lie behind the arduous quest for a child, further described in the following two chapters.

As explained in the theoretical framework, infertility is socially constructed and there are many factors influence this construction. In this chapter I will focus on two components of Weiss' model of the cultural construction of illness: the influence of the social context and Kleinman's explanatory models. I will make use of Kleinman's explanatory model (1980) – which lays the emphasis on the personal experience of illness – to reveal how the interviewed couples make sense of their childlessness, drawing upon his idea that neither health nor ill health can be ascribed solely to behavior and biology. Beliefs and perceptions surrounding infertility are intricately interwoven with all other aspects of life, including the available means to overcome infertility.

To conclude, this chapter will examine how couples experience childlessness and make sense of their infertility. In line with other anthropological researchers, I have found that the meaning of childlessness in Ghana may be explored within several different domains: those of personal experience, and of family, societal and religious influences.

# 5.2 Personal grief: 'Am I that useless?'

The first domain determining the meaning of childlessness in Ghana is that of personal, painful experience. All the couples described how the agony of childlessness caused immense personal grief which in turn caused feelings of individual pressure. Particularly the women in this study

refer to an 'instinctive need' for a child, as illustrated during an interview with Caroline, a 43 year old woman with a university degree: 'The pressure is coming from myself! I feel I need it. And my husband also feels we need it. But nobody has ever confronted me'. Another woman confirms this feeling when she claims: '...if I'm under any pressuring, then maybe it's myself', she claims.

The personal pressure expressed by the informants is caused by different factors. To start with, infertility issues were not anticipated: from an early age on, these men and women expected to marry and start a family, just like anyone else in their community. They took their fertility for granted. This unexpectedness added to the burden. It also indirectly demonstrates the impact of pronatalism, and shows the child-centered focus of Ghanaian society. Within this context we could say that the couples perceived infertility – as has also been shown in the United States by Becker (1994) and Jennings (2010) – as a disruption of their life plan as parents. One of the women tells me: [Debby] 'When I was getting married, I never thought for a second it would get to this time without a child'.

The attitude towards having children appears to be very positive in Ghana (Hiadzi, 2015). During a group counseling session, Nana asked why the couples 'need a child'. Several couples answered: for 'happiness' and 'companionship'. The idea that children enhance the fulfillment of life providing companionship was also expressed by Elizabeth, who is married for seventeen years: 'I would be happy being with the child, talking to the child, sending the child to do things in the house and be in the company with that child'. Not having a child, therefore, causes feelings of loneliness and sadness which consequently increases feelings of personal pressure. Particularly for the interviewed women, children are seen as the essence of life and considered indispensable for happiness. Many stated they cried often as a result of their childlessness. According to Jennings, the loneliness and incompleteness experienced by women is caused by the fact that 'mothering is centered as a normative feature of female identity' (2010:217). When this normative feature cannot be accomplished, women sometimes question their usefulness, which was the case with Eileen. After two miscarriages, the inability to conceive makes her at times very insecure: 'Sometimes when you think about it [childlessness], you may be thinking are you that useless? [I wonder] how can even small girls, teenagers, are even getting pregnant, and end up like this, and you are not?'

Another factor causing personal grief is linked to the fear of losing one's partner. Children are a seen as a security for marriage (Hiadzi 2014:101). Divorce was feared by the women in particular, and for good reason. According to the Ghana Statistical Service (GSS 2013) infertility and childlessness have been suggested as the main reasons for divorce in Ghana

(Osei 2014:19). One of the women who clearly expressed the fear for divorce was Patricia. Although she has only been married for a year, and according to herself to a caring and committed husband, Patricia worries about the future; if the problem remains, will he still be there for her? Her smiling face suddenly becomes serious when she frowns and says: 'Sometimes I feel that I understand that maybe I will lose him, because of this matter [infertility]. And I don't want to lose him, because I love him... So that's my fear'. The couples feel that, without children, it is more difficult to ensure marital security.

Kate's story shows that childbearing may sometimes be valued above marriage. Her first marriage 'ended on the rocks' after ten years because she was not able to conceive. Now she has a new partner to whom she is not married. We are sitting outside the clinic and the burning sun is slowly taking over our secluded shady spot. She wipes her forehead as she tells me very determinedly: 'So my priority is not marriage now for me as I sit here, because of what I'm going through, my priority now is having a child'.

There is also a fear of growing old alone. The majority of the couples fear that they will not have someone to take care of them in old age or to bury them when they pass on. Since Ghana does not have a social security system, the elderly are dependent on their children. This apprehension shows that this personal pressure cannot be seen out of its socio-cultural context. Although the couples describe a 'pressure from within', there is always interaction with the environment on which I will elaborate below.

# 5.3 Family pressure: 'Marry a different woman!'

As mentioned above, the meaning of childlessness and the pressure experienced by couples occurs in the interaction with the environment, which brings us to the second domain: that of family. In Ghana, the (extended) family is an important part of this environment, contributing to the meaning of childlessness.

Most respondents either felt pressure from their own family, their extended family or from both. Being the firstborn of nine children the 38-year old Sophia mainly experiences pressure from her own family. Although all her siblings are younger, they all have children and she is the only one without. She is often questioned: 'Tell sister why, what are you waiting for? What are you doing?' they ask her. Although Sophia knows that such questions are not necessarily intended to hurt, they often cause pain and feelings of pressure. Kate recounts how her first marriage 'ended on the rocks' after ten years because she could not conceive. Her

husband was not very committed and had a child outside the marriage unbeknownst to her. Her family does not show much support either:

'They come around and ask 'Why didn't you have a child? When will you give birth?' Or they say 'I want my grandchildren!' as if they are joking. But those questions sometimes affect your emotions and what you are going through. It happens like that, and it makes me sad, I feel sad and I feel discouraged. And I feel so frustrated. But I was trying hard not to let it weigh me down'.

Some families take it even further. This is the case with Peter, for example, who has no offspring after ten years of marriage. Since some years he experiences a great deal of pressure from his own family: 'As for family matter, they normally disturb me. My family [asks me] to leave the woman, and marry a different woman'. The family sometimes encourages the husband to separate and leave the marriage. The pressure is serious and creates insecurity and raises questions among the respondents. 33-year old Eileen, who had two miscarriages shares her worries with me: 'what if my in-laws just poison my husband's mind and let him get another wife?' But it can also be the other way around. Khadijah, a 28-year old Muslim woman, is her husband's third wife, to whom she was married off when she was eighteen years old. Her husband has not been able to get her pregnant and therefore Khadijah's relatives ask her to separate: 'It's only my mother's side, they say I should divorce', she assents.

Another woman, Anna, stresses that having a child is a requirement to be accepted into the extended family. Her husband had fathered a child as a teenager, but has no child within their marriage. Anna's own family is supportive, but the husband's family is causing her worries:

'But actually the condition which I'm in [childless], he [husband] is not happy about it. He told me that I also should give him a child, even if it should be one child then it is to sustain that family. You know, this [is] Africa<sup>28</sup>, marrying and not having a child: your husband family will not like you. You know. Wherever you are they do

<sup>&</sup>lt;sup>28</sup> Respondents often interspersed their stories with: 'this is Africa' or 'in Africa here...' Anthropologist Rachel Spronk has reflected that this mode of self-representation may be recognized as a generative concept. However, it is beyond the scope of this study to elaborate on this theory.

not want to near you because you have no child in that marriage. At least if we have one, just to sort in the family, it will be better.'

The attitude from family often creates feelings of social exclusion for childless couples. Some participants mentioned they were insulted or neglected by family members. The social exclusion and pressure is experienced by many women during family gatherings, as one woman puts it: 'They [in-laws] come there with their child or their son and... [asking my husband] 'Why? Is she the only woman in this world? Why not going for a different woman to get a child?'

Although many respondents experience pressure from family, some indicated that their families were very supportive, offering prayers and advice. When I asked Amy, a 44-year old woman married for 15 years, how her family reacted to her childlessness, she told me that both her own family and her family in-law were very sympathetic. They did not exert pressure on the couple but offered prayers and advice. Although in the minority, helpful and understanding family members show that the Ghanaian culture is not static in its response to childlessness.

## 5.4 Societal pressure: 'How are the children?'

The couples do not just experience pressure within the family, but also on a societal level and within the community: the third domain determining the meaning of infertility. Peter, who is married for ten years to his wife Maria, clarifies this: 'It's like, in our area, if you don't get a child they'll be laughing at you. Some people disturb you'. Most respondents were reminded of their infertile state when confronted with children. 44-year old Anna describes her feelings: 'Oh, I'm not happy, I'm not happy at all. Because I see a whole [lot] of my friends are having their own child and I don't have a child. I feel so bad within it, but I trust in the Lord'.

This issue was often mentioned, because in Ghana children are simply everywhere. Walking along the dusty streets of Madina I constantly see women carrying their infants on their back while selling their goods. Small groups of children run hand in hand to the nearest primary school. Mothers breastfeed their babies in the street and youngsters play soccer on a field along the road. This can be very confronting, explains Rose, a teacher at a senior high school: 'Sometimes you walk and see beautiful kids, nice kids! And you wish you'd also have one...'

Elizabeth and Prince explain how they are confronted with their childlessness daily for as many as seventeen years, as they have struggled with infertility since their marriage in 1999.

Elizabeth: 'Especially when I'm in company with all those who have got a child, discussing their children and the rest, knowing that I don't have at least a child'. Her husband Prince continues with an example when he was confronted with his childlessness on the market: 'One day walking with your friend. Oh then, somebody is passing: 'How are you, how are the children?' Over here they talk a lot. And they say: I'm going to buy these sandals for my children. Then you are there...'

Another place where pressure is felt is the workplace. Catherine relates how she sometimes is insulted by her colleagues, who tell her that she is 'working for nothing' because she does not have a child. Sabrina has a similar story when she was told at one time that 'I don't know what to do with my money because I didn't give birth'. Others feel pressure at work because everyone is getting pregnant except for them, as Olive explains: I'm a seamstress, [at work] every year one of them got pregnant. [...] Even two at the same year! So it's not easy for me at all.'

As illustrated and as also has been shown by others (Donkor (2008); Fledderjohan (2012) Geelhoed et al (2002); Hiadzi (2015)) men and women without children experience high levels of stigmatization. The couples mentioned various forms of stigmatization such as humiliation, harassment, loss of social status and gossip. Debby, a fulltime seamstress, explains when such behavior often starts: 'If you marry for one year, two years without a child... Yeah you can get people gossiping about you'. All respondents agreed that women undergo a higher level of stigmatization than men, since they are the ones 'carrying the baby'.

## 5.5 Religious beliefs: 'God's time is the best!'

The final domain determining the meaning of infertility encompasses religious influences. As mentioned in the context chapter, it is of great importance to analyze religious beliefs to obtain a deeper understanding of the religious context surrounding infertility. Religion can be seen as the 'central organizing structure around which all else is organized'; it permeates Ghanaian institutions, including marriage, and, accordingly, reproduction issues (Heaton & Darkwah 2011). According to Geist et al. religion 'shapes world views and often provides explanations for life occurrences' (2013:166). In her article about culture, religion and infertility in South Africa, Sewpaul likewise states that 'people generally turn to religion to explain life circumstances that are beyond their control' (1999:748). Infertility may be considered such a life circumstance in which religion plays a central role in Ghanaian daily life.

In his article about religion, infertility and ARTs, Dutney provides a table that shows how infertility is experienced among five different religious groups: Judaism, Christianity, Islam, Hinduism and Buddhism (2007:174):

Table 1. How infertility may be experienced by participants in religion.								
	Judaism	Christianity	Islam	Hinduism	Buddhism			
Procreation a religious duty								
Infertility imposed by God	$\sqrt{}$	$\checkmark$	$\checkmark$					
Infertility caused by karma				$\checkmark$	$\sqrt{}$			
Infertility a punishment for wrong-doing	$\checkmark$	$\checkmark$	$\checkmark$	$\sqrt{}$				
Infertility points to a higher calling		$\sqrt{}$		$\sqrt{}$				

It is striking that the only infertility-related aspect that religions have in common is the perception shared by the participants of his study of infertility as a punishment for wrong-doing. This shared experience across all religious faiths affirms the association of infertility and God's displeasure. Given the importance of Christianity in Ghanaian society – as described in the context chapter – and the fact that all but two of the respondents were Christians, I focus on this particular religion and their guiding principle: the Bible.

From a biblical perspective, infertility thus may be perceived as a form of punishment. Sewpaul too states that, in a religious context, fertility is seen as 'a gift from God' and infertility as 'a punishment for wrong-doing' (1999:743). This was also confirmed in Ghanaian context (Hiadzi 2015). From a biblical worldview, God is seen as the key to everything that happens in the world and therefore childlessness is perceived to be a particular sign of His displeasure. However, most of the childless women in the Bible were not portrayed as being sinful or disobedient.

In order to better understand how religious beliefs shape the meaning of childlessness in Ghana, I will first briefly explore the biblical view of infertility. First of all, at the beginning of creation, God commanded Adam and Eve to "...be fruitful, and multiply, and replenish the earth" (Genesis 1:28). The 'bearing and possession of children' is regarded as a gift from God (Ober 1984:301). Procreation is thus seen as a blessing in Ghanaian society, explains Edward, one of the respondents who is also a pastor: 'the Bible says children are heritage from God. They are gifts from God.'

At the same time, many biblical passages can be found about people who struggled with infertility issues. In the Bible there are at least seven women – Sarah, Rebekah and Rachel

among others – who were initially childless. Strikingly enough, only one of them – Michal<sup>29</sup> – remained barren while the other six eventually conceived, often at an old age.<sup>30</sup> Once more, the value and importance of children is stressed.

According to Sewpaul – who did research on the impact of religion on the handling of infertility in South Africa –, the reason why these infertile women in the Bible ultimately conceived was because 'they were seen to be worthy in God's eyes' (1999:749). Only one woman remained 'barren' for the rest of her life because she was unworthy. According to Salzer (1999) the word 'barren' is associated with 'arid, unproductive land, implying that the woman has limited value' (Sewpaul 1999:749). In her study, Sewpaul noticed that it was 'not unusual that those participants who were deeply involved with their religions experienced profound guilt' (ibid). She argues that the impact of religion on the experience of infertility is influenced by three important factors, namely: 'the individual's level of involvement with religion, their personal conception of God, and their sense of self in relation to God' (1999:741). While biblical texts about infertility are interpreted in forms of punishment, none of the respondents in this study claimed to experience pressure directly from the Biblical texts or from their religion in general. They did not feel that their infertility was the result of wrong-doing or was in any other way a form of punishment.

Another aspect of religion that could cause pressure has to do with the 'fulfillment of scripture', according to counselor Nana. During the group counseling session Nana mentioned that many childless couples feel that they are not 'fulfilling scripture' because it teaches that children are a heritage from God and couples should procreate. As also found by Patterson et al, 'it can become very confusing and disconcerting to a married couple when children are not conceived as planned or desired' (2012:798). During the group counseling sessions, Nana intends to disprove the arguments that have a strong negative influence on the lives of childless couples. When the couples themselves are able to refute these negative ideas, it will help them to overcome these theories and defend themselves whenever they are confronted with them. In order to refute the 'not fulfilling scripture' idea, for example, Nana quotes the Bible: 'Blessed are the barren and the wombs that never bore and the breasts that never nursed' (Luke 23:29 ESV). Turning a pressuring religious aspect into supportive advice, he continues: 'Not having

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<sup>&</sup>lt;sup>29</sup> Only the first wife of King David never conceived: 'Michal the daughter of Saul had no child unto the day of her death' (2 Samuel 6:23).

<sup>&</sup>lt;sup>30</sup> In the end, God blessed Sarah with a son called Isaac, to whom she gave birth at the age of ninety (Genesis 15-21).

a child is also fulfilling scripture! Don't get psychological problems because you think you are not part of God's plan!'

Sewpaul argues in her article that whether religion is experienced as a source of strength or a source of immense pain and guilt depends on 'one's conception of God and one's perception of one's self' (1999:748). This was also apparent in my study. Despite many years of childlessness, none of the couples in my study lost hope. They all have a strong belief that 'one day, one day' there will be children in the house. Notwithstanding the pressure from their environment, the couples would adhere to their faith. In fact; religious belief was an important source of support (cf. Donkor & Sandall 2009:88). All couples indicated that their religion sustained and supported them, as for example expressed by Beatrice: 'I have hope that, I have God, and he will give me mine at his own time'. 44-year old Anna explains that her friends have children, colleagues mock her and she is rejected by her in-laws: 'But I'm trusting the Lord, He will give me a baby soon. If He wants me to get a child, in His own time. I'm trusting the Lord'. Another woman, Agnes, expresses how she experiences God as a source of hope:

'So now that my mother has neglect me, but me I know that God gives. Everything: God gives. So I'm always continue praying that God must give me. So that they see that God is the power. It's only God who can give. So me, if they neglect me, I don't mind, I always pray to my God. And if any treatment I start to do it, and I know one day one day, God will do it.'

Most respondents struggle to find explanation and give meaning to their infertility. Though the majority received medical explanations for their infertile status, such as blocked fallopian tubes, fibroids or a low sperm count, the fact that they were still childless continued to raise questions. While analyzing the data it became clear that most respondents felt that it was impossible for a mere human to understand the reason for their affliction; only God knew. Sophia elucidates: 'God knows the reason, me I don't know. And I cannot fight anybody for it'.

All respondents possessed a strong faith, and as one of the respondents, Anna, formulated: 'There is nothing than to trust in the Lord. Because we went to a whole lot of fertility centers, we went to a whole lot of hospitals. I took a whole lot herbal drugs, but I still trust in the Lord'. All respondents insisted that their future remained in the hands of God: "God's time is the best." The 24-year old Muslim Oumaima offers a similar interpretation: 'God gives it in his own time. And usually the preachers, they preach to us like you don't know the child you'll have if you're like rushing into it. Maybe God is trying to prevent you from

something, maybe a child who will be sick...'. Aaron has a slightly different perception. He narrates about his youth, growing up in a broken home in a small village; managing to escape that life and moving on. This gave him a particular view on life, allowing him to interpret difficult situations in the following way: 'So my life wasn't easy, but I also had that perception of belief that any situation you find yourself, God allowed it cause he knows you can handle it'.

Although the couples did not experience direct pressure from their religion, a couple of them mentioned the church, as it is a public space where many people gather, including pregnant women and children. After the service, people often ask whether you already have children.

As I have showed, the meaning of infertility is partly shaped by religious beliefs. In his article about religions, infertility and ARTs, Dutney notes that 'infertility is experienced as a religious crisis' because family formation is central to many religions (2007:179). This is also the case in Ghanaian traditional religions, where 'infertility is depicted as a form of spiritual pollution' (Adongo et al. 1998:38). I found similar results in my study. In the first place, religious beliefs give a negative connotation to infertility in Ghanaian society. Since children are 'gifts from God', childless marriages are seen as 'not blessed'. In a religious context, infertility therefore causes great uncertainty. Olive tells me in confidence: 'Well, sometimes I got worried. Crying: 'Oh God, why me?' Because it's not easy'. These same religious beliefs offer support: only God knows what is best. The couples find support, hope and encouragement in their beliefs. This was also found by Donkor and Sandall in their study on 'coping strategies of women seeking infertility treatment in southern Ghana', who stated that 'the majority of the women coped through drawing on their Christian faith' (2009:88).

## 5.6 Conclusion

In this chapter I have argued and illustrated that the meaning of childlessness in Ghana is constructed in the context of the personal domain, family domain, societal domain and religious domain. The high value set on childbearing by society and the strong desire for children creates deep anxiety among Ghanaian childless couples. Childlessness is marked by feelings of personal grief and the fear of being abandoned. This feeling is often reinforced through social pressure by the (extended) family, creating a sense of social exclusion. Pressure also arises from the confrontation with children and pregnant women. Religious beliefs tend to play a double role: causing pressure but also providing support and explanations. Taking all the above into

consideration, it is not surprising that childless Ghanaian couples will do almost everything within their means to conceive. In the next chapter, the avenues open to them will be described.

# 6. Help-seeking behavior

As we have seen in the former chapter, childbearing is highly valued and children are of great importance in Ghanaian society. But what to do when the longed-for child fails to appear? Particularly in a pro-natal society like Ghana, where 'the ultimate purpose of marriage is to bring forth children to perpetuate the family name' (Donkor 2008:23), it is not surprising that a couple will begin to seek help. This chapter will provide insight into the help-seeking behavior of Ghanaian childless couples. Within a broader perspective, these efforts to overcome the inability to conceive correspond to the 'help seeking' component of Weiss' model, which illustrates that certain elements should be taken into consideration to better understand help-seeking behavior. It shows how the help-seeking process does not stand on itself but is related to the social context and explanatory models, for instance, which will also be discussed in this chapter. Therefore, I argue that the help-seeking process of childless couples is influenced by many different factors which fall into the following categories: the explanations people ascribe to their childlessness, the availability and accessibility of fertility services, social pressures and the advice given by family and community members, influence of religious beliefs and gender. Each of these will be discussed in turn.

The duration of childlessness of the interviewees ranges from one to eighteen years, but the vast majority of the respondents has been childless for more than six years. Most started seeking help within less than a year of marriage and their treatment-seeking behavior followed many different paths over the years and brought them to different places. Throughout this chapter I will refer to the concept of pragmatism to demonstrate how this has determined all stages of the couples' moral journey.

## 6.1 Explanations for infertility

The first factor influencing the help-seeking behavior of childless couples is their explanatory model. Kleinman describes illness as a cultural phenomenon wherein perceptions about the cause of the illness are related to the experience of the symptoms and decisions about treatment. Within this explanatory model, the focus lies on the impact of sociocultural factors, such as cultural beliefs, on the explanation of illness. In their studies, Foster and Anderson (1980) have shown that, 'health seeking behaviors are borne out of the explanatory models that the individual has regarding the particular ailment/disease' (Hiadzi 2015:162). Accordingly, Van

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<sup>&</sup>lt;sup>31</sup> Although other factors cannot be ruled out, these were the ones most prominently reflected by the data.

Balen and Gerrits state that 'fertility-seeking behavior of the infertile is partly related with the perceived cause of the infertility problem' (2001:217). In Ghana there is a broad spectrum of explanations for infertility, ranging from supernatural forces to biomedical causes. Furthermore, there is a recursive relationship between the explanation ascribed and the type of treatment sought.

Many of the respondents stated that, according to traditional beliefs, infertility is caused by witchcraft and evil spirits, although they themselves did not seem overly convinced. Some thought it was a possibility; but none seemed convinced that this was the cause of their personal infertility case. Although many traditional beliefs were stated not to be shared by the childless couples themselves, yet they had been confronted by others who did hold these beliefs. Daniel describes that he was told that infertility is caused because the woman is 'holding her eggs in her stomach'. After seeing my confused look, the research assistant intervened to help out: 'He's trying to tell you that the number of children you're supposed to get or give birth to; you've eaten them all. [...] The ovulation that you're supposed to get, all the ovaries; you've chewed them up'. Such beliefs or perceived causes could lead to the advice to visit a fetish priest or witch doctor, who was likely to provide a spiritual explanation for infertility (cf. Donkor 2008).

While almost none of the couples ascribed a spiritual explanation to their infertility, all respondents gave a religious explanation to their situation, as described in detail in the former chapter. In terms of help-seeking, only two couples mentioned that they have sought help of a religious healer in the past when herbal medicines had no effect. Holding belief in the supreme power of God, they visited a prayer camp to pray for His help to 'open her womb'. Others stated not to attend prayer camps, but mentioned that the pastor in church would sometimes pray for the childless. The personal convictions held by most of the respondents was characterized by the belief that they could also pray privately and did not necessarily have to visit a religious healer. As one of the women (Beatrice) describes it with an undertone of skepticism:

'Going to see a religious healer to pray for you? I'm wondering if that can open the blocked tubes... And if a religious leader can pray for the tubes to be open, then I can also pray for the tubes to be open. So I've never been to a religious leader for this problem. [...] I don't have to waste my time.'

This opinion reflects the pragmatic attitude and choices made by the couples to seek help. Various religious and non-religious explanations inform help-seeking behavior in a pragmatic

way: costs and benefits are weighed and decisions are based upon what is believed to be helpful. Later in this chapter I will go more deeply into on the influence of religious beliefs on help-seeking behavior

While many Ghanaians may not receive exposure to medical explanations for infertility through formal education or from their communities, couples seeking medical support for their affliction are subsequently exposed to biological and medical information which changes their perception. The study participants who sought medical help had developed a relatively clinical gaze as a result of repeated visits to hospitals and fertility clinics involving lengthy conversations with doctors and medical staff. Biomedical explanations of their infertility, such as blocked fallopian tubes, a low sperm count or sexual transmitted diseases, helped the couples to perceive their childlessness as a biological flaw. Once the couples ascribe biological explanations, they tend to seek medical support rather than spiritual treatments. Thus, there is a recursive relationship between the explanations ascribed to infertility and the treatment sought. Help-seeking behavior is clearly driven by pragmatic thinking.

## 6.2 Access and availability

The likelihood of seeking medical assistance depends on availability and accessibility of medical services. The respondents in this study mentioned that they often had to travel a long way to reach a health care center offering fertility treatment or had to pay a great amount for medicine or treatments. The couples initially sought help that was cheap and nearby, but as soon as there was no improvement they began to look further. This confirms what Van Balen & Gerrits argue in their article: the availability and accessibility of health care services and practitioners influences fertility-seeking behavior (2001:217).

The infertility treatment in Ghana can either be biomedical or traditional (Tabong & Adongo 2013:2). Traditional medicine is often cheaper, more readily available and easily accessible within communities, particular those in more remote parts of Ghana. This type of infertility treatment includes faith-based healing often performed by religious healers, spiritual healing carried out by fetish priests or witch doctors, and herbal treatment given by herbalists. Although religious healers and fetish priests were not popular amongst the respondents, almost all respondents stated that they – at a certain moment – had visited traditional herbal healers, often under pressure from family or community members, which will be covered in the next section. After telling the herbalist about the infertility issues they were facing, the couples were

given various herbs and leaves to prepare and drink at home, eliminating the often expensive and regular journeys to medical facilities.

However, 'the medicalization of infertility has led to the emergence of different types of modern treatments available for solving infertility', such as medical herbalism, low technology treatment and high technology treatment (Hiadzi 2015:39). Medical herbalism refers to 'the combination of knowledge of traditional plant remedies with modern medical science' (ibid) and takes a more scientific approach to treatment of illness than traditional herbalism. Low technology treatment of infertility refers to 'technologies that do not involve the retrieval of oocytes (female egg cell) or fertilization outside the body' (Fiddler & Berstein 1999:501) and includes the use of fertility drugs, IUI and 'surgical procedures to repair reproductive organs' (Hiadzi 2015:41). In Ghana, these treatments are generally available in public hospitals such as the Pentecost Hospital in Madina. High technology treatment involves infertility treatments that 'utilize the power of technology to fertilize human eggs and sperms outside the human body for the purpose of helping establish pregnancy' (Hiadzi 2015:45). This type of treatment is referred to as ARTs in this thesis and includes, amongst other techniques, IVF and ICSI. ARTs are very costly and in Ghana only available in private clinics, which makes them inaccessible for the majority of childless couples (Hiadzi 2015:50). I will elaborate more on these biomedical health care services, with particular reference to tWE-IVF, in the next chapter.

## 6.3 Advice given by family and community members

Another factor influencing couples' fertility seeking behavior is the advice they receive from family and community members. All respondents indicated receiving solicited and unsolicited counsel from family or community members. These advisers would also use explanatory models to determine the best treatment option for their childless acquaintance or relative, often based upon previous success stories. Depending on the couple, help-seeking behavior was influenced by the recommendations of relatives and friends. When confronted with advice, couples would decide whether to follow it or not. This decision was often based upon their own explanatory model and – again – characterized by pragmatism.

As stated earlier, almost all respondents visited traditional herbal healers, sometimes from an intrinsic motivation but often urged to do so by family or friends. Many respondents reported being 'pushed' by family members who were eagerly hoping for a pregnancy. This was often a pragmatic choice to please relatives and friends and avoid further questioning. It is

important for childless couples to show the outside world – the source of the pressure – that they are doing everything within their power to conceive. In response to a question by an acquaintance, Prince stated:

'So I said 'Oh, we are not just sitting, we are doing something'. But the thing [baby] is not coming. So we try our best, we try our best, we try our best. Up to this time. We don't sit on it and we are doing something as we're here [at the clinic] too.'

In the end, none of the respondents claimed to have benefited from their visits to herbalists. Sometimes the treatment would even aggravate the situation, explains Caroline. She herself was advised by a cousin that her sister in law had become pregnant after taking a particular herbal treatment. Caroline followed her cousin's advice, but after two visits she decided that this was not going to help her: 'I realized that when I was taking it, I was bleeding heavily. So I stopped'. For most of the women, it was a case of trial and error; a pragmatic decision would be made when a certain treatment turned out to be unsuitable.

Unlike following advice from family and community members, it was easier for the couples to follow advice from other childless couples. Being in the same situation and sharing the same anguish, created feelings of trust, solidarity and connectedness between them. Some women indicated that they shared experiences and advice about hospitals, treatments and doctors with other couples facing infertility.<sup>32</sup>

In a few cases, the choice was made not to follow the advice at all. Three women were strongly opposed against the use of herbal treatment and other traditional medicines, as the remedy is often taken without proper supervision or prescribed dosage, which – they felt – could lead to wrong consumption of the medication. It is often expected of couples that they act upon all this – often unsolicited – advice, and so it is not appreciated when it is put aside. Olive decided not to follow her uncle's advice because she does not believe in the healing power of herbs:

'I remember one day my uncle asked me to go to see an herbal doctor. But I said I won't go, so he said as for me I'm not serious because I'm not following him to that place. So since then he didn't come close to me again. [...] He was saying, as for

<sup>&</sup>lt;sup>32</sup> The formation of social relationships on the basis of a shared genetic or biological condition, in this case infertility, is called 'biosociality', a term introduced by Paul Rabinow (1996).

our family nobody is there without children, so he's not happy with our situation. So he forced us to go to the place that he mentioned, but I refused.'

As illustrated above, help-seeking behavior of childless couples is partly influenced by advice from family and community members. Since the costs and benefits of each response are carefully weighed, the decision to follow or ignore advice is characterized by pragmatism.

## 6.4 Religious beliefs

As shown in the former chapter, religion plays a very important role in all facets of Ghanaian life, and it is the next important factor influencing help-seeking behavior. In her article about the way in which a religious or spiritual mindset may help infertile women in the United States, Miller states the following: 'One in eight couples has trouble conceiving; it stands to reason that, for some percentage of these couples, intense religious belief informs the way they approach this problem' (2008:18). Within the scope of my research, Millers statement applied for all respondents in the current study. All childless couples we interviewed were religious (either Christian or Muslim) and the influence of a religious background on the way infertility was explained and approached was clearly visible. However, how this influence expresses itself depends on the religious movement they adhere to and the individual, as Dr. Amenga-Etego<sup>33</sup> explains.

'The whole idea is that: God helps those who help themselves!' Dr. Amenga-Etego tells me with a smile during our interview. Although it sounds like a scriptural quote, this is one of the most often quoted phrases not actually found in the Bible. In 'The new dictionary of cultural literacy', Hirsch and his colleagues explain this proverb: 'God will not come to the aid of those who refuse to try; we must exert ourselves if we want to succeed' (Hirsch, Kett & Trefil 2002:51). If we translate this motto to the situation of the childless couples, seeking infertility care could be seen as a form of 'helping oneself'. The quote stresses the importance of self-initiative.

According to the respondents, in Ghana there are many different ways to 'show God' that you are ready to conceive. Sometimes churches, for example, advise buying baby clothing as a way to express your desire for a child. According to Dr. Amenga-Etego the whole idea is that these acts 'give room and invite': they demonstrate that you are caring and prepared to

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<sup>&</sup>lt;sup>33</sup> Dr. Amenga-Etego is a Senior Lecturer in the Department for the Study of Religions at the University of Ghana with whom we had a conversation.

receive a child. She also explains how women in traditional society started to wear a second wrapping cloth, which 'was not as a sign that you were matured and ready to marry, but the second cloth was that you were ready to carry a baby, you have what it takes to carry a baby'.

In one of the couple interviews, with both partners holding a university degree, Mike explains there is another way to show God that you are ready to conceive:

'The African perception is that kids are blessing because they are innocent. [...] We have the view that once kids are around you, they are blessing. So once they're around you and you treat them well, God will look at the way you are treating them and will reward you. And the reward will be having kids.'

It is a strong belief that God will bless you with your own child if you are taking care of the children around you, and therefore, adopting or looking after children could also be interpreted as a form of help-seeking behavior.

For me, the outsider, it often sounds like a contradiction: on the one hand you have to take initiative; but on the other hand, God's time is the best. Some of the couples also struggled with this discrepancy. Hence, Denise, a 45-year old woman and the only respondent with a child, tells me how her perception of this paradox slightly differs from that of her husband's:

'My husband is a man of faith and he keeps telling me 'why do you keep bothering yourself when God is going to do it?'. And I know that faith without work you know... if you have faith and God is meant to do it, but you also have to do what you need to do.' She starts laughing while she continues: 'So he's the one who says 'don't worry about it, God will do it'. [...] But if I leave it to him, then nothing will get done!'

This is a very good illustration of the complexity of religious beliefs affecting treatment-seeking behavior of childless couples. While all couples possessed a strong belief in the power of God, at the same time all were convinced that they have to undertake action themselves.

#### 6.5 Gender and social pressure on women

Strikingly, help-seeking behavior was different between men and women. Most husbands took responsibility for the financial issues or brought their wives to the fertility clinic for

appointments. The wives often took the initiative to seek help and acted as active agents in the treatment-seeking behavior. The couples often mentioned that they did it together, but the initiative was never taken by the husband only.

This could be explained by the fact that women are expected to procreate and are often blamed for childlessness (Donkor 2008; Geelhoed et al. 2002; Inhorn & Patricio 2003). During the FGD the group – both women and men – was asked how a (wo)man without children is perceived in Ghana. Many examples were given, such as 'people say she aborted', 'she committed a sin, she is a witch', 'she ate all the children in the womb' and 'man living with another man' (referring to the childless woman because of the inability to conceive). Another participant explained: 'It is disrespectful for a woman to say that my husband is infertile'. These examples and many others illustrate that Ghanaian women carry most of the burden of infertility. This could contribute to the fact that women, out of despair, often take a leading role in searching for a way out, sometimes even having to beg their husbands to cooperate. Sophia narrates: 'Then I say: Oh daddy please try for me, I beg you. Let's go!' The 38-year old Cecilia experiences similar problems and is quite desperate since she is the only one of her six siblings who has no children. Her alcoholic husband who has already two children from a previous relationship refuses to pay for the treatments. However, Cecilia needs his support to continue the fertility tests, and so she is 'waiting to ask him in the nice time, in a nice way' to pay the treatment costs. This illustrates that women are often more keen to find a solution than men, often as a consequence of the accusations and their suffering.

Another explanation for women taking the lead as active agents in this treatment-seeking behavior is because there is more at stake for them. Anna explains what many women felt: 'what we are all looking for in the marriage is just to have a child, that's all. So that the marriage will continue'. A child is often seen as a means of security for the marriage for women, to secure that she will not be divorced by her husband. Denise, a 45-year old, well-educated woman describes it as follows:

'The woman is the person who has to hold on, the woman will always try to hold on... For the man it's an ego thing, you know? 'I should have a child, I'm a man.' But for the woman it's the fear of losing their husband, losing their home, that's what they fear for. [...] Because of that women are so desperate it is the woman who always does this, you know, searching for a way out.'

This quote reaffirms how the burden of infertility mainly falls on women.

## 6.6 Conclusion

In this chapter I have shown and argued that help-seeking behavior of Ghanaian childless couples is influenced by many different factors. The data show that patterns of help-seeking exhibited by these couples are characterized by perseverance. Childless couples, and the women in particular, have exhausted all sources of help and have done everything within their power to achieve parenthood before resorting to ARTs/the clinic, on which I will elaborate in the next chapter. Additionally, above insights show that couples can be remarkably pragmatic in their search for a solution to their infertility, constantly being on the look-out for better options.

# 7. Pioneering

While her husband is providing us with answers to our interview questions, Elizabeth casts down her eyes. Then she breaks down. Tears are rolling silently down her cheeks. 'You see...' Prince puts his arm around his wife, 'Tears... So that's why we are here... Any means to make it happen in her lifetime. It's very serious... very serious...' (Part of interview with Elizabeth and Prince)

In the former two chapters I have illustrated and argued how the cultural importance of childbearing in Ghana has led childless couples to seek for various solutions. Although they each made a different journey, their help-seeking behavior led them all to the Madina fertility center, as is illustrated by Elizabeth and Prince's quote. As mentioned earlier, many couples developed a biomedical view of their affliction, due to their exposure to biomedical treatment and counseling. When they turned to the formal medical system – after all other options – this brought them into contact with a new field: that of assisted reproductive technologies, including tWE-IVF. Just a few, higher educated couples had some experience with this relatively new field, having undergone ART treatments (IUI or IVF) at other clinics. However, the vast majority were complete newcomers to this novel high-tech area. Where expensive ART treatments used to be only accessible to those with higher incomes, the relatively low costs of tWE-IVF now opens the doors to others.

Thus, the introduction of tWE treatment created a new target audience. Confronted with a new technology, its members have to regain their moral position in relation to this technology and decide whether or not to implement it. In this chapter I will make use of Rapp's concept of 'moral pioneers' in order to argue that childless couples adapt the role of pioneers by moving into the field of ARTs. The term 'pioneer', defined in the Oxford Dictionary as 'original investigator of something', could be interpreted more broadly as someone who is among the first to enter a particular area, finding his or her way without the benefit of the experience of others. This is not so much a physical area – although we might consider the fertility clinic to be an unknown terrain – but rather an ethical field strewn with various moral ideologies. Here, I show and argue that the interviewed couples, by considering the use of ARTs – and tWE-IVF and third-party-involvement in particular – and by making a well-informed decision after weighing the risks and benefits, may justifiably be called moral pioneers.

Attention will be paid to three pioneering moments: decisions about ARTs in general, possible third-party involvement and the use of tWE treatment. I will also take into account

how these moral and ethical choices are influenced by religious beliefs and family and community pressure, as introduced in the previous chapters.

### 7.1 Pioneering in the field of ARTs

We live in a rapidly changing world when it comes to technological inventions. This also applies to the medical field: new methods, equipment and tools are designed in order to facilitate, optimize, specialize and improve health care services. In their article about antenatal screening, Williams et al. state that 'the implementation of innovative medical technologies (IMTs) can raise unprecedented ethical, legal and social dilemmas, particularly in the linked specialties of obstetrics and fetal medicine' (2005:1983). Similar dilemmas arose during the debates in the era of assisted reproductive technologies as shown in the context chapter. I argue that the first pioneering moment takes place when childless couples decide to enter the field of ARTs. Their pioneering role is reflected by their secretive approach towards these technologies, as I will show below. After all, their lack of openness about their treatment is a confirmation of the fact that they are entering an area that is not yet socially accepted.

All couples stated that they did not share their problems, struggles or worries about infertility and its treatment with others, since the subject of childlessness is very sensitive within Ghanaian society. On the one hand, this secrecy is caused by the cultural meaning of childlessness and the stigmatization of infertility in Ghana, as shown in chapter five. On the other hand, ARTs are 'deeply culturally embedded', and their acceptance and use depends on whether they are 'perceived as reasonable in the context of existing social relations, cultural norms, and knowledge systems' (Inhorn and Birenbaum-Carmeli 2008:178). The respondents appointed three reasons for their secretive behavior regarding childlessness and infertility treatment, deriving from the stigmatization of childlessness and the non-acceptance of ARTs, which I will briefly discuss below.

First of all, couples appeared to be afraid that others would 'start a rumor' once they had shared the story of their struggles. 'In our society, sometimes people talk too much', Aaron claims during our interview. This perception was shared by many, leading to a high level of suspicion and withholding them from confiding in others. The issue of infertility is one that is strictly kept between husband and wife, reflecting a strong need for privacy. When I asked 40-year old Eleanor if she had ever shared her struggles with close friends, she looked at me perplexedly and shook her head fiercely when she answered:

'No! Never. Because I don't trust them. Yes, I really don't trust friends. I love talking to you, but I don't trust... [my friends]. I only talk about it when I'm in the room and talk to God. I only talk to God, that's what I do. I pray, I always pray. Me, my problems I just share it with God.'

Although it sounds paradoxical – not trusting friends – this feeling was shared by the majority of respondents. Only some shared their worries with a close friend or family member, but still then would not go into detail, as the results of blowing off steam were unpredictable. The childless couples felt no need to share their concerns and they did not want to take the risk. In order to protect their 'secret', on occasion couples would simply avoid telling the truth. When asked: 'how are the children?' they were likely to respond 'they're fine', despite the absence of children, to avoid further questioning and to avoid the need to justify themselves.

This brings us to the next reason for keeping infertility issues private. More than once, childless couples mentioned that certain information could be 'used against you'. Although they asserted not to hold these beliefs themselves, childless couples chose to err on the side of caution. To a certain extent, many Ghanaians adhere to spiritualism, believing that witchcraft and evil spirits could cause infertility. Denise explains why this is one of the reasons why people often do not tell others that they are pregnant: 'Nobody tells anyone they're pregnant, that's for sure. Because they don't want some witches coming to get the baby or maybe some bring them bad luck or something and lose the baby'. When the news about a (desired) pregnancy reaches the wrong people, this might be used against them and the couple could be attacked by bad spirits. In the same vein, when the wrong people would get to know about the couples' use of ARTs, this too might be used against them and lead to failed treatment. Dr Lartey explains that many of the couples are also a bit 'superstitious' and do not want to call themselves 'childless' or 'infertile'. They fear that repetition of their childless condition could compartmentalize them and in actual fact seal their infertility.

Another argument for keeping silent about infertility and its treatment was the fear that others would try to change their mind. The community these couples are from will rarely understand the procedures offered at the clinic. As one woman puts it: 'If you have a baby through IVF... Lots of people don't understand what IVF is about. They don't understand the process, so to them you gone to buy a baby. That's the way they see it'. This lack of knowledge and understanding could drive them to make discouraging remarks. Some of the couples are apprehensive of friends or family members talking them into discontinuing the treatments.

As illustrated, infertility problems are seldom shared with friends, family members and acquaintances, so as to minimize the potential adverse effects. However, in contrast to their secrecy towards others, it seemed very easy for the couples to open up to doctors, medical staff and to ourselves as researchers, possibly because of our 'medical' background. According to Dr Lartey, the couples implicitly trust the pastors and the doctors: 'There's a perception that maybe doctors are Gods, they have the solution to most of the problems. So that also helps them to open up a lot easier to us than other people'. This conscious attitude to sharing or avoiding to share demonstrates – once again – how these couples' behavior is influenced by pragmatism and the weighing of costs and benefits. Childless couples make an informed and pragmatic decision to whom they open up to, opting for those who can help them with their problems.

The use of ARTs was not seen by any of the respondents as conflicting with religious beliefs (cf. Hiadzi 2015). On the contrary: couples drew on their religion to explain fertility failures and successes, as shown by Meredith: 'But my feeling is that even IVF is not 100%, so still God picks the one that works'. Although all respondents were very positive about the ARTs offered at the clinic and told us it did not interfere with their religion, other studies have shown that this is not always the case. In their study among Nigerians, Aluko-Arowolo and Ayodele argue that some infertile couples do not use ART facilities due to religious belief. 'ART specialists said that PLWI [people living with infertility] did not access ART service because of social costs, in term of lack of support from the religious community. Religion and belief system hindered the use of ART, which also reinforced its poor adoption' (Aluko-Arowolo & Ayodele 2014:88). This is in contrast with my findings that ARTs are not necessarily disapproved by the churches, further supported by the fact that some pastors introduced the couples to the infertility clinic. Although I myself have not spoken to couples that were not positive about ARTs because of religion, I was told about parents who turned away from their children after a pastor had told them that children conceived through ARTs are the devil's spawn.

## 7.2 Third party involvement: donor gamete and surrogacy

When couples are not able to achieve pregnancy through traditional infertility treatment and ART, they might consider so-called 'third party assisted ART methods'. Depending on the infertility cause, a couple can opt for sperm donation when the husband produces very low numbers of sperm, egg donation when the wife does not produce healthy eggs or a surrogate if

the woman is unable to carry a pregnancy to term.<sup>34</sup> I argue that the second pioneering moment takes place when childless couples have to decide whether or not to use third party assisted ARTs. Rapp stated that women who were offered amniocentesis tests during pregnancy were thereby put in the difficult position of 'moral pioneers' as they were forced to make moral decisions about 'what constitutes an acceptable human life' (Inhorn 2006:428). I show and argue that the couples in the current study are also forced to make moral decisions, namely to decide what constitutes an acceptable way to conceive. The interviewed couples remained divided in their opinion about the use of donor gamete and surrogacy. Their reasons to accept or reject third party involvement are discussed below.

Despite the ethical concerns about biological and social parenthood, the vast majority of the participants had no objection against third party involvement in the form of gamete donation. These couples indicated implicitly that the end justifies the means, stating that they would employ this technique as long as it would give them a child. Other couples were not concerned about this issue as their semen and eggs were of good quality or because they had not received the results of their tests yet.

A minority, however, had issues with third-party gamete transaction. In his article, Dutney also argues that 'the use of donated gametes or embryos has been questioned because of the way in which they introduce a third party to the relationship' (2007:175). Mike, who has a Master's degree in reproductive health, explains why he is not interested in the use of donor gamete:

'If it is my sperm and her egg fused together, I don't have problem with it. But if it's somebody's sperm fused to her egg or somebody's egg fused to my sperm, psychologically... I won't do it myself. I will know, the baby in a way, is not fully our baby.'

He is afraid that the physical characteristics and traits of the child may turn out to be very different than his own. If a child has no resemblance to his parents, people would doubt its provenance. To avoid questions about kinship and fearing the lack of a bond with the child, Mike refuses the use of donor materials. Similar concerns were expressed by a few others.

ets/thirdparty.pdf

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<sup>&</sup>lt;sup>34</sup> American Society for Reproductive Medicine. (2012). *Third party reproduction (sperm, egg, and embryo donation and surrogacy): A guide for patients*. Retrieved July 20, 2016, from <a href="http://www.asrm.org/uploadedFiles/ASRM\_content/Resources/Patient\_Resources/Fact\_Sheets\_and\_Info\_Bookl">http://www.asrm.org/uploadedFiles/ASRM\_content/Resources/Patient\_Resources/Fact\_Sheets\_and\_Info\_Bookl</a>

An even more controversial alternative for couples is surrogacy, where the pregnancy is carried by another woman. For many infertile couples it is often the last option to achieve parenthood (Nakash and Herdiman 2007:246). Only few women in my study said they would consider surrogacy if necessary, and preferably within the family. Most stated they objected to surrogacy, as carrying one's own child is proof of fertility and evidence of being the biological mother. Eileen emphasizes the importance of the pregnancy itself: 'We are Africans. So far it doesn't come from you, they may think it's not yours. No matter the explanation you'll give, they might think it's an adoption.' Surrogacy has great social consequences: because of lack of understanding about the procedure, others might not accept a child born through surrogacy. Prince confirms the importance of giving birth: 'if you conceive and accidentally the child dies, everybody has seen that at least you conceived before. [However, in our case] nobody has seen you [with a child], so the stigma is there'. Both women feel a strong need to give birth since being pregnant – even with a miscarriage – disproves one's infertility.

In making these choices about third party involvement, the influence of religious beliefs should not be forgotten. From a traditional religious perspective, the involvement of a third party in the act of procreation is unacceptable since conception should take place between husband and wife in the context of marriage. In her recent article about ARTs in Ghana, Gerrits describes the current situation towards third-party involvement: 'While the initial introduction of 'traditional IVF' did not lead to too much societal concern in Ghana, the more recent and increasing use of third-party involvement in conception did raise questions about its acceptability, both on the part of the Ghanaian government and the Pentecostal Church' (2016:36). This was confirmed by Dr Attoh who explains that the Pentecost Hospital and the Pentecostal Church do not support third-party services. However, they have never officially prohibited it, 'so we still have a grey area, because we have not been categorically told not to accept a third party' he clarifies.

## 7.3 Double pioneering: The Walking Egg treatment

When childless couples move into the 'field' of treatment and approach a relatively new area within this field, such as 'ARTs', we can consider these couples to be pioneers. When they go one step further and enter another, untrodden domain – the tWE procedure – I would like to call them 'double pioneers', who venture within an already pioneering group. This third pioneering moment has to be placed explicitly in the debate about doubts and skepticism concerning the Walking Egg treatment, as described in the context chapter.

The third pioneering moment is characterized by the decision-making about a completely new concept, since Ghana is the first country in the African continent where tWE treatment has been introduced. Simpson and Hampshire accurately characterize pioneering thus: 'the idea of people moving into new conceptual terrains as 'pioneers' for whom technoscientific innovation initiates decision making that, in cultural terms, is as risky as it is novel' (2015:13). The decisions taken by the (potential) tWE-users are truly novel as they are the first on the African continent to undergo this treatment, and they are risky as the couples are aware that there is no guarantee for success. As Charles, one of the respondents, explained referring to the first tWE batch: 'They [embryos] were twenty-four in number, and none of them were able to survive. So I asked myself 'why?' [...] What is the guarantee?' However, despite the uncertainty and risks, and the negative and judgmental comments, the couples decided to make use of tWE treatment. This dedication partly springs from a certain measure of despair. Couples indicated they wanted to try tWE-IVF despite its uncertainty and possible risks: 'so far as I'll get my baby at my lab' explains Eileen. Remarks such as: 'I told my wife that maybe we will be the first achiever' indicate that couples are aware of their pioneering role.

The majority of these childless men and women indicated that they shared their story with others who had trouble conceiving. Sharing a similar background – as also shown by Dyer et al. (2002) – provided for trust between the couples and created an atmosphere wherein the subject of childlessness could be discussed. Mutual understanding led to the exchange of personal experience with clinics and treatments and offered an opportunity to share advice. Some women shared experiences through WhatsApp groups with other childless women, such as Meredith: 'We're all trying to get pregnant. So if someone is going to do something she can ask, 'I'm going to do this test, is it painful?' 'Has anybody done it before?' Stuff like that'. The women encourage each other and share their knowledge.

This process of lending advice to other childless couples becomes interesting when considering Rapp's concept of moral pioneers. After all, a pioneer is someone who sets foot onto new and unfamiliar territory so that others may follow later. From that perspective, the couples took a leading role when entering the territory field of more affordable ARTs and deciding to use tWE treatment. A part of them expressed a wish to share their experiences with others, or even wanting to become a tWE ambassador to promote the Walking Egg project; others remained more reserved. More than once, a couple stated their intention to first conceive, returning to their village or family with the living proof of tWE-IVF, before convincing others to use the new technology. They said they did not want others to spend, or even waste, money on something that might not work, first wanting to be assured of the fact that the procedure

worked for them, before recommending it to other childless couples. From that point of view, the interviewed couples could be considered economic pioneers as well, taking a financial risk by using a technique that had not yet been proven to be effective in Africa.

#### 7.4 Conclusion

In this chapter I have used Rapp's concept of 'moral pioneers' to argue that childless couples adapt the role of pioneers when entering the field of ARTs. I assert, and have illustrated, that the respondents in this study may experience three pioneering moments: decisions about ARTs in general, third-party involvement and the use of tWE-IVF. As the couples were entering an area not yet socially accepted, the pioneering moments were often characterized by secretiveness. All respondents were very positive in their attitude towards ARTs and none were of the opinion that ARTs interfered with their religion. Just a small minority indicated having problems with third-party involvement, the majority being willing to use donor gamete, if necessary, despite ethical debates concerning the sanctity of the embryo. tWE-users may be dubbed 'double pioneers', pioneering within an existing group of pioneers. Finally I have argued that the respondents, by taking financial risks, may be considered economic pioneers as well.

## 8. Discussion and Conclusion

This study was carried out to explore how childless couples in Ghana perceive and respond to the innovative Walking Egg fertility treatment. There is a distinct lack of sociological or anthropological research on the adoption of ARTs in an African context, and it is to be hoped this study will make a significant contribution to the literature concerning this topic. By providing an insight into the meaning and implications of childlessness in Ghana, it is the intention to put the issue of infertility on the international reproductive health care agenda.

To study this issue, I have relied on both anthropological literature and my own empirical data, also using Weiss' cultural construction of illness as an anthropological lens through which to look at childlessness and the response to infertility treatment in the Ghanaian context. The three empirical chapters map onto the elements of this framework, exploring how Ghanaian couples ascribe meaning to their childlessness, how this subsequently influences their help-seeking behavior and finally situates their response to tWE within this context.

To fully understand local perceptions and choices I have first elaborated on the meaning of infertility and childlessness within the Ghanaian context, focusing on two components of Weiss' model of the cultural construction of illness: the influence of the social context and explanatory models. I have used Kleinman's explanatory model – which lays the emphasis on the personal experience of illness – to show that beliefs and perceptions surrounding infertility are intricately interwoven with all other aspects of life.

I have argued and illustrated that the meaning of this affliction in Ghana is constructed within four different domains: personal, family, societal and religious. The high value set on childbearing by society creates a strong desire for children and simultaneously feeds the anxiety of remaining childless. Childless couples are highly stigmatized and experience feelings of personal grief and a fear of rejection. It was also found that these couples experience both stress and support from their religious beliefs.

The pronatal nature of Ghanaian society and the strong individual desire for a child have led to help-seeking behavior, corresponding to the 'help-seeking' component of Weiss' model, on which I have further elaborated. I have found that help-seeking behavior is influenced by several factors: explanations for infertility; access and availability of fertility care; advice given by family and community members; religious beliefs and gender. The data have shown that patterns of help-seeking exhibited by these couples are characterized by a process of trial and error and defined by pragmatic behavior. Following exposure to biomedical counseling, many couples developed a biomedical view of their affliction, which finally steered them into the

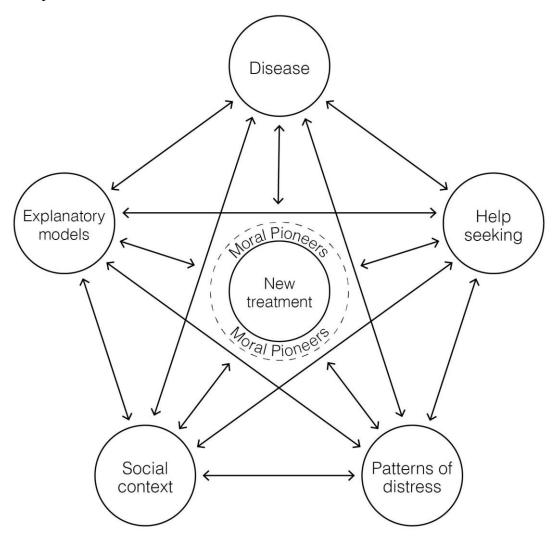
uncharted territory of ARTs. Although the implementation of ARTs in poor resource settings remains the subject of debate, often revolving around overpopulation, there is evidence (Osei 2014) for a real need for this treatment in Ghana, a country with a high infertility rate.

In many African countries the demand for ARTs has risen significantly as a consequence of the suffering and stigmatization of infertile patients. However, for the majority of childless couples in developing countries, these technologies are still unaffordable and therefore out of reach. Medical scientists have responded to these needs by developing a more affordable reproductive technology: 'the Walking Egg IVF'. Although the project has had its setbacks and the first pregnancies have not yet been confirmed, earlier results in Belgium are very encouraging and tWE will renew its efforts. It is demonstrated that the introduction of tWE treatment has created a new target audience. Using a concept of Rayna Rapp (1998), I argue that childless couples – confronted with a new technology and obliged to regain their moral position towards this technology – may be called 'moral pioneers'. They may experience three pioneering moments, depending on the nature of their infertility and their personal decisions: choosing for ARTs in general, third-party involvement and the use of tWE-IVF. I have shown that, through their help-seeking behavior induced by the socio-cultural meaning of childbearing, Ghanaian childless couples may become moral and even double pioneers in their quest for parenthood.

In addition, I argue that Rapp's concept of (moral) pioneering may be incorporated into Weiss' cultural model of illness when people are confronted with, and decide to use, a new form of treatment or technology. After all, each innovative treatment has its pioneers. With the implementation of any new type of treatment or technique, there will be a pioneering group, indirectly responsible for the future implementation and acceptation of the therapy. When pioneers are satisfied with, for instance, the positive results, minimal side effects, and low financial costs, the treatment will find its way into society more easily and conquer a position within the cultural construction of the concerned illness. However, when pioneers are unsatisfied, this will also have an effect on the implementation and acceptation of a new form of treatment.

As described in the theoretical framework, Weiss' model is characterized by the complex relationships between the components (disease, explanatory models, social context, patterns of distress, help seeking and treatment), each influencing the other. By adding the concept of pioneering to this framework, I argue that it is relevant to all other components and thus contributes to the construction of illness. In order to sustain this argument, I will briefly describe the influence of a pioneering group on three components within this construction. The

concept of pioneering is represented by the dotted line encircling Weiss' treatment component (see figure), representing the barrier that will have to be breached whenever a new form of treatment presents itself.



Source: Weiss (1988:6): adapted

First of all, by using a new form of treatment, pioneers exert influence on the 'explanatory models' component, since they slowly adopt a more biomedical perspective on their affliction while moving in the field of ARTs. I have observed an interaction between the type of treatment chosen and explanations ascribed to infertility. Secondly, pioneers influence their own and others' help-seeking behavior. Through sharing their stories about the new treatment options, pioneering couples may change the way in which others seek treatment. And thirdly, pioneers affect the treatment component itself by taking the lead, levelling the path to this unknown terrain for other childless couples.

Pioneers play an essential pivotal role in the acceptance and adoption of new treatments. They play a leading role in the socio-cultural construction of infertility in Ghanaian society by exerting their influence on the way people explain, experience, perceive and deal with this affliction, and by demonstrating how the concept of pioneering constitutes a valuable contribution to Weiss' framework. Since tWE-IVF focuses on low-cost fertility treatment, these moral pioneers (middle- and low-income childless couples) have more territory to challenge the current stigma of childlessness. tWE-IVF moral pioneers speak to a much larger audience than users of regular expensive IVF-treatments, which only focuses on high-income couples.

This thesis also stresses the importance of 'sharing' experiences and views among fellow infertile women and men – in which the activities of ACCOG are crucial – which increases support and may lead to destignatization of childless women and men. Future research could explore other ways of sharing and peer support.

I have been able to conclude that the Ghanaian childless couples in this study, responding to tWE-IVF in the role of pioneers, perceive this new technology as a welcome, more affordable opportunity to conceive. Over time, it will become apparent whether the Walking Egg in Ghana will be able to bring a change to their lives, substituting hope for despair.

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# **Appendices**

Appendix 1: Map of Ghana



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# Appendix 2: List of abbreviations

ACCOG Association of childless couples of Ghana

AISSR Amsterdam institute for social science research

ART Assisted reproductive technology

CDE Child development and education (master's program)

CEO Chief executive officer

FGD Focus group discussion

ICSI Intracytoplasmic sperm injection

iCSi International consumer support for infertility

IUI Intrauterine insemination

IVF In vitro fertilization

LCIVF Low-cost in vitro fertilization

MAS Medical anthropology and sociology (master's program)

NGO Non-governmental organization

NMIMR Noguchi memorial institute for medical research

tWE the Walking Egg

tWE-IVF the Walking Egg in vitro fertilization (method)

# 1. Personal data of woman, man or couple

(Date of birth/age, religion, country/region of origin (nationality), ethnic group, date of marriage, children, foster children, family background, school/education, profession, economic status, languages)

## 2. Personal history of involuntary childlessness

(First encounter fertility problems, reaction, partner's reaction, reaction of family and friends, influence on relationship, influence masculinity/femininity, relation parenthood and (wo)manhood. How does infertility affect you in daily life?)

#### 3. Personal history with treatments

(When did you decide to start treatment, what kinds of treatments, herbal, religious healing, biomedical treatments, your experiences, how does it influence your personal life and relationship)

## 4. Course of and experiences with ACCOG and the fertility center

(First acquaintance with ACCOG, experiences with the treatment, what do other people say about you being treated here?

#### 5. View on ARTs

(Personal view on ARTs, other people's view on ARTs, involvement in infertility treatments over time, experiences with ART, ethical and moral position, from a religious perspective)

### 6. View on surrogacy and donor gamete

(What is your perspective on surrogacy and donor sperm/eggs? Religious beliefs)

#### 7. More affordable IVF (tWE)

(How do you experience this new treatment, what does it mean to you, how does your environment react, do you share your experiences?)

#### 8. Financial issues

(How much does the treatment costs (consults, medicine)? Did you have to save a lot of money to start these treatments? Difference regular and more affordable IVF treatment)

## 9. Religion and infertility

(How does religion play a role on your experience of involuntary childlessness? Counseling/pressure? Do you find support/pressure? What does the Bible say?)

## 10. Future expectations

(Expectations of life, expectations of treatment. How do you see your future? With or without children? What are alternatives? Adoption, foster children? Consequences of childlessness?)

Appendix 4: Details of study participants

R#	Pseudonym	F/	Age	Religion	Ethnic	Years of	(Illegitimate/Foster) Children	
		M			group	marriage	Taking care of other children	
R1	Oumaima	F	24	Muslim	Gao	3	0 children	
R2	Maria	F	44	Christian	Ewe	10	Care of R3's child	
R3	Peter	M	49	Christian	Ewe	10		
R4	Elizabeth	F	42	Christian	Adangbe	17	Care of 1 child	
R5	Prince	M	44	Christian	Ashanti	17		
R6	Meredith	F	36	Christian	Unknown	8	0 children	
R7	Beatrice	F	43	Christian	Akan	5	Care of R7's 4 children	
R8	Patience	F	34	Christian	Akan	15	3 foster children	
R9	Charles	M	39	Christian	Akan	13		
R10	Catherine	F	40	Christian	Akan	6	Responsible for husband's 2 children, who live elsewhere	
R11	Anna	F	44	Christian	Ewe	7	Husband has 1 child	
R12	Eve	F	38	Christian	Akan	8	Husband has 2 children	
R13	Debby	F	29	Christian	Akan	3	0 children	
R14	Caroline	F	43	Christian	Ewe	8	Care of 2 children	
R15	Nora	F	44	Christian	Akan	17	2 foster children	
R16	Kate	F	37	Christian	Ewe	Divorced, new relationship	Current partner has 2 children	
R17	Mike	M	38	Christian	Ewe	2	R17 has 2 children from previous	
R19	Rose	F	38	Christian	Ewe	2	relationship	
R18	Sophia	F	38	Christian	Ewe	6	Care of 1 child	
R20	Agnes	F	47	Christian	Ashanti	9	Husband has 5 children	
R21	Eileen	F	33	Christian	Akan	5	Previous care of 1 child	
R22	Denise	F	45	Christian	Unknown	Divorced, new relationship	Has 1 child with ex-husband	
R23	Amy	F	44	Christian	Unknown	15	Previous care of 2 children	
R24	Khadijah	F	28	Muslim	Mole- dagomba	10	Husband has 3 children with his other two wives	
R25	Daisy	F	31	Christian	Akan	3	0 children	
R26	Adam	M	37	Christian	Akan	7	0 children	
R27	Eleanor	F	40	Christian	Akan	11	Care of 1 child	
R28	Isabel	F	42	Christian	Bono	Divorced, new relationship	Care of 2 children	
R29	Edward	M	44	Christian	Ashanti	15	3 foster children	
R30	Olive	F	33	Christian	Akan	8 0 children		
R31	Daniel	M	36	Christian	Akan	8	0 children	
R32	Patricia	F	28	Christian	Akan	1	0 children	
R33	Sabrina	F	39	Christian	Ewe	18	Care of 2 children	
R34	Cecilia	F	38	Christian	Unknown	4	Husband has 2 children	
R35	Jane	F	33	Christian	Akan	7	3 foster children	
R36	William	M	36	Christian	Akan	/		
R37	Aaron	M	53	Christian	Ewe	10	2 children from previous marriage	

<u>Professions</u>: accountant, administrative officer, architect, bank auditor, cosmetic seller, electrician, general management trainer, hairdresser, IT technician, musician, nurse, optometrist, pastor, seamstress, trader, (primary) teacher, secondary school teacher, shop employee, service and public servant, welder.

## Appendix 5: Focus Group Discussion: Program and Topics

On Easter Monday (28 March 2016) Evelien, Margot and I organized a focus group discussion at the fertility center in Madina with help from Nana. Nana suggested that we combine the FGD with an IUI briefing to make the event more attractive for the couples. Four couples attended the session, which took place in the reception/waiting room of the fertility center. The program and topics are described below.

- 10:00 11:00 The couples arrive and have breakfast
- 11:00 11:30 Information about IUI technology
- 11:45 12:00 A brief introduction of ourselves and the participants (name, region etc.)
- **12:00 12:45** Discussion about the following statements:
- I share my thoughts and/or struggles about my childlessness with friends and family;
- Once I have a child, all the stigma will be gone/all my problems will be solved;
- In Ghana, a man/woman without children is seen as... [complete the sentence];
- This treatment is my last hope;
- The more I pray, the sooner I will get a child;
- The government should finance fertility treatment.
- **12:45 13:00** Short break for a snack and a drink
- 13:00 13:45 Discussion of cases

The group is divided into separate small groups of men and women. Each of the groups was asked to discuss 3 different 'case studies'. After 30 minutes, we compared the differences between these groups. We discussed the following cases:

- 1. You're at the market and a stranger walks up to you and asks 'Hello, how are you? How are the children?' How do you react?
- 2. During a conflict an acquaintance tells you not to interfere, suggesting only 'useful people' (those with children) should be allowed to do so. According to him/her, childless people do not have anything worthwhile to say. How do you respond?
- 3. An aunt recommends an herbalist to you. What do you say?
- **14:00 14:30** Time for any questions and issues the participants would like to share.
- 14:30 14:45 Final prayer led by Nana

Appendix 6: Participant Information Letter

Title: Women and Men with Fertility Problems: A Qualitative Study on a New IVF Treatment and

Fertility Support Group in Ghana.

General information about the research

This study is part of a broader study on people with fertility problems, fertility associations and the introduction of a new In-Vitro Fertilization (IVF) treatment that will be carried out in Ghana and in

Kenya. The ultimate aim of the study is to improve care to people facing fertility problems.

This information letter is focusing on the study that will be conducted in Ghana, and is only about part of the study in which we are gathering information by means of observations, in-depth

interviews, and informal or casual conversations which could be recorded.

What does your participation in the research entail?

The participation in this research project involves an in-depth interview with questions related to your situation of having fertility problems, and or being childless or trying to conceive a child. When you agree to participate, our research assistant will make an appointment with you and will explain once more the abovementioned goal of the study and the in-depth interview. Doing the interview

will take about one hour.

Preferably, we will ask both partners to participate in the study. Nevertheless, we also welcome men

and women whose partner does not want to participate in the study.

The appointment will be organized in a way that is most convenient for you: it is up to you at which

moment and place we can arrange to meet you.

Your decision to take or not to take part in this study will not affect in any way your relationship with the Association of Childless Couples of Ghana (ACCOG) or influence any further treatments at the

Pentecost Hospital.

Possible discomforts

Some of the interview questions asked may concern your private life or experience that you do not wish to share. You are free to decline to answer any question you do not wish to answer at any time

or stop with answering the questionnaire at any time. Your answers will be kept confidential.

If you are feeling discomfort after the interview and if you want to talk about this with a counselor you can contact:

Association of Childless Couples of Ghana (ACCOG)

N. Yaw Osei (CEO of ACCOG)

P.O. Box MD 55

Madina-Accra

Ghana

Tel: +233 (0) 244 441690

E-mail: info@accog.com.gh

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Possible benefits

By participating in this study you help to improve the knowledge about the experience of fertility

problems and help to improve the care for people facing fertility problems in Ghana.

Confidentiality

The information you provide in the interview will be kept confidential and anonymous and will be

stored in secured computer files, and your names will not appear in any record and will not be

included in reports or publications.

Voluntary participation and right to leave the research

If you agree to take part in the study you are free to withdraw at any time without giving a reason. A decision to withdraw at any time, or not to take part at all, will not affect in any way your relationship

with the Association of Childless Couples of Ghana (ACCOG) or the Pentecostal Clinic or influence any

further treatments.

If you in principle agree to be part of this study, the following will occur:

1) The researcher will contact you (by email or phone) to make an appointment.

2) During that appointment the Research Assistant will provide you more information about the study,

if required from your side.

3) At the beginning of the appointment we ask you to sign an Informed Consent Letter. This form is to

confirm that you have understood what the study is about and that you have agreed to participate in it.

4) The appointment can be scheduled at a place and time most convenient for you.

**Contacts for additional information** 

If you, after reading this information letter, have any further question about the study or the requirements for your participation, please do not hesitate to contact one of the researchers:

Prof. dr. E. S. Donkor

College of Health Service, School of Nursing, University of Ghana

P.O. Box LG 13

Lego, Accra

Ghana

Telephone number: +233-243114968

Email: <a href="mailto:esdonkor@ug.edu.gh">esdonkor@ug.edu.gh</a>

Your rights as a Participant

This research has been reviewed and approved by the AISSR Ethical Advisory Board of the University

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