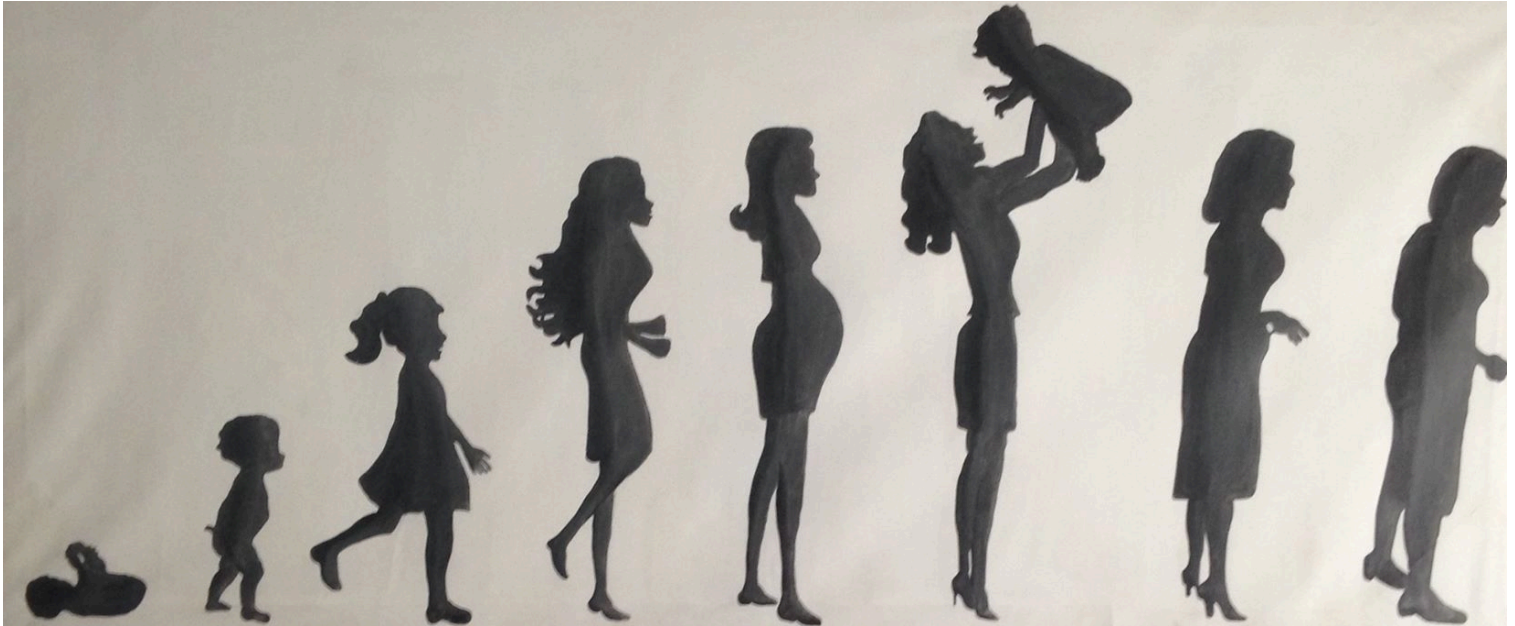


Informed Medicalization

A study on how women and men facing fertility problems in Nairobi, Kenya experience the medicalization of infertility.



Medical Anthropology and Sociology (MAS)

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Luca Koppen

Student number: 10356312

E-mail: lucakoppen@gmail.com

Supervisor: T. Gerrits

Second reader: R. Gerrets

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Photo on front page: painting in the waiting room of the Footsteps to Fertility Centre in Nairobi,
Kenya (permission granted by Dr. Ndegwa).

Abstract

Infertility is a major and highly stigmatized health problem in sub-Saharan Africa, but it is rarely addressed within the global and public health field. As a result, fertility treatment is only available in the private health care sector, which makes assisted reproductive technologies (ARTs) unaffordable and inaccessible for the majority of people. The aim of this research is to gain an understanding of the ways in which women and men facing fertility problems in Nairobi, Kenya – a context where infertility is highly stigmatized and there is limited access to ARTs and information about infertility and fertility treatment – experience the medicalization of infertility. My research took place at the Footsteps to Fertility Centre in Nairobi, Kenya. Through in-depth interviews, focus group discussions and observations, I found a contradiction in the experience of women and men facing fertility problems in Nairobi, Kenya with the medicalization of infertility. On the one hand, the medicalization of infertility and use of ARTs is desired by the participants as it provides hope and a way to gain reproductive agency. On the other hand, the limited (access to) information about infertility and fertility treatment and a lack of financial resources makes it difficult for some women and men facing fertility problems to obtain the desired and needed treatment, making reproduction for infertile women and men in Kenya an endeavor that is highly stratified.

Key words: Infertility, Kenya, ARTs, medicalization, information

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1. Introduction

Okay, my grandmother, my grandfather, they used to say that, euhm, you can be rich in two ways; either with money or with children...So, you see, those are two ways of being rich. So, they normally say if you are not rich moneywise, you have children, because you are not very rich, you can get children...You see now...I need something to love, so much not, away from my wife, but, you know, something I can hold, a kid.

- Nate

Nobody ever tried to diagnose me in Kenya when I was going through that [infertility]. So, you know, the lack of medical facilities it can lead to horrible consequences...Now, I know fertility ranges from simple to complex, but it would be nice if the simple was taken care of and then you are grappling with the complex. But, you know, even the simple is not always taken care of unless you have money, because you can't go to a government hospital and get a diagnosis you know.

- Clara

Infertility is a major health problem around the world. It has been estimated that around eight to twelve percent of all reproductive-aged women and men face fertility problems of some sort in their lives (Inhorn & Patrizio 2015: 2). These rates, however, differ per continent and country. The prevalence of infertility is specifically high in, among others, sub-Saharan Africa (Ibid.: 2). In most sub-Saharan African countries having children is highly valued (Inhorn 2009: 173) and parenthood is a central aspect of one's identity (Greil et al. 2011: 740). In effect, in an African context, not being able to conceive a child has numerous negative social, marital, physical and economic consequences for people, especially women (Gerrits 2012; Inhorn 2009). The same applies to Kenya, where I conducted my research. As Nate's quote above illustrates, being able to conceive a child is of great importance. According to Mburugu and Adams (2005: 12), not being able to conceive a child in Kenya has a negative impact on the persons facing infertility, as they become '...an object of pity in the family and the society at large'.

In a context where childbearing is highly valued and consequently not being able to live up to this cultural ideal creates many challenges, it is not surprising that people facing fertility problems show a willingness '...to go to considerable physical, emotional and economic lengths to achieve a pregnancy that will result in a child...' (Simpson & Hampshire 2015: 4). In Kenya, with 99 percent of the population being religious, 'faith healing' – the belief that God can redress ones fertility problems by believing in and praying to him – is the fertility

treatment most often practiced (Kamau 2011: 16). More and more people are, however, interested in or using assisted reproductive technologies (ARTs) (Ibid.: 19).

Since most sub-Saharan African countries, including Kenya, are marked by population growth and high fertility rates, little action has been undertaken within the global and public health field to address fertility problems in this region (Gerrits 2012; Hörbst & Wolf 2014; Ndegwa 2014). In effect, ARTs are often only available in the private sector and are thus very expensive, as the introductory quote of Clara illustrates. This results in a limited access to ARTs for the economically disadvantaged majority (Gerrits & Shaw 2010: 199; Hammarberg & Kirkman 2013: 191; Inhorn & Patrizio 2015: 2). In Kenya, with a population of 38,6 million people, six private clinics are currently offering ART services (Ndegwa 2014: 21). Infertility is, however, a major problem in this country. It is estimated that the prevalence of primary infertility – the inability to conceive – is around 2 percent. Secondary infertility – the inability to conceive following a prior pregnancy – affects 10 to 30 percent of all reproductive-aged women and men in Kenya (Ministry of Health Kenya 2007: 22-23). With 42 to 46 percent of people in Kenya living below the poverty level¹, the only real hope for the majority of infertile people in Kenya, Ndegwa argues (2014: 22), lies in the advent of more affordable and accessible ART services.

The inattention to infertility in the global and public health field and the consequences thereof for infertile women and men in sub-Saharan Africa has motivated some medical professionals to develop and introduce more affordable IVF treatment (Inhorn & Patrizio 2015: 2). A NGO called The Walking Egg, for example, has created a new IVF-technique that bypasses the high costs of laboratory procedures (Ombelet 2014: 269). Initially, the introduction of more affordable IVF treatment² was planned to take place in March 2016 in a private fertility clinic – the Footsteps to Fertility Centre – in Nairobi, Kenya by The Walking Egg. Originally, as I am part of a larger project, funded by Sharenet, called ‘Involuntarily Childlessness, “Low-Cost” IVF and Fertility Associations in Ghana and Kenya’, I intended to look at the experiences with and opportunities created by this new technique for women and men facing fertility problems in Nairobi, Kenya. The overall aim of the project is to disseminate knowledge and increase awareness of infertility and childlessness among relevant stakeholders and to generate insights about the impact of activities undertaken to address infertility issues in resource-poor countries.

1. See: http://www.unicef.org/kenya/overview_4616.html (05/04/2016).

2. This technique is still relatively expensive as the treatment is still out of reach for the majority of people in Kenya.

Due to unforeseen circumstances, however, the introduction of more affordable IVF has not (yet) taken place in Kenya. My research focus therefore shifted, filling two gaps I have identified in the literature. First of all, research conducted on the issue of infertility in Kenya is scarce (Kamau 2011: 3). Secondly, only a few studies have looked into the ways in which ARTs are ‘offered, used and experienced’ by people (Gerrits & Shaw 2010: 195). The aim of this research is therefore to gain insights into the experiences of women and men facing fertility problems with fertility treatment in Nairobi, Kenya – a place where conceiving a child is of great importance, but access to fertility treatment is limited for the majority of people.³

To do this, this thesis is divided into seven chapters. After the introduction, the second chapter offers a review of important literature as well as the theoretical framework of this thesis. First, some important anthropological and sociological literature on infertility and the affordability/accessibility of ARTs in sub-Saharan Africa will be given. In discussing these topics, I also explore the linkage with the theoretical orientation of social constructionism and the concept stratified reproduction (Colen 1995). Next, I elaborate on the context of fertility care in Nairobi, Kenya, using empirical data and policy documents. Then, theoretical debates around the medicalization of infertility and the role of information in patient empowerment, medicalization and trust are set out. Lastly, the research questions are discussed. Following this, in chapter three, I set out the research design and methods used to collect and analyze the data. Also, the limitations of the research, my positionality and some ethical considerations are dealt with in this chapter.

The following two chapters – chapter four and five – set out the empirical data in an ethnographic manner. Chapter four focuses on the way women and men facing fertility problems in Nairobi, Kenya perceive and experience the medicalization of infertility and (the use of) ARTs. In contrast to feminist critiques towards the use of ARTs, I illustrate that women and men in Kenya – where childbearing after marriage is of great importance and infertility is stigmatized – see ARTs as technologies of hope and as a way to gain reproductive agency. This reproductive agency, I argue, is, however, stratified. Chapter five provides insights into the way in which the limited access to and provision of information about infertility and fertility treatment is experienced and challenged by the participants, with which I enter into the debate about the role of information in patient empowerment. I argue that some participants are seeking to empower themselves by actively searching for

3. As ARTs are expensive, I have mostly spoken with women and men from middle and higher socio-economic classes. In this thesis, however, I also incorporate people’s experiences with treatment from lower socio-economic classes.

information about their fertility problem(s) and possible treatment options. However, this self-empowerment is stratified.

To conclude, in chapter six, I argue that a contradiction can be observed in the experience of women and men facing fertility problems in Nairobi, Kenya with the medicalization of infertility. On the one hand, participants desire the medicalization of their infertility. On the other hand, only those people who have the financial resources to pay for fertility treatment and who can inform themselves appropriately about their fertility problem(s) and fertility treatment needed are in reality able to become reproductive agents and gain from the medicalization of their infertility. This reflects the fact that reproduction for infertile women and men in Kenya is an endeavor that is highly stratified.

2. Literature Review and Theoretical Framework

For a long time, there was little attention for and interest in human reproduction within the field of anthropology. Instead, anthropologists focused on issues related to kinship (Greenhalgh 1995: 3). This has, however, changed from the 1970s onwards. From then on, human reproduction, including infertility, became an often-researched topic by anthropologists (Ginsburg & Rapp 1991: 312). This chapter sets out some anthropological and sociological insights on infertility and fertility care/treatment. A lot is known about the experience of infertility and help-seeking behavior in various African contexts (Van Balen & Bos 2009; Gerrits & Shaw 2010), but hardly anything is known about these issues in Kenya (Kamau 2011: 3). Here, I will therefore primarily focus on the literature that provides information about the experiences of women and men with infertility and fertility treatment in sub-Saharan Africa, followed by an elaboration on fertility care in Kenya, using empirical data and policy documents. Furthermore, I will set out some important theories and concepts – social constructionism, stratified reproduction, medicalization and the role of information in patient empowerment, medicalization and trust – which form a lens for the analysis of the way women and men facing fertility problems in Nairobi, Kenya experience fertility treatment. Following this, the research questions will be discussed.

2.1. Social constructionism: the experience of infertility in sub-Saharan Africa

While on average eight to twelve percent of all reproductive-aged women and men are affected by infertility, the burden of infertility is highest in regions such as Central and South Asia, the Middle East and sub-Saharan Africa (Inhorn & Patrizio 2015: 2). Generally, a distinction between primary and secondary infertility is made in the literature on infertility. In this, primary infertility is ‘...the inability to conceive after 12 months of regular unprotected intercourse...’ (Greil et al. 2011: 736) and secondary infertility is defined as ‘...the inability to conceive following a prior pregnancy...’ (Inhorn & Patrizio 2015: 4), including women who have had miscarriages. In sub-Saharan Africa, secondary infertility is the most common form of infertility, often caused by reproductive tract infections (RTIs) (Inhorn & Patrizio 2015: 4; Nachtigall 2006: 872; Zandvoort et al. 2001: 564). Sexually transmitted diseases (STDs) such as HIV/AIDS and chlamydia play an important role in the high rates of these RTIs, as such infections, when not treated on time, can impair a person’s fertility (Zandvoort et al. 2001: 564).

All around the world, women and men who are being confronted with infertility experience profound consequences on their physical and mental well-being (Van Balen 2000:

120-121). The meaning given to, experience and implications of infertility are, however, also dependent on people's social, cultural and economic context and consequently differ greatly among people around the world (Gerrits 2012: 1; Gerrits & Shaw 2010: 195; Greil et al. 2011: 740; Nachtigall 2006: 871). Infertility can thus be seen as socially constructed. Social constructionism is a theoretical orientation that developed in the 1960s opposing the ideas of positivism (Burr 2015: 2). Social constructionists asserted that 'a critical stance' should be taken

...towards our taken-for-granted ways of understanding the world and ourselves. It invites us to be critical of the idea that our observations of the world unproblematically yield its nature to us, to challenge the view that conventional knowledge is based upon objective, unbiased observation of the world (Ibid.: 2).

In effect, social constructionists argue that the categories and concepts people use not necessarily portray how the world in "reality" is (Ibid.: 3), but that people actively construct them (Greenhalgh 1995: 14) within their social, cultural and historical context (Burr 2015: 4).

Following this, medical anthropologists and sociologists have argued that '...health and illness are best understood, not as objectively measurable states, but as socially constructed categories negotiated by professionals, sufferers, and others within a socio-cultural context' (Greil et al. 2011: 736). In this view, what comprises illness and how a particular illness is defined and experienced are all highly dependent on the social and cultural context (Ibid.: 736). In this thesis, I address infertility as socially constructed.

In most sub-Saharan African countries, childbearing is of great importance due to the strong pro-natalism (Bochow 2015: 139; Greil et al. 2011: 740; Inhorn 2009: 173; Simpson & Hampshire 2015: 6). In a context like this, a lot of studies have shown that people, especially women, with fertility problems face devastating social, economic, mental, physical and marital consequences, such as stigmatization, isolation, disrespect from family and/or community members, social segregation, emotional and/or physical abuse, divorce and polygamy (Dyer 2008; Gerrits 2012; Hammarberg & Kirkman 2013; Inhorn 2009; Nachtigall 2006). In his study on the experience of infertility among married Kenyan women, Kamau (2011: 29) illustrates how 'procreation is the goal for virtually every marriage in Kenya'. People who are not able to conceive after marriage are seen as defiant by society (Ibid.: 16). People, especially women, who experience fertility problems therefore face significant 'social, psychological, [and] financial' consequences (Ibid.: 25).

The fact that women often experience more devastating consequences than men in sub-Saharan Africa when being confronted with fertility problems can be explained by the fact that ‘women are often blamed for infertility’, even when, seen from a biomedical perspective, it is the man who is facing the “problem” (Inhorn & Patrizio 2015: 8). Traditional beliefs about gender (roles) in as well as the patriarchal nature of most of these countries reflect the basis of this (blaming) process (Greil et al. 2011). In effect, even though involuntary childlessness is caused by male infertility in about fifty percent of the cases, ‘male infertility remains a “hidden” reproductive health condition...’ (Inhorn & Patrizio 2015: 8). This, as demonstrated in the literature, often leads to women carrying the biggest burden of infertility in sub-Saharan Africa.

Seeing infertility as socially constructed thus provides a window for me as a researcher to analyze the experiences of women and men facing fertility problems within their socio-cultural context. In addition, as argued by Van der Geest and Finkler (2004: 1996), seeing infertility as socially constructed provides a reflection of the main social and cultural ‘values and beliefs’ of a society through which these experiences come into existence.

2.2. ARTs in sub-Saharan Africa: accessibility and affordability

In 1978, the first baby – Louise Brown – conceived through IVF was born in the United Kingdom. Since then, ARTs have rapidly spread around the world – first mainly to Western countries, but from the end of the 1990s around the globe – helping women and men facing fertility problems to conceive their long-desired child (Simpson & Hampshire 2015: 1-2). With the use of ARTs already more than five million babies have been given birth to across the globe (Ibid.: 1). ART is an umbrella term that refers to high-end biomedical technologies that are used to overcome infertility, namely intra-uterine insemination (IUI)⁴, in vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI) and surrogacy. ARTs are very expensive, since ‘...all diagnostic and treatment interventions require a certain degree of technology and advanced equipment’ and ‘...specialized laboratory facilities and skilled, specialized providers’ are needed in all treatment centers (Zandvoort et al. 2001: 565). For a long time, ARTs were therefore only available in the private health care sector in most countries. In a recent anthropological book, Simpson and Hampshire (2015: 3) argue that ARTs have now also begun to spread to the public sector in some developed and developing

4. While IUI is in the Western context often not depicted as an ART, I consider IUI as an ART in this thesis, as IUI is not offered to people in most public clinics in Africa, including Kenya (Ministry of Health Kenya 2007).

countries, making it affordable and accessible for more people than just the global elite. This development in the spread of ARTs is what they refer to as the ‘third phase’ (Ibid.: 3).

The spread of ARTs to the public health care sector has, however, not yet occurred in most countries in sub-Saharan Africa; ARTs are often only available in the private sector in these countries (Gerrits & Shaw 2010: 198-199). In theory, everybody should have access to ART services as reproductive rights have been accepted as a basic human right at the International Conference on Population and Development in Cairo in 1994 (Ibid.: 194). This means that all women and men should be free to decide on when and how to reproduce (Hardon & Hayes 1997: 5). In addition, everyone should ‘...have access to the information, education and means to enable them to exercise these rights’ (Ibid.: 3). In practice, however, not a lot of attention has been given to the issue of infertility in sub-Saharan Africa by the global and public health field. In contrast, reducing the population, poverty, life-threatening illnesses such as HIV/AIDS and the lack of health resources and a good medical infrastructure are regarded as priority problems and used as a justification to explain for the lack of attention to infertility (Gerrits 2012; Gerrits & Shaw 2010; Hörbst & Wolf 2014; Inhorn 2009; Inhorn & Patrizio 2015; Nachtigall 2006; Simpson & Hampshire 2015).

Due to the inattention to the issue of infertility in the global and public health field, when ARTs do travel to countries in sub-Saharan Africa, this often happens before any regulatory framework is in place (Gerrits 2015: 102). In effect, medical professionals who provide ART services have to self-regulate their practices (Hörbst & Gerrits 2016: 13). In addition, ARTs are often only available in the private health care sector. The majority of people in sub-Saharan Africa are therefore not able to access and/or afford ART services (Bochow 2015: 136; Gerrits & Shaw 2010: 199; Inhorn & Patrizio 2015: 2; Nachtigall 2006: 874; Zandvoort et al. 2001: 565). The introduction of ARTs in sub-Saharan Africa has thus created great inequalities between people in their access to appropriate fertility care (Gerrits 2012: 3; Inhorn & Birenbaum-Carmeli 2008: 184). Colen (1995: 78) conceptualized these inequalities bound to reproductive practices as ‘stratified reproduction’:

By “stratified reproduction” I mean that physical and social reproductive tasks are accomplished differentially according to inequalities that are based on hierarchies of class, race, ethnicity, gender, place in global economy, and migration status and that are structured by social, economic, and political forces.

The notion of stratified reproduction thus conceptualizes the idea that some people’s reproductive capabilities are valued more than the reproductive capabilities of others (Hough

2010: 1758).⁵ The flow of ARTs to sub-Saharan Africa, Bochow (2015: 137) argues in her study on infertility in Botswana, not only creates new inequalities, but also reproduces and intensifies older inequalities between the rich and the poor, creating an even bigger gap between them.

The stratified reproduction for infertile women and men in sub-Saharan Africa largely caused by the inattention to infertility within the global and public health field illustrates the notion of politics of reproduction coined by Ginsburg and Rapp (1991). With this concept they try to grasp the interrelationship between the global and the local, as, they argue, global power relations increasingly shape local reproductive decisions, practices and experiences of men and women all around the world (Ibid.: 312-313). The unequal access to treatment for women and men facing fertility problems in sub-Saharan Africa illustrates this interrelationship well. To conclude, the accessibility and/or the affordability of ARTs is thus ‘...a complex product of public and private health policies and economic, political, and social/cultural forces that determine the allocation of personnel, equipment, and facilities’ (Nachtigall 2006: 873).

2.3. Fertility care in Kenya⁶

In Kenya, the formal (i.e. biomedical) health care sector consists of two branches: the public and the private-for-profit health care sector (Ministry of Health Kenya 2007: 9). In providing public health care, there are two levels. At a national level, the government develops health policies. At the county level, the implementation of these health care policies is done. The national level, in effect, oversees that these policies are rightfully implemented and executed on the county level.

The public health care sector in Kenya, however, faces some challenges, as the government is not willing to prioritize health. Despite the promise of the Kenyan government to prioritize health, health expenditure in Kenya is about 4.8 of the GDP, which is far below the targets set by the World Health Organization (WHO) (Luoma et al. 2010: 17-18). The medical professionals I have spoken with acknowledge this. For example, Dr. Gichuhi⁷, a doctor running a private fertility clinic, says: ‘it’s very difficult for the government; the gross

5. The previous sentences are based on and partly copied from an earlier paper I have written about infertility – Reproductive Interrelationships – during the MAS course Contemporary Topics in Medical Anthropology and Sociology.

6. In this section, I use my empirical data as well as policy documents to set out the context of fertility care in Kenya in which I have conducted my research, as little research has been conducted on infertility and fertility care in Kenya.

7. In this thesis, I use doctors’ and NGO founders’ real names. For women and men facing fertility problems I use pseudonyms. The section ethical considerations in chapter three provides more information on this decision.

domestic product is very low, so they can't afford to put a lot of money in health. To them, it's not the major priority'. The fact that health is not the main priority of the Kenyan government negatively impacts public health care provision in Kenya, which is '...evident in the shortage of medical supplies, inadequate human resources, and poorly maintained infrastructure' (Ibid.: 18).

Due to the lack of money available for health in Kenya, the government is not able to prioritize infertility, as a representative of the Ministry of Health, whom I interviewed, states:

At the moment, as a country, we are still dealing with a lot of preventable maternal deaths, a lot of preventable, I mean...we still have a lot of issues with reproductive tract cancers, with, euhm, sexually transmitted infections, with infectious diseases. So, I think, in terms of priority, infertility tends to take a back banner...I think as long as women are still dying from preventable as in maternal death, infertility will take a bit of a back banner, because you are not dying from it.

In correspondence to the findings in other sub-Saharan African countries, as illustrated above, the Kenyan government sees infertility not as its main priority, '...mainly due to its ranking against other perceived more pressing and competing national health priorities', such as HIV, malaria and maternal health (Ministry of Health Kenya 2007: 9). In addition, 'it may also be partly because of the perceived high fertility and population growth rates' (Ibid.: 9).

Health priorities set by international funders also play a role in the lack of attention to infertility by the Kenyan government. A representative of the Ministry of Health, whom I interviewed, states: 'the ministry develops the plan and then the funders pick the priority'. The funders, however, do not see infertility as their main priority. Instead, these organizations are busy with 'the mainstream things...[which] is reducing the population, HIV and malaria...and all these things' (Dr. Ndegwa). The lack of interest to infertility among both of these parties as well as the high costs of fertility treatment have resulted in the unavailability of ARTs in the public health care sector in Kenya (Ministry of Health Kenya 2007; Ndegwa 2014).

ARTs are, however, becoming more and more available in the private health care sector. Since 2004, six private fertility clinics that provide ART services for women and men facing fertility problems have opened in Kenya (Ndegwa 2014: 21). All of these clinics are located in Nairobi. As stated earlier, the private sector is for-profit, meaning that it is 'a business at the end of the day' (Dr. Ndegwa) and patients thus have to pay money to be treated. To undergo an IVF cycle in a fertility clinic in Kenya, for example, a person has to

pay around 4000 US dollars. People have to pay all costs for their treatment out of their own pockets, since there is no health insurance or financial assistance for people facing fertility problems in Kenya.

Due to these high costs, ARTs are unaffordable for the majority of people in Kenya (Kamau 2011: 30; Ndegwa 2014: 21). For example, Daisy, a 34-year-old woman with damaged fallopian tubes, needs to undergo IVF to overcome her fertility problems, but she is not able to afford it, because as she explains it:

It's [IVF] too expensive... Yeah, like, too much. So, for me, when I have never even seen not a million, 50000 shillings [500 US dollars], I have never. No. The little money I get, I eat and life goes on.

This quote illustrates that even though technologies now exist to help people conceive when they are not able to do so naturally, ARTs are only available for a few 'particular people' (David, 48-year-old) in Kenya, namely for women and men facing fertility problems from middle- and higher socio-economic classes, while inaccessible for the majority of people – people from lower socio-economic classes. In Kenya, as in many other sub-Saharan African countries, reproduction for women and men facing fertility problems is thus clearly stratified (Colen 1995).

In addition, medical professionals who offer ARTs in the private sector can themselves decide how they regulate their practices, as there is no legislation that regulates practices within fertility care in Kenya. This has also been observed in other sub-Saharan African countries (Gerrits 2015). The Kenyan government has, however, recently decided to step in and affirmed to regulate the practices in the field of fertility care. It actually took a female member from parliament, who experienced fertility problems herself, to highlight this issue and set in the process of policy development. At this moment, the In-Vitro Fertilization Bill⁸ is being written. With this bill, the Kenyan government intends to regulate the use of ARTs in its country. In addition, a representative of the Ministry of Health, whom I interviewed, sees the bill as providing an opening to more affordable and accessible ARTs, because with 'the attention it [ARTs] will get by passing it as a bill, then they are likely to see a lot more curiosity in the, the public sector'.

While most of my study participants are hoping for more affordable/accessible ARTs to be introduced, they are, however, not very optimistic about the chances of this happening

8. For the first draft of the bill, see: <http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/In-VitroFertilizationBill2014.pdf> (05/31/2016).

following the introduction of the new bill. In contrast, many participants doubt the impact of the bill, as implementation of policies has often been a problem in Kenya. The representative of the Ministry of Health confesses that ‘at the moment, we [the Ministry of Health] are not very involved in the actual implementation’. When implementation fails, participants argue, fertility treatment will not be regulated, but rather only be legalized, which does not change the way fertility care is practiced. The introduction of the bill has, however, the potential to raise some awareness about the fact that there are facilities that provide ARTs.

2.4. Critiquing ARTs: the medicalization of infertility

While in Kenya people are eagerly looking forward to the introduction of (more affordable and accessible) ARTs, since the advent of ARTs in the 1970s, the use of these technologies has been highly critiqued in the Western context (Gerrits forthcoming: 3). These critiques are often related to the medicalization of infertility. ‘Medicalization describes a process by which nonmedical problems become defined and treated as medical problems...’ (Conrad 1992: 209). So, the process of medicalization is marked by the use of a medical framework to define and treat issues that were otherwise seen as “social” (Ibid.: 210). This decontextualization of social problems – the process in which a “social” problem is taken out of its socio-cultural context and into the medical realm – has been highly critiqued as it individualizes the issue and puts people under medical control (Ibid.: 223-224). During the 1970s and 1980s a perspective that Lupton (1997: 94-97) has termed ‘the medicalisation critique’ arose, which was dominant among medical sociologists at that time. This perspective is based on the idea that individuals should be autonomous rather than controlled by medical professionals (Ibid.: 96). According to them, however, biomedicine as a domain has ‘...increasingly amassed power and influence’ (Ibid.: 95). Medicalizing an issue that was once a “social” problem therefore ‘...denies rational, independent human action...’ as medical professionals command others how to act upon this issue (Ibid.: 96).

For a long time, there has thus been an assumption that the process of medicalization only stemmed from the medical realm. This idea, however, has been resisted. While the medical profession can be responsible for the medicalization of certain issues, other actors may also play a pivotal role in this process (Conrad 1992: 211, 219; Lock & Kaufert 1998: 17-18). Increasingly, Conrad and Bergey (2014: 31) argue, drug firms, patients themselves and the insurance industry become the ‘engines of medicalization’. In addition, the process of medicalization is increasingly becoming a ‘global’ phenomenon (Ibid.: 31).

Infertility is a good example of the process of medicalization. While infertility in the 1960 and 1970 was seen and discussed in the literature as the *social* condition of involuntary childlessness, the advance of ARTs as well as more and more medical professionals specializing in the field of infertility marked the transformation of involuntary childlessness to the *biomedical* disease of infertility (Becker & Nachtigall 1992: 457; Greil et al. 2011: 736-737). In addition, cultural norms concerning the value of children also appear to be essential in the medicalization of infertility, as not being able to conceive a child ‘represents a failure to meet cultural norms’ and ‘may be construed as deviant’ (Becker & Nachtigall 1992: 457-458). With the medicalization of infertility, Becker and Nachtigall (1992: 457) argue, more and more women and men choose to use medical treatment as a solution for what once was considered a “social” problem, as medical treatment offers them hope to overcome their childlessness. Franklin (1997: 169-170), however, argues that this hope in ARTs inevitably disguises the fact that these technologies are, due to low success rates, ‘also all about failure’.

The medicalization of infertility and specifically the use of ARTs have been highly critiqued by feminist scholars. While some feminists initially supported the advance of reproductive technologies as they were viewed to increase reproductive rights and agency for women, this view turned around among radical feminists at the end of the 1970s when they ‘...began to wonder whether these technologies were not already or could not become the tools of further patriarchal social control, exploitation, and coercion of women’ (Chokr 1992: 318), as technologies like ARTs continue to focus on women’s rather than men’s reproductive roles in society (Simpson & Hampshire 2015: 7) and objectify – the separation of a person’s body from a person’s identity – women’s rather than men’s bodies (Cussins 1996: 576). So, in line with ‘the medicalisation critique’ (Lupton 1997), radical feminists critique the use of ARTs, as it ‘...increases medical intervention and decreases women’s control over their own reproduction abilities’ (Parry 2005: 194). For example, Franklin (1997), a feminist scholar, argues that, in a Western context, IVF is seen by some women as a technology that provides agency, but in “reality” – looking from a feminist perspective – this technology transforms agency into oppression as women have to pursue all options available in order to fulfill their reproductive role (i.e. motherhood). In effect, radical feminists argue that women should resist the medicalization of their (in)fertility (Lock 2001: 481).

Lock and Kaufert (1998: 2), however, show that women are not passively accepting or actively resisting the use of biomedical technologies, but they will use them when the ‘technology serves their own ends’. The use of ARTs should thus be regarded as a pragmatic decision taken within a particular hegemonic socio-cultural context. In this view, the

biomedical power of ARTs over women's bodies may by some women '...be experienced as enabling, or as providing a resource which can be used as a defense against other forms of power' (Ibid.: 7). Hörbst (2015), for example, shows how for women in Mali the objectification of their body when undergoing ARTs is part of their agency to reach their desired goal: motherhood. Correspondingly, Bochow (2015: 150) illustrates how even though ARTs 'subject women to...cost intensive procedures with only moderate success rates', in Botswana – a society where children are highly valued and childlessness is stigmatized – ARTs 'represent a tool of empowerment'. While the medicalization of infertility and the use of ARTs can be seen as oppressing in some contexts or by some people, they can also be regarded as a means of empowerment or providing agency in other contexts or among other people. In this thesis, I therefore intend to look at how women and men facing fertility problems in Nairobi, Kenya perceive and experience the medicalization of infertility and (the use of) ARTs.

2.5. Information: patient empowerment, increased medicalization and trust

Not only the use of ARTs, but also the way ARTs are offered to people within the biomedical realm has been critiqued. In the Western context, since the introduction of ARTs,

doctors and clinics were criticized for being paternalistic, for their reluctance to inform patients about the possible adverse affects of hormonal drugs used in IVF treatments, and for their tendency to present biased, incomplete and sometimes manipulated information on IVF success rates, which raised unrealistic expectations and distorted informed decision-making (Gerrits 2014: 125).

Medical professionals have thus been critiqued for offering ARTs without providing the appropriate medical information to people facing fertility problems, who therefore face difficulties making informed decisions and challenging decisions made by their doctors (Gerrits 2014; Gerrits forthcoming). To overcome these challenges in offering ARTs, it has been argued that providing patients with the appropriate information is essential, as this can empower them within medical encounters (Holmström & Röing 2010).

The idea of patient empowerment derives from '...the assumption that to be healthy, people must be able to bring about changes, not only in their personal behaviour, but also in their social situations and the organisations that influence their lives' (Ibid.: 168). For patients to be able to do this, medical professionals should inform patients appropriately so that they are and feel they are 'in control of their health' (Ibid.: 170). In this process, however, patients are not passive receivers of information, but are rather active in defining what the provided

information means to them and in using the information that seems suitable in their situation (Schulz & Nakamoto 2013: 5). The more information people have about the medical issue they are facing and the possible treatment options, the better they are able to make informed choices and negotiate with their doctors about their treatment trajectory (Gerrits forthcoming: 239). The empowerment of patients through the provision of appropriate information in medical encounters is seen as important by scholars (Camerini et al. 2012: 338; Schulz & Nakamoto 2013: 5), as it proves to lead to people experiencing a better health status than when they are not empowered in this manner.

The provision of information by medical professionals is especially important for informed decision making among fertility patients, as women and men undergoing fertility treatment have to make ‘...decisions about complex medical issues at various points along their treatment trajectory’ (Gerrits forthcoming: 4). So, when biomedical issues and technologies become more complex, lay people become dependent on their medical professionals in appropriating health information (Ibid.: 323). Gerrits (forthcoming) agrees with the idea that the provision of information by medical professionals is important for patient empowerment, but, based on her research in a Dutch fertility clinic, she also reveals a paradox inherent to this process: the (dependence on the) provision of information by medical professionals may lead to increased medicalized views among lay people, as they increasingly come to define their problems in medical terms (Ibid.: 321).

The trust of people facing fertility problems in their medical professionals is, Gerrits (forthcoming: 321) argues, important in understanding this paradox. She illustrates how in a Dutch fertility clinic trust among patients was enlarged when doctors were transparent ‘...about the limitations of their knowledge, medical science in general, and IVF in particular, and the risks and uncertainties involved’ (Ibid.: 182-183). Similarly, Franklin and Roberts (2006: 201), in their study on preimplantation genetic diagnosis (PGD) in the United Kingdom, found that doctors’ openness about uncertainties of this technology increases feelings of trust among patients. This trust, Gerrits (forthcoming: 321-323) argues, influences the decision-making process of people facing fertility problems, making them more inclined to pursue biomedical treatment. The finding that sharing risks and uncertainties may enhance trust, Gerrits (forthcoming: 322-323) suggest, might be related to the specific context in which she did her fieldwork: a Dutch fertility clinic, where a large amount of information is provided to people facing fertility problems and users of ARTs are already ‘satisfied with other aspects of patient-staff interaction’. Gerrits (forthcoming) therefore questions how this

would work in a context where this “basic” trust is missing and less information is given to people using ARTs.

In sub-Saharan Africa, as Gerrits and Shaw (2010) have shown in their overview on the ‘availability, quality, accessibility and acceptability’ (p. 203) of fertility treatments in this region, the provision of adequate information to fertility patients is often lacking, due to the lack of regulation in the field of fertility care and a lack of trained health staff, affecting the way fertility treatments are experienced and practiced (p. 199-200). In this thesis – bearing in mind the paradox as introduced by Gerrits (forthcoming) – I examine how information – and the lack thereof – plays a role in the way women and men facing fertility problems in Nairobi, Kenya go about their treatment (i.e. how do fertility patients acquire medical information, what do they do with this information and how does information affect them).

2.6. Research questions

In this chapter, I have illustrated that the use of ARTs and the way ARTs are offered have been critiqued in the Western context. However, I have also illustrated that these critiques must be seen in their specific context. In this thesis, I would therefore like to engage in the debates around ARTs by posing the following research question:

How do women and men facing fertility problems in Nairobi, Kenya, a context where having children is highly valued and access to ARTs is limited, experience the medicalization of infertility?

To answer the main research question, I have developed some sub research questions: how does the social and cultural context (i.e. the social construction) influence the way infertility is experienced by men and women facing fertility problems in Nairobi, Kenya? And how does this experience of infertility influence the way women and men in Nairobi, Kenya perceive and experience the medicalization of infertility and the introduction/use of ARTs? How do women and men facing fertility problems acquire information about infertility and fertility treatment in Nairobi, Kenya? And how does this process influence the way they experience and are affected by the medicalization of infertility and the use of ARTs?

3. Methodology

In the following section, I will discuss the ways in which I have come to collect and analyze data to answer my research questions. First, the field site locations and the ways in which I recruited participants are explored. Then, I will look at the methods of data collection and data analysis. Lastly, the limitations of the study, my positionality and some ethical considerations will be discussed.

3.1. Field site locations and recruitment of participants

My research, as also mentioned in the introduction, is part of a larger project, funded by Sharenet, called ‘Involuntarily Childlessness, “Low-Cost” IVF and Fertility Associations in Ghana and Kenya’. Within this project, ten other students (five from the Netherlands, three from Ghana and two from Kenya) and I have been conducting research in two different countries: Ghana and Kenya. In both countries, one Dutch student from the Master Preventive Youth Care and Parenting conducted quantitative research and two Medical Anthropology and Sociology students conducted ethnographic research, both with their own research focus. The three Ghanaian students were research-assistants. The two Kenyan students conducted their own research.

In the spring of 2016, I – together with another Dutch student – conducted ethnographic research in Nairobi, Kenya. Our fieldwork started at the Footsteps to Fertility Centre (FFC), a private fertility clinic in Nairobi, Kenya. Gaining access to the clinic was very easy, because the FFC is linked to the larger research project that we are connected to. At the moment of fieldwork, one doctor (Dr. Ndegwa), one psychologist, one receptionist and one accountant were working at the FFC. The FFC was still in a starting up phase, which meant that only a few patients (two or three per day) came to the clinic. In addition, only half of the people that visited the clinic came for consultations about and treatment for fertility problems, while the other half attended the clinic for issues related to antenatal care.

During the entire fieldwork period – ten weeks – the other Dutch ethnographic research student and I recruited participants⁹ by means of convenience sampling in the FFC. In the first week, we made a pamphlet introducing and explaining the research, which we then distributed in the clinic as well as by email. Also, while being at the FFC, we asked people who seemed fit for our research if they were willing to participate in the study. Recruiting participants in this manner thus depended on the presence of people in the FFC during the

9. We decided to recruit participants together, as we planned on sharing all gathered data with each other. This was possible due to the fact that we both used the same topic guide during interviews, but we chose a different focus for our thesis.

fieldwork period and their willingness to be involved in the study. Finding enough participants in the clinic was, however, difficult due to it still being in the starting up phase, as illustrated above. Therefore, we soon realized that if we wanted to get a big enough sample, we needed to recruit participants outside of the FFC.

We therefore started to use the snowball method in various ways. By asking Dr. Ndegwa, who runs the FFC, and using the Internet, we were able to contact other doctors and clinics performing fertility treatment. Some of them helped us to get in touch with new participants. We also asked our earlier participants if they knew anyone else who was facing fertility problems and would be willing to talk to us. Even though the FFC remained our main field site location during the entire fieldwork period, we thus used the snowball method to reach other channels and people to talk to.

Lastly, we recruited some participants by means of purposive sampling, building on the work of our fellow quantitative research students who collected data through questionnaires. At the end of the questionnaire participants were asked if they were willing to participate in the qualitative study and if they agreed whether one of the other researchers could contact them to make an appointment for an interview. When people indicated that they wanted to be part of the qualitative research, one of us contacted them afterwards to ask if they were still willing to participate in the study.

In total, I interviewed nine women, one man and one couple facing fertility problems (see Annex II for detailed information). In addition, the other ethnographic research student interviewed eleven women and two couples facing fertility problems (see Annex II for detailed information). Furthermore, together with the other research students, I organized two focus group discussions to which respectively six and twelve women came to talk about their own experience with and/or general perceptions of fertility problems. Most people we spoke with – both in the interviews and focus group discussions – were between the ages of thirty and forty and were from middle or higher socio-economic classes. All of the participants lived in or around Nairobi and all of them spoke sufficient English, with the exception of one woman.

While I was initially interested in people's experiences with more affordable/accessible IVF treatment, as discussed in the introduction, I decided to shift the focus of my research after some weeks of being in the field to people's experiences with fertility treatment in general. Therefore, I decided to speak with several people who are in some way related to fertility care and/or policy in Kenya (see Annex III for more detailed information). First of all, I interviewed someone from the Reproductive Health Department of the Ministry of

Health. Secondly, I interviewed three different gynecologists/obstetricians that do operate or want to operate in the field of infertility. One of these gynecologists/obstetricians works in the public health care sector, the other two work in the private sector. Lastly, I interviewed the founders of two NGOs, which are both related to infertility in one way or the other.

3.2. Data collection

The data were mainly collected through in-depth interviews. The interviews all lasted between one and two hours. Before the interview started, the aim of the research was discussed and after providing participants with information about the research and their rights (see ethical considerations), formal informed consent was signed (see Annex IV). All interviews were informed by a topic guide (see Annex V, VI & VII) that suited the particular participant (i.e. women and men facing fertility problems, NGO or Ministry of Health, gynecologist/obstetrician). However, the interviews were loosely structured. I only used the topic guide if specific topics did not arise during the interview itself, which rarely happened. All interviews were held at a time and place participants saw fit. Most interviews were held at the clinic, a public place (e.g. a café) or at people's workplace or home. All interviews were audio recorded and transcribed verbatim.

Next to in-depth interviews, my fellow research students and I organized two events at the FFC, one after three weeks and one after six weeks of being in the field. Both events were organized around a specific theme related to infertility (the first one was about PCOS¹⁰ and the second one about endometriosis¹¹), which was elaborated upon by Dr. Ndegwa, the doctor running the FFC. As part of each event we did a focus group discussion, in which specific issues (e.g. gender, religion, care and policy) related to the experience of infertility in Kenya were discussed. These discussions were very useful to cross-check the findings gained so far from the one-on-one in-depth interviews as well as in providing new topics or issues to be discussed in upcoming interviews.

Lastly, I observed the daily activities as well as staff-client interactions in the waiting room of the FFC. However, these observations were limited, as not a lot happened in the waiting room (there were only two to three people per day and clients didn't interact a lot

10. Polycystic ovary syndrome (PCOS) is caused by high levels of male hormones in women, which can lead to, among other things, irregular ovulation. Irregular ovulation can, in effect, impair a person's fertility. See: https://en.wikipedia.org/wiki/Polycystic_ovary_syndrome (06/16/2016).

11. For women who suffer from endometriosis, the tissue that usually only grows in the lining of the uterus is found outside of the uterus – for example in the tubes or ovaries – which can impair a person's fertility. See: <https://en.wikipedia.org/wiki/Endometriosis> (06/16/2016).

with staff members or other clients when waiting). In addition, I was not allowed to be present during consultations, which means that I never saw the actual interaction between the gynecologist and the patients. I did, however, have some informal conversations with people in the waiting room of the FFC. Finally, I observed in churches, where the importance of childbearing was a topic regularly talked about, and I had a lot of informal conversation with people I met in daily life (e.g. taxi-drivers, people at parties) about the Kenyan culture and/or their cultural views on infertility.

3.3. Data analysis

To analyze all interviews, focus group discussions and observations, I used thematic content analysis. The analysis started out as being quite inductive since I was, after I found out that I was not going to be able to conduct my original research, in the field without a clear research question and/or theoretical orientation. After some weeks of being in the field, looking at the data I had already collected, I decided to focus my research on issues related to people's experiences with fertility treatment. With this in mind, I focused the rest of my data.

Towards the end of the data collection process, I already started to familiarize myself with the data by reading all the interview transcripts, followed by marking recurring themes relevant for my research topic. Through this, I developed a list of codes. After I collected all the data, I transported these data into the qualitative data software program Atlas.ti. Using the codes that I had developed in an earlier stage of analysis, I started indexing, which is '...the process of applying codes to the whole data set in a systematic way...' (Green & Thorogood 2014: 218). In this process, new codes were also developed. Then, I did what is called charting, which '...involves rearranging the data according to this thematic content...by theme' (Ibid.: 218). Through looking at how (many) people used or talked about different themes or concepts, I was able to develop a good insight into the way in which my participants experience the medicalization of infertility in Nairobi, Kenya.

3.4. Limitations

An important limitation of my research is the derived research sample. This limitation is twofold. First of all, Greil et al. (2011: 739) argue, with regard to their study population in the United States of America, that 'infertility patients represent a subset of infertile women who have both a strong desire to become pregnant and the social and material resources that will allow them to do "whatever it takes" to have a child'. Similarly, the sample of my study in Kenya is also limited in the sense that I mostly talked to people from the middle- and higher

socio-economic classes who want to overcome their fertility problems by seeking help in the biomedical realm and who also have the financial resources to do so. So, I have spoken with a particular ‘group’ of people and not others – people who don’t have the resources or who don’t want to use ARTs – which leads to some bias in the research sample and data.

Secondly, it was very difficult to recruit male participants for the research, which is also mentioned in other studies on infertility in sub-Saharan Africa (Gerrits & Hardon unpublished). The lack of male interest in the study seemed to correspond to cultural ideas about gender in Kenya, since all people I have discussed this with responded to me with an affirmative nod, followed by an expression along the lines of “Kenyan men don’t talk about these issues”. While this also provides some interesting cultural insights, the fact that I did not interview a lot of men has led to a sample in which women predominate, which means that my sample is biased.

A third limitation of this research is the short time frame of the fieldwork period. In only ten weeks, I had to introduce myself in the different field sites and find enough participants. While finding enough participants was already a struggle because it took some time to find the right connections, this process was even further complicated by the fact that I had to “share” all people willing to participate with my fellow research student. In addition, due to the short period of time in the field I was not able to meet most of my participants more than ones. I have thus only spoken with most of them for a few hours, which means that I can never be sure of how well I have understood their stories. Also, I do not know if changes have occurred over time. Furthermore, ten weeks was definitely far too short to fully grasp all aspects of the Kenyan culture, which might have affected the data collection process as well as the interpretation of the data during data analysis.

Lastly, as stated earlier, observations I did at the FFC were limited. First of all, I was not allowed to be present during consultations, which means that I was not able to observe the doctor-patient interactions at the FFC. Secondly, observations in the waiting room of the FFC were limited, as I was not allowed to talk to people without permission and, as stated earlier, not a lot happened in the waiting room. Due to the limited observations, there is a “gap” in my ethnographic data.

3.5. Positionality

When conducting ethnographic research, it is important to reflect on your position as a researcher, as ‘who you are...will inevitably shape the kind of data gathered’ (Green & Thorogood 2014: 24). My personal characteristics have influenced my research significantly.

First of all, the fact that I am a white, educated woman, has, according to many people I spoke with, helped me in finding participants. However, due to the same personal characteristics and my connection to the clinic, there has also been some misunderstanding among participants about my position in the clinic and their gains from participating in the study; some participants thought I was a doctor and wanted medical advice, while others wanted to take part in the study because they thought I could help them in gaining access to fertility treatment (i.e. by helping them financially). Even though I tried to be very clear to my participants about the research and my intentions from the beginning, a request to help them financially or medically sometimes still followed at the end of an interview. Lastly, my lack of knowledge about the local culture as well as local language use (both English and Kiswahili) sometimes caused misinterpretations during the process of data collection.

3.6. Ethical considerations

In Kenya, infertility and the use of fertility treatment are considered sensitive topics. Conducting research on such sensitive topics raises ethical considerations. Therefore, ethical clearance from both the ethical advisory board in Amsterdam (the AISSR) and Kenyatta Hospital ERC and a research permit from Nacosti were requested and approved. In addition, I have foreseen in a number of procedures to maximally respect and protect people's right to be well informed about the research before consenting to participate in the study. Before every interview, I fully informed every participant about my research, the study objectives, that he or she could withdraw at any point in time and that response to questions was not necessary if not wanted. If, after providing this information, the participant was still willing to participate, I asked him/her to sign an informed consent letter (see Annex IV). Permission to audiotape the interview was also asked of all participants.

Furthermore, I dealt with issues of confidentiality and privacy during and after the interviews; I had all interviews at a place the participant saw fit, I stored all data files on a password-protected private laptop, I anonymized the interview transcripts by using pseudonyms instead of people's real names and (in this thesis) I do not present participants' stories and views in a way that they might be identifiable to others. I did not, however, use pseudonyms for the medical professionals and founders of the NGOs, as all of them gave me permission to use their real names. I was even more careful when using their transcripts in order to protect them. In addition, in the empirical chapters that follow, when portraying negative images of fertility care I build on participants' accounts about *different* clinics and medical professionals than those I have attended or talked to.

Despite these measures taken, talking about experiences with fertility problems still affected some of the participants emotionally. From the reactions and text messages I received from my participants after the interviews, it became clear to me that many people experienced the participation as a welcome opportunity to talk at length with a researcher about their fertility problems and their efforts to overcome it. Some participants told me that talking about their experiences, which they often couldn't do with people around them, has given them new energy and hope.¹² While talking about the experiences with fertility problems has emotionally affected some participants positively, others encountered some negative effects. Whenever people expressed these feelings during the interview, for instance in the form of crying, I offered my emotional support as well as the number of a psychologist related to the FFC so that people, if they wanted to, could seek professional psychological support.

Lastly, it is important to notice that in this thesis I do not wish to harm anyone I have spoken with, or for that matter, not spoken with. My work is solely based on stories of participants. I did not check or otherwise control any of these stories. Therefore, I do presume the statements in this thesis to be truths.

12. For example, Nate, a 42-year-old man, texted me after the interview I had with him and his wife that they were now – due to participating in the study – better able to talk about their fertility problems together and were ‘happy together’ again.

4. Medicalization and ARTs: hope, reproductive agency and stratification

Cecilia, a 40-year-old woman, is one of the study participants facing fertility problems. When she was 24, she became married. Immediately, Cecilia and her husband started trying to have a baby, but they 'could not conceive'. After three years she decided to go to the hospital in Nairobi to see if something was wrong. She went alone and did all the tests. The doctor told her that everything was fine. Still, she was given some fertility tables. After one year, when still 'nothing was happening', she went back to the doctor, who told her that her husband also needed to be checked. After he did the tests, the doctor told Cecilia and her husband that he had a low sperm count. Cecilia's husband was, however, reluctant to take the medication prescribed by the doctor; he told Cecilia that he was not the one with the problem. He then became very violent. In addition, her mother-in-law accused her of intentionally marrying her son for the dowry. After six years, the marriage ended. Cecilia soon married another man. After marriage, she couldn't wait to conceive to show the world that she was not the one with the fertility problem. However, with her new partner she was again not able to conceive. When she went back to the doctor, she found out that by this time her fallopian tubes were blocked. To overcome this, the doctor told her that she needed to do a laparoscopy¹³. Her husband, however, was not willing to support her financially. After two and a half years of marriage, her husband evicted her from their home. Cecilia was devastated and didn't want to marry any other man before she was sure she could have children. She therefore decided to save the money for a laparoscopy herself. After some time, she was able to pay for and undergo the procedure. At that time, she was dating a man. After the procedure, she became pregnant without the help of any other treatment. When the baby was born, she married the man. Now she is pregnant of their third child. Due to her experiences with infertility, she decided, with the encouragement of her husband, to set up Fertility Kenya (FK), a NGO that provides support to women and men facing fertility problems in Kenya. FK organizes monthly meetings, in which women and men facing fertility problems

13. Laparoscopy is a surgical procedure in which doctors make small incisions in the abdomen to examine and diagnose problems within this part of the body. In the case of blocked fallopian tubes, a laparoscopic surgery is used to open the tubes. See: <http://www.healthline.com/health/laparoscopy#Overview1> (06/23/2016).

are able to share their stories and are educated about their reproductive health system and the available treatment options. According to Cecilia, fertility treatments should become more affordable and accessible, as the majority of people in Kenya are not able to use these technologies. In addition, Cecilia sees more affordable and accessible ARTs as the only means that can de-stigmatize infertility in Kenya.

The experience of infertility among all participants facing fertility problems was, as illustrated by the story of Cecilia, marked by the confrontation with their own or partner's impaired fertility, societal pressure and a search for treatment. In this chapter, I specifically focus on the last marker. However, I first elaborate on the social construction of infertility in Kenya. Against this backdrop, I illustrate that women and men are eagerly looking for a solution. While some participants have pursued faith based treatment or treatment from traditional healers, I only focus on participants' quest for a child within the biomedical realm, with which I enter into the debates around the medicalization of infertility as illustrated in the second chapter. I demonstrate that the medicalization of infertility is highly gendered, but is still seen as a welcomed opportunity by many, as participants view ARTs as 'technologies of hope' (Franklin 1997). In contrast to feminist critiques, I argue that the (gendered) medicalization of infertility and use of ARTs may enhance the reproductive agency of women and men facing fertility problems in Kenya. This reproductive agency is, however, stratified.

4.1. 'Society has already decided for you'

Societal pressure

In Kenya, conceiving a child after marriage is very important (Kamau 2011). All my participants told me that following marriage women and men are expected to bear children within one year. Many of them therefore see getting children not as a choice, but as something that society has already chosen for them, as for example Mary, a 41-year-old woman facing fertility problems in Kenya, states:

Okay, now, in Africa, in Kenya in particular, when you get married, it is expected that you have children... Having a kid is not something you decide, it is something the society has already decided for you, kind of, and it is something that you just follow.

Like Mary, many other participants describe conceiving after marriage as a norm in Kenyan society. From a young age, some participants argue, women and men are socialized with this norm. For example, Esther, a 33-year-old woman who has been dealing with fertility problems for three years, explains that she ‘really can’t say I wanted or I didn’t want [children]’, as ‘the society prepares you as a girl child that one day you get married, you get kids of your own’. From a young age, Esther’s mother made her take care of her younger cousins – she had to bathe them, dress them – because, as her mother used to say, ‘one day you will have kids of your own’.

At the same time, the dominant view in Kenya, according to Dr. Gichuhi, is that ‘if you can’t have a family you are deficient, you are not hundred percent, you have a problem’. Several participants explain that some people in Kenya, especially in the rural areas, may depict infertility as something caused by witchcraft. Such views in Kenya about women and men facing fertility problems reconfirm the stigma – which can be defined as ‘...undesired difference...that makes us turn away from another human being in fear, disgust, anger, pity or loathing’ (Scheper-Hughes 1992: 373) – that, participants argue, is still attached to this issue. This stigma may create challenges for women and men facing fertility problems in Kenya, as the stories of the women and men in this study demonstrate.

Daisy, for instance, a 34-year-old woman living in a poor neighborhood in Nairobi, explains that due to her fertility problems she is not allowed to touch other people’s children in her community, because the mothers are afraid she will cause bad luck to their children. Likewise, Alexandra, a 35-year-old woman from a lower socio-economic class, describes that she was segregated from her community and her friends when they came to know about her fertility problems. Nadia, a 42-year-old woman, and her husband face similar challenges:

Yeah, [people in the community say] you’re useless, you’re useless in bed, they hit you, they started talking, “you can, you are doing work, but work for nothing, you’re”, you know, things like that. In fact, when they see my husband [coming home] from the shopping, they tell, like, “why you need shopping when you have nobody to feed?” Yeah, things like that. “You are tired, but you’re doing work for what?” Yeah.

Community members thus see Nadia as ‘useless’ because she is not able to conceive a child. In addition, Nadia’s in-laws make a lot of comments about her inability to conceive. Several times she has been accused of wasting the resources of their son/brother. Such negative attitudes have great impact on her own feelings as well as of the feelings of other participants who are being confronted with similar reactions.

However, not all participants experience such negative attitudes from people around them. While all participants said to feel the societal pressure to conceive after marriage, especially the women and men from higher socio-economic backgrounds seemed to be able to protect themselves and their partners from negative familial and communal attitudes (cf. Donkor & Sandall 2007). One example is Sabrina, a 30-year-old, well-educated woman. She has been able to protect herself from external negative attitudes related to childlessness by being and portraying herself as a “businesswoman”. As she has always been a woman who found her study and career important and has also been seen as such by family and friends, they rarely ask her any questions about the absence of children in her marriage. Another way of protecting oneself can be found in the story of Esther. Esther explains how in-laws are often the ones putting pressure on women and men to get a child. However, her husband has, as she explains it, ‘never allowed anyone to ask me about children at all’. By doing this, Esther says ‘he has really protected me’ from negative attitudes from his family.

A woman’s problem

Women, most participants argue, experience more negative attitudes from family- and/or community members than men in Kenya (cf. Dyer 2008; Gerrits 2012; Hammarberg & Kirkman 2013; Inhorn 2009; Nachtigall 2006). According to them, this is due to the fact that women are traditionally blamed for infertility in Kenya (cf. Kamau 2011; Ministry of Health Kenya 2007), because, as Abby states, ‘there is a general perception that fertility [problems] doesn’t affect men’. Currently, this view is strengthened by cultural ideas about the use of contraceptives and the effects thereof on a person’s fertility, as Nate, a 42-year-old man, expresses:

To my opinion, women are pointed at, because most of the time they are seen as the ones with the problem, like, if I give an example of us at the point of reproduction...the women take the medication, men only use the condoms. So, you see, even all that medication is taken by women and if you see all of them are implanted in them. So, most women are seen as the problem.

Like Nate, a lot of participants express their own or other people’s beliefs that some contraceptives – the coil (i.e. IUD) and the birth control pill, patch or implant –, which are solely used by women, can lead to impaired fertility.

The cultural belief that women and not men are responsible for a couple’s impaired fertility has in some cases led to a husband divorcing his wife, as illustrated by the story of Cecilia at the beginning of the chapter, or finding a second wife in order to procreate (cf.

Inhorn 2009; Inhorn & Patrizio 2015). Not all female participants, however, experience this. Some of them, especially the women and men with higher educational levels, said to experience an increased closeness in their relationship due to their fertility problems, as has also been observed by Greil et al. (1988) in America. For instance, Esther, a 33-year-old, well-educated woman, feels closer to her husband than ever before. As she explains it: ‘until you experience something that can tear you apart, that’s when you know whether this person is for real’. Esther has seen a ‘new side’ of her husband, as he has been so supportive during the entire process, making her appreciate him even more. For Rose, a 35-year-old, high-educated woman, the fertility problems did cause a gap in the relationship with her husband, mostly because the fertility problems have made her husband feel very down and have negatively affected their intimate life. Despite this gap, they are planning on staying together.

Personal feelings of grief, incompleteness and loneliness

All participants facing fertility problems express the grief they felt when being confronted with their impaired fertility. For example, Daisy, a 34-year-old woman who has been dealing with fertility problems for about ten years describes her first reaction as following:

It was bad, I cried a lot, like, for two months [after I heard the news that I had damaged fallopian tubes] I spend my days crying, my nights crying. It was so bad. I even had to take some alcohol to calm me down, because I was alone, completely, like, alone. I had no one.

Similarly, Tara, a very successful businesswoman of 46-years-old, expresses her grief of her inability to conceive as a ‘gap’ in her life, since only a child would make her ‘feel complete’.

Many other participants point to a same sense of incompleteness. Some of them relate this gap to their inability to fulfill local expectations of woman- or manhood. In Kenya, according to most participants, woman- and manhood are closely related to parenthood (cf. Ministry of Health Kenya 2007). Eunice, for example, a 41-year-old woman who has been struggling to get pregnant for 16 years explains that in Kenya ‘without a baby you cannot be called a woman’. David, a 48-year-old, well-educated man, argues that this is similar for men since manhood is largely dependent on fatherhood:

Well...for men, for those who are married, there is the idea that you can’t have problems with getting children, because then you are not a man. There are, for instance, jokes like, euhm, as a man you can’t stand in front of people and talk when you don’t have a woman or children, because then “who are you”? You are nothing.

The idea that fulfilling woman- or manhood in Kenya is dependent on conceiving a child after marriage has profoundly affected some participants' feelings of being a woman or man. For instance, Morgan, a 28-year-old man, explains that if he and his wife are not able to bear a child at the end of the day, he will start to think of himself as 'meaningless'. This process is, however, not static; feelings of (not) being a man or woman can change over time (cf. Gerrits 2012). Suzy, for example, said to feel 'not a woman enough' when she was confronted with her impaired fertility. By now, however, she feels that she is a 'very important human being' and she is a woman, whether she has conceived or not.¹⁴ Generally, women and men who already have a child or who have supportive partners experience less feelings of being an incomplete woman or man. For example, the 38-year-old Cecile 'found a lot of consolation' in herself and her life due to the fact that she already has a son. Similarly, while Esther does not have a child, her husband told her 'whether you have kids or not, it does not make you less of a woman'. This support has made her confident in her own womanhood.

Lastly, a lot of participants express a feeling of being alone in the experience of infertility. A factor that contributes to this loneliness, according to the participants, is the fact that people are not expected to talk about their fertility problems. In Kenya, issues related to reproduction and sexuality are, according to most participants, seen as matters only discussed between the couple in question. Cecilia, the woman portrayed in the story at the beginning of the chapter, explains that women and men are sometimes 'counseled' by the church when they get married: 'you [are told] that you don't remove bedroom matters to the public'. As a result of infertility being a "silenced" topic in Kenya, almost all of the participants discuss their fertility problems only with a few people around them, mostly their mothers and/or sister(s). Some don't share it with anyone. The fact that people don't share their experience of infertility makes many participants feel extremely alone, as they do not have a lot of support, but also are not aware of other people facing similar challenges.

4.2. 'After I knew that you can do IVF and get a baby, that kept me going'

In such a context – where childbearing after marriage is of great importance and the experience of infertility is marked by societal pressure, stigma and feelings of grief, incompleteness and loneliness – it is not surprising that people facing fertility problems in Kenya are eagerly looking for a solution. Participants seek for help in different domains, such

14. Though I do not have the information to explain how Suzy managed to change her feeling of being a woman over time, this case does illustrate the fact that these feelings are not static.

as faith-based treatment, traditional medicine, from witchdoctors and the biomedical realm. In this thesis, I focus on help-seeking behavior of participants in the biomedical realm. Participants have found their way to the biomedical realm through the Internet, other media such as radio and television, a doctor, a relative, a pastor or a friend.

Gendered medicalization

For almost all of the participants who chose to seek help in the biomedical realm and thus medicalized their infertility, this process of medicalization was, as evident in the story of Cecilia at the beginning of the chapter, gendered. The fact that fertility problems are highly gendered in Kenya – mainly resulting from the cultural notion that women are the cause of infertility – has led to a situation in which it is often the woman who first seeks fertility treatment (cf. Gerrits 2015), entering the clinic without a man by her side. For example, from his experience in his own private fertility clinic, Dr. Gichuhi states:

Men, even if they have a problem, they would not come and it's very difficult to investigate men in this country, because of the belief that if they are able to perform sexually then they are not infertile. They don't seem to understand that, actually, that you are sexually able does not mean that the sperms are normal. So, there is a disconnection on that issue. So, they refuse to come for checking, yeah. So, you find that almost, it is very rare that you find the couple coming, the man and the wife, no, it's the women who will come, then men. Fifty percent [of men] may not come at all.

Many of the female participants experience(d) this in person. For instance, Rose, a 35-year-old highly educated woman, entered the biomedical realm alone. Even when the doctor told her that there were no problems with her fertility and that her husband should now be checked as well, Rose's husband was not willing to go to the hospital for over six months. Many men, however, do not come for a check-up at all, as the quote of Dr. Gichuhi above illustrates. Suzy's – a 46-year-old, well-educated woman – husband, for example, is not willing to go for the medical check-up ever. This has been very difficult for Suzy, since the doctor told her that there was nothing “wrong” with her fertility. She was, at one point, so ‘desperate’ that she even took some fertility tablets in the hope of conceiving. Hörbst (2010: 26) argues that men often avoid diagnosis, as this may provide “proof” of their infertility, which makes them vulnerable to stigmatization and blaming. While I do not know if this is true for men in Kenya, the gendered aspect of medicalization became clear during my observations at the FFC. Even though Dr. Ndegwa, who runs the FFC, underlines the fact that involuntary childlessness is in half of the cases caused by male factor infertility (cf. Inhorn &

Patrizio 2015: 4), there were often only women sitting in the waiting room of the FFC, while men were nowhere to be found.

Dr. Ndegwa, however, emphasizes that she is ‘getting more men lately’. Dr. Gichuhi acknowledges this, but adds that this is only true for the urban areas. Besides, sometimes it is also the woman herself who wants her husband to be incorporated as late as possible. For example, the 33-year-old Brenda deliberately chose to first get herself checked out, as her husband is less open-minded and more conservative than she is. Before including him in the process, she wanted to ‘rule out’ the possibility that she was the one causing the fertility problem.

When men, however, decide not to go to the clinic with their wives when necessary, medical professionals sometimes felt placed into very difficult situations. Dr. Gichuhi explains that when the husband doesn’t want to come, he sometimes has to “over-medicalize” the woman, because she is so desperate, by giving her fertility drugs, as illustrated by the case of Suzy, even though there is nothing medically wrong with her fertility and he has not checked the man yet. For some time, Dr. Ndegwa therefore tested both the man and the woman – when they were both present – immediately. However, her experiences with testing both husband and wife immediately, as illustrated in the following quote, have made her hesitant about this decision:

I do [test women first], because at the beginning I was like no, no, no, we have to test everybody and then women would come and we have tested everybody and they are the ones in the problem and the man doesn’t come anymore, because he knows okay, I’m okay. So, I do try to first test the woman, let’s go through the things, but I do on that appointment tell the man that it’s a couple thing...and I stress the fact that this should be done, but let’s start with the woman.

So, Dr. Ndegwa now first tests the woman and then the man to protect the woman against the possible negative reactions of her husband when he finds out he is not “the problem”.

The gendered medicalization of infertility in Kenya may have, in correspondence to what Kimani and Olenja (2001: 203) have argued, ‘...inadvertently feminized infertility as well as legitimized the traditional belief that infertility is essentially a woman’s problem’. However, as the quote of Dr. Ndegwa illustrates, in a society where women are traditionally seen as the one responsible for infertility, gendered medicalization not only reinforces and legitimizes such traditional beliefs, it may also protect women from being confronted with negative attitudes from their husbands. At the same time, the medicalization of infertility,

even if this is gendered, could also provide “evidence” of the incorrectness of the cultural belief that a woman is always to blame for infertility; testing may rule out female infertility and show that it is male factor infertility (cf. Inhorn & Patrizio 2015). The (gendered) medicalization of infertility could thus also provide a way to oppose traditional gendered beliefs about infertility in Kenya.

Hope versus failure

After participants entered the biomedical realm and thus medicalized their infertility, they learned about and/or had to use ARTs. For both female and male participants, the existence and/or use of ARTs provide a sense of hope that something can be done about their fertility problems, as Cecilia expresses:

Because, for me, what kept me going, after I knew that you can do IVF and get a baby, that kept me going. I knew even if I stayed for ten years, I'd rather go work extra hard, get this money and get my baby. So, whatever you talked about me behind my back, I didn't care, because I knew there was a solution.

The possibility of overcoming infertility provided by ARTs thus gives participants hope. This hope, as illustrated by the quote of Cecilia, makes it easier for some participants to cope with the negative attitudes and personal feelings that they experience due to their fertility problems, as they know there is a possibility to conceive in the end.

For some people facing fertility problems, the hope gained from ARTs increases when they hear about other people's successful use of these technologies. Abby, for instance, is one of the women who became pregnant through IVF. One of her friends, whom she met in the clinic where she was undergoing the treatment, was inspired by her story; it convinced her that even though her first IVF cycle was not successful, she should opt for a second IVF treatment cycle as she is now sure that the procedure can result in a pregnancy. Many participants also regain hope by hearing other people's success stories. Like Nadia, who says: 'it [the success stories] gives hope of the treatment'. Such success stories increase participants' willingness to undergo fertility treatment. Even if women and men did not (yet) have the financial resources to pay for the treatment, like Nadia, the hope they have in these technologies for providing a solution at some point in their lives makes the experience of infertility more bearable.

ARTs, however, always bring with it the risk of failure, as the success rates of ARTs are low (i.e. around twenty to twenty-five percent) (Gerrits 2014: 128; Hörbst 2010: 26).

Franklin (1997: 176) argues that the hope of women in IVF ‘...overrides the fact that the technique fails for the majority’. In my study, most of the stories of participants who used ARTs are indeed “stories of failure”. From all women and men who had done IUI or IVF (thirteen participants in total), there are only two participants who conceived. Three other women (Cecilia, Ashley and Clara) got a child, but this was with the help of other (biomedical) interventions.

Even though all participants who did IUI or IVF are aware of the low success rates of the treatment they had undertaken, most of them were, before starting the treatment, convinced that they would be the ones who would conceive using such technologies. Esther, for example, a 33-year-old woman, was a hundred percent sure that IVF would work for her: ‘so, even me, I thought it [IVF] will work, there is no way it will fail’. In effect, when it did fail, it was a ‘huge shock’ for her. The experience of a failed IUI or IVF treatment had a deep emotional impact on the participants involved. After getting their hopes up, they were crushed when they hear the procedure didn’t result in a pregnancy. Brown et al. (2015: 210) acknowledge this “messiness” of hope; they illustrate that hope is a means to cope at times of vulnerability and uncertainty, but hope at the same time makes a person vulnerable to disappointment.

Despite of the fact that a lot of female participants see IUI and IVF as emotionally draining and the feelings of disappointment after a failed treatment cycle are difficult to cope with, most participants are willing to do more than one cycle. For example, Esther states the following:

IVF is somehow painful and it’s emotional draining, yeah, cause, you know, it gives you so much hope and then now the waiting period, the two weeks before you go for the pregnancy test is the worst time. So, I rather do it the normal way, but I don’t mind going for a second IVF if I have to. Maybe if it’s the only way then I don’t mind.

Another example of the willingness to use ARTs more than once is the story of Eunice. Eunice, a 41-year-old woman from a lower socio-economic class, has been dealing with fertility problems for sixteen years. She underwent one IVF treatment. This IVF, however, failed. Instead of adopting a child, Eunice is determined to try a second IVF cycle first. For her, conceiving through IVF is important, because adopting means that she, as she explains herself, ‘can’t stay where I am staying. I will just evacuate to somewhere else’. Despite the risk of failure, Eunice and some other participants see ARTs as attractive, because of the possibility of conceiving in secrecy (cf. Gerrits 2015).

So, when using ARTs nobody ever has to find out that one used these technologies to conceive, as Magy, a 47-year-old, highly educated woman, expresses:

When you see a woman pregnant, you don't know if she went to a clinic. You don't know if she had a baby naturally, you never know anything. But with adoption, you will know. I mean, especially if the child doesn't look like anybody. So, maybe, they [people facing fertility problems] are maybe more inclined [to use ARTs], because the secret is kept.

Thus, conceiving with the use of ARTs can be a way to provide a visible sign (i.e. pregnant belly) to the outside world about a person's ability to conceive (cf. Hörbst 2010). In a society where infertility is stigmatized, but conceiving a child of your own is of great importance, a technology that provides women and men hope of overcoming their fertility problems in secrecy is therefore welcomed with open arms. Even though some participants had experienced failed treatments, the risk of failing and disappointment are still preferred over the risk of other people knowing about their fertility problems. Adoption is for most participants an option, but only as a last resort.

Agency versus oppression

Following the previous passages, I argue that the (gendered) medicalization of infertility and the use of ARTs may enhance the reproductive agency of women and men facing fertility problems in Kenya – a context where the decision to have children is already made for you by society and infertility is highly stigmatized (cf. Bochow 2015). Reproductive agency must be seen as a human action that does not involve the transformation of institutions or discourses on reproduction within a specific society, but is rather about negotiating a space within existing structures of reproduction.¹⁵ By medicalizing their infertility – even though this process of medicalization is often gendered – and using ARTs, the participants are able to create space for themselves to move within the existing dominant reproductive landscape, as the use of ARTs provides a way for the participants to outrun or cope with societal pressure and negative attitudes from people around them (cf. Bochow 2015), while at the same time hoping to fulfill their long-term wish for a child – may this wish be forced on them by society or not.

The idea that the medicalization of infertility and the use of ARTs may enhance women's and men's reproductive agency stands in contrast to what Franklin (1997), a

15. I have partly copied the definition of reproductive agency from an earlier paper I have written – Reproductive Rights or Reproductive Fights? – for the Cultural Anthropology bachelor course Reproduction, Health and Technologies.

feminist scholar, has argued. According to Franklin (1997), ARTs can turn what users might experience as reproductive agency into a new kind of oppression, as they can no longer “choose” to pursue ARTs, but face a new kind of pressure or obligation to use these technologies. In Kenya, however, where the choice to have children has already been made by society and at the same time childlessness is highly stigmatized, rather than ARTs imposing a new kind of pressure on women and men in Nairobi, ARTs offer a (hope of) relief of the constant societal pressure they face, as has also been argued by Bochow (2015) in her study on infertility in Botswana.

The reproductive agency that the medicalization of infertility and the use of ARTs can provide to women and men facing fertility problems in Kenya is, however, stratified. The fact that ARTs are only available in the private sector and thus very expensive, as illustrated in the second chapter, creates a situation wherein some women and men are able to medicalize their infertility and use ARTs to gain reproductive agency while others are not. This reflects the notion of stratified reproduction, as only some infertile women and men are empowered to realize their reproductive wishes (cf. Bochow 2015).

Medicalization as de-stigmatization

To overcome the stratified character of reproduction in Kenya, ARTs should become more affordable and accessible according to all participants. The need for more affordable and accessible ARTs in developing countries is acknowledged by Inhorn & Patrizio (2015). They argue that access to ARTs can positively affect women and men facing fertility problems in developing countries as it may decrease stigma and normalize infertility by providing the evidence that it is something medical that can be treated (Ibid.: 8). Similarly, some participants see more affordable and accessible ARTs as a solution to de-stigmatize infertility in Kenya. Cecilia, the woman from the story at the beginning of the chapter, explains this process as follows:

So, for me, I want, I want a stigma free country on infertility. On how we are going to get it stigma free country is when we have cheaper, easily available treatment of infertility, because today if, if I cannot get a baby, you're talking about me, second year I don't get, the third, the fifth, the tenth, eleventh year, what will happen? The stigma will still be there. But, for example, today you talk about me and say “Cecilia doesn't get a baby, he [the husband] need to get out of that marriage” and then the second year I get a baby, what is that? It means that people will shut up, because there will be a solution for, for infertility.

So, by making ARTs more affordable and accessible, not only will the stratification decrease, as more women and men will be able to medicalize their infertility and use ARTs, the medicalization of infertility and especially the (successful) use of ARTs by more people may also decrease the stigma attached to the issue of infertility in Kenyan society, according to some participants. This, they argue, is because the (successful) use of ARTs, as has also been argued by Inhorn & Patrizio (2015), can provide the evidence that infertility is something medical that can be managed and defeated.

4.3. Conclusion

In this chapter, I have illustrated how the experience of infertility is socially constructed. In Kenya, childbearing after marriage is of great importance. Thus, having a child is often not a choice but a decision made for people by society and infertility is highly stigmatized. In effect, the experience of infertility is marked by societal pressure and stigmatization, especially for women, and feelings of grief, incompleteness and loneliness for most participants. These findings reconfirm the situation that has been sketched of the experience of infertility in other parts of sub-Saharan Africa. Not surprisingly, in such a context many participants see the medicalization of infertility and the subsequent use of ARTs as a welcomed opportunity. Due to cultural notions about gender and infertility, the medicalization of infertility in Kenya is, however, also gendered; women are often the (first) ones to seek biomedical help and undergo treatment. While this may legitimize the cultural ideas about infertility being a woman's problem, I have illustrated how the gendered medicalization can also protect women in Kenya and may, as Inhorn and Patrizio (2015) have also argued, provide "evidence" of the fact that infertility is not solely caused by women. In addition, despite the risk of failure, participants see ARTs as 'technologies of hope' (Franklin 1997) and as technologies with which to conceive in secrecy. In contrast to feminist critiques towards the use of ARTs, I have argued that both the (gendered) medicalization of infertility and the use of ARTs have the potential to enhance the reproductive agency of women and men facing fertility problems in Kenya (cf. Bochow). This reproductive agency is, however, stratified (Colen 1995); while some women and men are able to use ARTs to gain reproductive agency, others are not able to do so as these technologies are too expensive. In accordance with Inhorn & Patrizio (2015), participants therefore argue for more affordable and accessible ARTs, as more people will then be able to use these technologies and increased access to ARTs can de-stigmatize infertility.

5. (Lack of) Information: patient (dis)empowerment, (broken) trust, increased medicalization and stratification

Abby, a 33-year-old, highly educated woman, is one of the study participants facing fertility problems. After being in a loving relationship for about two and a half years, Abby and her husband, Alexander, married in 2011. Immediately after marriage, they tried to get pregnant, but they were not conceiving. At first, no alarm bells were ringing, since both Abby and Alexander were traveling out of Kenya a lot for their jobs and they therefore did not have a lot of sexual intercourse. When they stayed together in Kenya for four months and still nothing happened, they started to suspect something was wrong. Therefore, they decided to go and see a doctor just outside of Nairobi, at the place where Abby's mother lives. The doctor asked Abby and Alexander about their lifestyle – e.g. their work – and concluded that they had to be patient, as they were both out of the country often. Alexander, who himself is a medical doctor, opted for a second opinion. When explaining their situation to the second doctor they visited, he told them to do some tests. Based on these tests, the doctor told Abby that she had blocked tubes and that she needed to do an IVF. Again, Alexander wanted to get a second opinion. When he asked the doctor to refer them to another gynecologist, he refused this and told them that they were better off in his clinic. This shocked Abby and Alexander and made them believe that this doctor 'just wants us to pay money'. Alexander stood his grounds and they left the clinic. Through a personal contact, they were able to find another gynecologist who specialized in infertility. At the third doctor, Dr. Gichuhi, again all tests were done and he confirmed that Abby had blocked fallopian tubes. Also, he told her that she had fibroids, which needed to be removed before a successful IVF treatment could take place. For the first time, Abby and Alexander trusted the doctor in his medical decisions as they felt that 'he is not just after money'. After Abby got the fibroids removed and recovered from the operation, Dr. Gichuhi informed them about IVF and asked them to decide if they wanted to do the treatment. Abby and Alexander decided to do it. Already at the first try, they got pregnant.

Almost all study participants, as illustrated by the story of Abby, had difficulties in finding the appropriate fertility care. In this chapter, I will focus on these difficulties, entering into the

debate about the role of information in patient empowerment, trust and increased medicalization as discussed in the second chapter. To do this, I first illustrate that in the Kenyan context (access to) information about infertility and fertility treatment is limited. In this context, Holmström & Røing (2010) argue, medical professionals should provide information about infertility and fertility treatment to their patients in order to empower them. However, for medical professionals in Kenya, I argue, providing appropriate information about fertility treatment may contradict the aims of the private sector as a “business”, as has also been observed by Palihawadana & Seneviratne (2015) in Sri Lanka. These contradictory aims in the private sector may lead to some medical professionals not fully informing people facing fertility problems. I illustrate that the limited information provided by medical professionals, in correspondence to the argument made by Franklin and Roberts (2006) and Gerrits (forthcoming), and their focus on “money-making” affects the trust of people in them. As a result, some women and men facing fertility problems become active in informing themselves about their illness and the possible treatment options, which empowers them in obtaining the care they need. However, this self-empowerment is stratified.

5.1. ‘I didn’t find a lot of information in the local context’

In Kenya, most participants told me that (access to) information about infertility and fertility treatment is limited. The limited information about infertility has, as Sabrina states, to do with the fact that ‘fertility is a taboo’ in Kenya. The consequence of fertility being a taboo subject is twofold. First, within the regular school curriculums in Kenya, education about sexuality and the reproductive health system is often not given. As a result, Dr. Gichuhi, who runs a private fertility clinic, says that ‘people are not aware how their body works’. Also, he argues, most people are not aware of the implications of having, for example, unprotected sexual intercourse, such as STDs, which can have an adverse affect on a person’s fertility.

Secondly, issues related to reproduction and sexuality, as also highlighted in the previous chapter, are silenced in the public arena. In effect, many participants told me that people in Kenya do not openly talk about issues related to (in)fertility, which contributes to their limited knowledge about the subject. According to one of the women in the first focus group discussion, for example, the limited information about infertility is partly due to the fact that ‘people don’t share these stories [of infertility]’. By sharing their stories people could, as the 30-year-old, well-educated Sabrina says, ‘provide support for each other and...they pass also the information’.

In addition, most study participants face difficulties finding information about the most prominent causes of infertility in Kenya, as, for example, Brenda, another well-educated woman explains:

When I was looking for information, euhm, around this on my own, I didn't find a lot of, euhm, information [about the causes of infertility] in the local context....[as] a lot of information was based on data in, you know, other countries.

Like Brenda, many other participants share her struggle in accessing information about infertility in Kenya.

Not only did participants have difficulties in finding information about the causes of infertility in their local context, they also have a hard time finding their way to a gynecologist who provides fertility treatment. While there are six fertility clinics in Kenya offering ARTs at this moment (Ndegwa 2014), Sabrina states that 'online it [information about treatment options for infertility in Kenya] is really hard to get'. Similarly, Abby says that 'it was not easy to find information out there about where IVF is done in Kenya'. The fact that not all gynecologists, as illustrated by the story of Abby, are willing to refer people facing fertility problems to another doctor doing fertility treatment enhanced this problem for some. Sabrina recognizes this, saying that 'there is not that referral [among doctors in Kenya] yet'. In a context where there is limited (access to) information about infertility and fertility treatment, this can create barriers for women and men seeking fertility treatment.

Dr. Gichuhi, for example, explains that due to the limited (access to) information about infertility as well as fertility treatment, people facing fertility problems postpone seeking help in the biomedical realm. This, in effect, can lead to lesser results, as women are often too old by the time they reach a gynecologist who provides ART services. This can also be observed in the sample of this research: most women and men I have spoken with are around or above the age of forty. Dr. Gichuhi therefore states that people should be educated to visit the doctor when they 'have not conceived after one year'. In this, he argues, people should also be educated that 'you have to come as a couple...it is not a female thing, it can affect the man also'. The lack of information about infertility and fertility treatment among many people facing fertility problems, as has also been observed in many other places in sub-Saharan Africa (Gerrits & Shaw 2010), can thus result in women and men delaying their search for biomedical treatment.

5.2. 'I would like to be informed [about] what is happening...I am paying for this'

Despite the fact that information about fertility treatment in Kenya is not easily accessible, the participants have found several ways of coming into contact with medical professionals that provide ART services, as illustrated in the previous chapter. From the perspective of patient empowerment, in a context where (access to) information about infertility and fertility treatment is limited, medical professionals need to provide appropriate information to their patients, so they can become empowered to make informed decisions about their treatment trajectory (Gerrits forthcoming; Holmström & Röing 2010; Lupton 1997). In addition, the provision of appropriate information to users of fertility treatment is especially important due to the complexity of the issue – treating infertility is a highly specialized field of expertise, the success rates of fertility treatment are limited and risks such as ovarian hyperstimulation syndrome and multiple pregnancies are involved (Gerrits forthcoming). However, some of the study participants experience a lack of appropriate information given to them by medical professionals.

An example in which medical professionals have not rightfully informed a patient is the case of Cheryl, a 44 year old, highly educated and wealthy woman. After a year of trying to conceive, she and her husband decided to see a doctor in Nairobi. This doctor gave her some injections to stimulate the ovulation process. After a couple of months, the doctor had to leave and another doctor replaced him. This second doctor tried to improve Cheryl's chances of getting pregnant by timing her cycles. As nothing was happening, the doctor referred Cheryl to another clinic where she was able to do an IVF. The first doctor she did IVF with explained to her that he was going 'to transfer only two' embryos, because the other two (she had produced four eggs in total) did not seem so 'promising'. Cheryl, however, became suspicious about the small amount of eggs she generated with the heavy hormonal medication she was on, as other people she knew who did IVF had many more eggs. After the IVF treatment failed, she went to another clinic, where two doctors were working together in providing ARTs. These doctors had the exact opposite approach and wanted to transfer four embryos (she had produced seventeen eggs). This made her quite scared since she didn't want to end up with four children. The doctor, however, told her not to worry. In this, he left out information about the risks accompanying the transfer of this many embryos. In the end, the IVF failed. Cheryl did two more IVF cycles at this clinic with the embryos that she had frozen after her first cycle. Both of these cycles, however, failed. She then decided to try IUI. After some failed IUI cycles, she thought 'okay, just give it [IVF] one more shot'. At a fourth try for IVF at the same clinic, her experience was quite disappointing as both doctors were

simply not willing to inform her about the trajectory they were going to take during the whole procedure. In the end, after pushing for it, a nurse informed her about what she wanted to know. Cheryl is (still) upset by the way this was done, saying:

It was so disappointing...to me. I mean, considering my age, I would like to be informed [about] what is happening, it is my body, it is my eggs, I am paying for this, so many reasons why you need to treat me a bit better, you know...give me the information.

When the IVF again failed, Cheryl remembered that the doctor who had sent her to do the first IVF had told her ‘that perhaps the best thing to do is to have an examination...to understand the problem first’. Therefore, Cheryl went to another doctor to do all the tests. This is when she found out that the failed IVFs and IUIs were due to the fact that there was a septum in her uterus.¹⁶ All of the doctors performing IUI and IVF, she then realized, ‘didn’t even bother to put me through a single [test]’ before starting the procedures, leading Cheryl to state that the ‘consequences are with the patient always, and never with the doctor’. Instead, it is the doctors who ‘go home with all the money’.

The idea that medical professionals are more preoccupied with earning money than providing good health care and adequate information, as illustrated in the case of Cheryl and the story of Abby at the beginning of the chapter, is a concern expressed by several other participants (cf. Gerrits & Shaw 2010). According to some of the medical professionals I interviewed, this has to do with the fact that a private practice is for-profit and thus follows a “business” model. In effect, this may lead to doctors not informing people facing fertility problems rightfully about, for instance, the success rates of the clinic – indicating higher success rates than they in reality are – because they have to attract as much people as possible. The fact that good results need to be made to keep the business running not only causes some medical professionals to make up success rates to attract clientele, it has other consequences too. As illustrated in the case of Cheryl, due to the lack of regulation of fertility care in Kenya, doctors themselves can decide how many embryos they transfer when doing IVF. The more embryos are transferred, Dr. Gichuhi argues, the higher the chances of conceiving (i.e. the higher the success rates).¹⁷ Therefore, some doctors decide to transfer three, four or even five fertilized eggs, because ‘then you get good, high results’ (Dr. Gichuhi). Transferring this many fertilized eggs back into a woman’s womb can, however, be

16. A uterine septum causes a division in the uterine cavity. See: https://en.wikipedia.org/wiki/Uterine_septum (06/19/2016).

17. This process is, however, not linear, as can be seen on the following page: <https://www.quora.com/How-much-does-IVF-increase-a-womans-odds-of-having-twins-or-multiple-babies-at-once> (06/08/2016).

very risky as it increases the chances of multiple pregnancies. Dr. Ndegwa emphasizes the fact that giving birth to twins, triplets or quadruplets can be very dangerous for both the woman carrying the babies as well as the babies themselves. In addition, she says that carrying more than one baby has a higher chance of causing complications during the pregnancy, which often also comes with a lot of extra costs (cf. Elster 2000). Of these risks, she argues, women and men facing fertility problems need to be informed.

In the private sector, medical professionals providing fertility treatment thus have to deal with contradictory aims; they have to balance between attracting as much clientele as possible to keep their business running and providing the appropriate medical information to patients so they are able to make informed decisions. From their own experience as medical professionals, Palihawadana and Seneviratne (2015: 175) illustrate this same tension in the private sector in Sri Lanka: ‘informing the public of the facilities available is a duty of all practitioners. Likewise, corporate promotion is a necessity for any private sector enterprise. Establishing a balance between each of these pulls is a challenge in a resource-poor setting...’. Likewise, commercial and medical interests in the private sector in Kenya may be contradicting, making it difficult for medical professionals to combine them.¹⁸ However, not providing the appropriate information may be good for business, but can have significant impact on the empowerment, financial situation and medical results of women and men involved, as illustrated by the case of Cheryl.

5.3. ‘My doctor said I do this...[so] I do this’

Despite the fact that some medical professionals do not inform women and men facing fertility problems appropriately, some participants feel they are dependent on the information provided by medical professionals due to the biomedical complexity of infertility and fertility treatment and the limited access to information about these topics in Kenya (cf. Gerrits forthcoming). This experience of dependence is prominent in the story of Mary, a 41-year-old and highly educated woman. Mary did one IVF cycle, which failed. Now, she is not sure about what she should do next. For Mary, while she has searched for information on the Internet herself, it is the doctor who needs to guide her in her choices about what to do next, as ‘different studies [on the Internet] will give different things [information]’ and she is not able to make the difficult decision about ‘what you want to believe, and what you not want to believe’. Mary believes that the doctor is ‘more knowledgeable...even than Google’, and he

18. This does not apply to Dr. Ndegwa and Dr. Gichuhi. All the participants who attended their clinics felt that they were informed appropriately and that these doctors were not in it for the money.

should therefore be the one informing her about the possible options to take, as ‘it [the treatment trajectory] is not a journey that should be left to the patient to walk alone’. Like Mary, some other participants feel dependent on the knowledge and information provided by their medical professionals and therefore “assume” that their doctor have the appropriate knowledge to help them.

Helen and Jerimiah, for instance, have been dealing with fertility issues for two years. Helen has been diagnosed with severe endometriosis. When Helen and Jerimiah went to a doctor to see what possible solutions were available for overcoming their fertility problems, the doctor – who knew about Helen’s endometriosis – advised them to try IVF. After they had borrowed the large amount of money needed for an IVF cycle from people in their direct environment, they went and did their first IVF, as their doctor told them to. During the entire procedure, the doctor told Helen and Jerimiah that everything was fine. The IVF, however, failed. Helen and Jerimiah were crushed by the news. It was only then – after the IVF treatment – that the doctor told the couple about the bad quality of Helen’s eggs. This left the couple wondering why he hadn’t told them earlier, as they had been building up their hopes. During the same consultation, the doctor told Helen to rest for one month and then come back so they could try a second IVF. In this month of rest, however, Helen had to visit another hospital for her endometriosis. Meanwhile, a nurse working in the hospital became very concerned about Helen, as she had a friend dealing with endometriosis and fertility problems. After telling her their whole story, the nurse gave Helen and Jerimiah the contacts of another doctor for a second opinion. When they visited this doctor, he was shocked about the fact that Helen had done IVF with her severe endometriosis, as this could have never been successful. It was then that Helen and Jerimiah realized to never ‘trust’ a doctor blindly and always seek for a second opinion if possible. However, looking back she says:

I didn’t consult any [other] doctor, because I just thought, yeah my doctor said I do this...[so] I do this.

Similarly, Eunice, a 41-year-old woman from a lower socio-economic class, who has been dealing with fertility problems for sixteen years, had a negative experience within the biomedical realm due to her trust in the knowledge of the medical professional she was attending. As with Helen and Jerimiah, Eunice’s doctor had advised her to do an IVF, as tubal blockage was her only problem. After saving money for a very long time, she was able to undergo an IVF cycle. This cycle, however, failed. That is when she wanted to find out why the IVF didn’t work. Her doctor told her that he didn’t know and sent her to another doctor,

who did several tests and explained to her that there was also something wrong with the lining of her uterus. In effect, the doctor said that ‘it [the embryos] could not be hold’. It was only then that Eunice realized that ‘when you go to a gynecologist, he needs to go step by step. Even if you need IVF, he needs to look [at] your uterus, how it looks like, to see whether it can hold a child, or not’. The limited diagnosis the first doctor had given her, made her realize not to trust a medical professional blindly.

These stories illustrate that some participants initially trust the advice given by their doctors, as they themselves do not have the appropriate biomedical knowledge to make a decision about their treatment trajectory and they “assume” that medical professionals do have this knowledge. This trust, however, decreases when participants find out about the inappropriate information the doctors have given them. At the same time, as both Franklin and Roberts (2006) and Gerrits (forthcoming) have also shown in their studies in Western contexts, trust in medical professionals increases when they inform the participants properly. For example, participants told me they fully trust Dr. Ndegwa and Dr. Gichuhi, because these doctors always take the effort to inform them appropriately. This is also what I observed in the clinic of Dr. Ndegwa; even when she was very busy or she had things to do outside of the clinic, she always took time for all people attending the clinic by listening and talking to them for as long as necessary. In addition, in the Kenyan context, where fertility treatment is only offered in the private-for-profit sector, the trust participants have in both of these doctors is enhanced by the fact that, as also stated earlier in the story of Abby at the beginning of the chapter, participants’ feel they are not in it for the money. Instead, Tara says: ‘deep down her [Dr. Ndegwa] wish is to see us succeeding’.

5.4. ‘You have to be aggressive and you have to do a lot of research’

As illustrated in the previous passages, patient empowerment and trust in certain medical professionals is limited in private fertility clinics in Nairobi. As a result, more and more people seeking fertility treatment want, as Brenda, a 33-year-old, highly educated woman, argues, ‘to get as much information to empower themselves, even in addition to seeing a doctor’. To be able to inform oneself and to gain access to the desired treatment options, Magy, a highly educated, 47-year-old woman, says that:

You have to be aggressive and you have to do a lot of research. You have to understand your sickness and you have to be pro-active when you are talking to your doctor.

Several of the study participants indeed pro-actively seek for information about infertility, their specific fertility problem(s) and fertility treatment, which empowers them in getting the care they needed.

An example of a person that informs herself comes from a woman who was present at the second focus group discussion. This woman went to five doctors at different health facilities, all of whom diagnosed her differently and set out a different treatment trajectory. When the last doctor she went to prescribed her some medication without telling her anything about the exact reason for her taking this medication, not telling her anything about the heavy side effects of the medicine or the other options that are or might be there, she went online to seek for information about her health issue herself. This information, she argues, has made her more demanding within doctor-patient interactions: ‘I ask him why do I use this and not this?’. Since health care is ‘about money’, she argues, ‘don’t just allow people to tell you what to do’. Another example is the story of Sabrina. She is a 30-year-old, well-educated woman, who demands information from her doctor every time she is giving her a test, diagnoses, drug or treatment option. In addition, she dives into books after talking to the doctor. With the information she gains from both the doctor and her own research, she sets out her desired treatment trajectory. These cases illustrate how, in correspondence to the literature on patient empowerment (Holmström & Röing 2010), information may empower women and men within medical encounters, as they become better able to make decisions about the treatment trajectory they are going to take and can challenge decision taken by their doctors.

Being able to inform oneself about infertility, possible treatment options and gaining access to them can thus empower women and men facing fertility problems in medical encounters and turn them into reproductive agents (cf. Gerrits 2015). At the same time, however, Gerrits (forthcoming) argues that participants’ increased biomedical knowledge, may also increase their medicalized views, as they increasingly seek for biomedical knowledge themselves and more and more come to define their problems in medical terms. The increased medicalized views among lay people as a result of people actively acquiring medical information has been critiqued by some scholars in the Western context (Gerrits forthcoming).

However, in the Kenyan context – where (access to) information about infertility and fertility treatment is limited and fertility treatment is only offered in the private-for-profit sector – when people are not informed about their own fertility problem(s) and possible treatment options exploitation in medical encounters can occur, as illustrated by some of the

stories in this chapter. So, I argue that the risk of patients acquiring too much information (i.e. increased medicalized views) is in this context less “dangerous” than the risk of too little information (i.e. exploitation). This illustrates the importance of what I would like to term “informed medicalization” in the Kenyan context; for women and men who, in this context, desire the medicalization of infertility, as illustrated in the previous chapter, gaining information about one’s fertility problem(s) and possible treatment options is very important for them in obtaining the appropriate fertility care and to outrun situations of exploitation in medical encounters.

5.5. ‘Some people have a lot of information and others have literally none’

Becoming empowered as a patient by informing oneself about issues related to infertility and fertility treatment is, however, not an option for everyone. In this research, it became clear that the ability of a person to inform oneself is highly dependent on the level of education and the social and economic capital a person has (cf. Song et al. 2012). Women and men in this study who are well educated and come from higher socio-economic backgrounds are better able to shape their reproductive lives to their own wishes than women and men who are less educated and come from lower socio-economic classes, as has been found in Botswana by Bochow (2015) as well. In this study, the latter group of women and men has fewer opportunities to inform themselves or to be perseverant when seeking medical care. For example, some of the participants from lower socio-economic classes have no access to Internet, which means that they get their information solely from medical professionals. In addition, due to a lack of financial resources, these women and men are less able to seek care in private facilities or from more than one doctor, since this is too expensive. The inability of these women and men to inform themselves disempowers them in their search for appropriate fertility treatment.

The inequality of women and men facing fertility problems in Kenya to inform oneself is caused by and leads to great asymmetries between people in their knowledge about (in)fertility and fertility treatment. The representative of the Ministry of Health explains that information asymmetry is a big challenge in Kenya (cf. Zandvoort et al. 2001), as ‘some people have a lot of information and others have literally none’. Mary, a 41-year-old, highly educated woman, elaborates on this challenge. She explains that if you are in a rural area in Kenya, ‘you do not even know whether IVF exists...I have been lucky that I know him [Dr. Gichuhi], so I have known about IVF. There are so many people who don’t’.

The disparity in people's ability to become informed about infertility and fertility treatment and the idea that information can empower patients within their quest for a child has led Cecilia, the founder of Fertility Kenya, to start a big campaign to promote the education of people facing fertility problems, especially those from lower socio-economic classes, about the different biomedical causes and treatment options for infertility. As Cecilia says, Fertility Kenya tries to 'impact knowledge into our members', so that nobody – no medical professional, no pastor, and no witchdoctor – can take 'advantage' of them. Fertility Kenya does this by organizing monthly meetings and regular events where medical professionals come to talk about different aspects of infertility and fertility treatment. In addition, Fertility Kenya advises all their members to go and get themselves tested, so that they know what is "wrong" with them:

I always told them go to the nearest hospital; get to know what your problem is, because most of them did not know what was happening with them (Cecilia).

In this, they encourage men to get tested too.

After members find out what the problem is from a biomedical perspective, Fertility Kenya counsels their members and provides them with information about the possibilities of biomedical treatment. According to Cecilia, educating women and men facing fertility problems is very important, because information about infertility and fertility treatment is lacking, but women and men who 'have this education, they have the power' (cf. Inhorn 2003). How this works is illustrated by the following quote of Cecilia:

Yes, because number one, you know what you, what is happening with you and you know what you are supposed to do. So, once you know those two things then nobody will come and tell me, if I don't have a uterus, you don't come and tell me that I will have a baby, that I'll carry my baby.

So, according to Cecilia, in line with what I have argued, women and men who know what is going on in their bodies regarding their fertility and the treatment options that apply to their specific situation are empowered, as they are less likely to be exploited by doctors or other people around them and better able to demand the care they need.

The idea of information as power corresponds to the literature on patient empowerment in which information is seen as the most fundamental factor for the empowerment of patients in medical encounters. In this research, however, as also illustrated in the previous chapter, I have identified another factor that is important in empowering women and men facing fertility

problems in Kenya. While information about a person's own reproductive health condition and possible treatment options may empower patients within medical encounters, to be fully able to walk the reproductive trajectory people wish for women and men also need financial resources to be able to undergo their desired fertility treatments.

One example that illustrates this point well is the story of Nadia, a 42-year-old woman, who comes, as she herself explains, from a 'poor family' and has been dealing with fertility problems for fifteen years. In these fifteen years, she has been pregnant once. This was, however, an ectopic pregnancy¹⁹ and she miscarried. After this, the doctor did some tests, which showed that she had blocked fallopian tubes. She saved money and underwent a laparoscopy, as her doctor had advised her, to open up her tubes. After the laparoscopy, the doctors told her that she would now be okay. However, she still was not able to conceive. Almost ten years later, after joining Fertility Kenya, she went to a doctor who could do an IVF, but she did not have enough money, so she was sent back home. At this moment, she is still not able to get the money she needs for an IVF treatment. While Nadia has been able to inform herself about her own fertility problems and the possible treatment options to overcome this by joining Fertility Kenya, she has not been able to raise the money to do an IVF treatment, which is the one thing she really wants as she feels that she 'need[s] a child'.

So, informing oneself or providing women and men facing fertility problems with information in the Kenyan context does not seem to be enough to fully empower all infertile people, as ARTs are only delivered in the private sector and a large number of people are not able to afford these technologies. For some women and men, when the means with which they can undergo the treatment they need are not provided to them, becoming informed is only a first step in becoming empowered. Patient empowerment in the Kenyan contexts thus illustrates an even further stratification; while some women and men facing fertility problems in Kenya are able to become informed patients, others are not. Within the group of people who have become informed, there are some people who have the capacities (i.e. the financial resources) to transform this self-empowerment into actual reproductive agency, while people without the means may be able to empower themselves within medical encounters, but are not empowered to walk the reproductive path they wish to take: undergoing ARTs in the hope of conceiving a child.

19. An ectopic pregnancy results from an embryo that implants not in the uterus, but somewhere else in the body. See: https://en.wikipedia.org/wiki/Ectopic_pregnancy (06/19/2016).

5.6. Conclusion

In this chapter, I have, in correspondence to literature on patient empowerment (Holmström & Röing 2010), argued that information about infertility and fertility treatment can empower patients in seeking and encountering health care. However, (access to) information about infertility and fertility treatment is limited in Kenya. In a context where this information is limited, Holmström & Röing (2010) argue that medical professionals need to provide patients with appropriate information to empower them. Due to the contradictory aims of the private-for-profit sector (making money versus providing information), not all medical professionals provide people facing fertility problems with the appropriate information in Kenya (cf. Palihawadana & Seneviratne 2015). The provision of this information is, however, important for people to trust the advice given by medical professionals, as has also been observed by Franklin and Roberts (2006) and Gerrits (forthcoming) in Western contexts, and for patients to become empowered. As a result, some participants came to empower themselves by actively seeking for information. While this may increase people's medicalized views, I have illustrated the importance of "informed medicalization" in the Kenyan context. Not all women and men, however, have the ability to educate themselves about the fertility problem they are facing and the treatment options necessary to overcome this and in effect to find the fertility care they need. This reflects an even further stratification (Colen 1995) in the experience of infertility and fertility treatment.

6. Conclusion

The aim of this research has been to develop an understanding of how women and men facing fertility problems in Nairobi, Kenya experience the medicalization of infertility. To do this, I have taken on a social constructionism perspective (Burr 2015) in order to analyze the experiences of infertility and fertility treatment among women and men in Kenya as shaped by the socio-cultural context in which they live. I have illustrated that conceiving a child after marriage is of great importance in Kenya. Getting children is therefore no longer a choice to make, but rather something the society has already decided for its people. The norm of conceiving after marriage has an impact on the way infertility is perceived and reacted upon by people in Kenya. People who are not able to conceive are seen as defiant. In effect, the experience of infertility is marked by societal pressure and stigmatization, especially for women – as they are traditionally seen in Kenya as the cause of infertility – and feelings of grief, incompleteness and loneliness for most participants. While little research has been conducted on the experience of infertility among women and men in Kenya, these findings reconfirm the situation that has been sketched of the experience of infertility in other parts of sub-Saharan Africa.

In a context where childbearing is of such great importance and infertility is stigmatized, it is not surprising that women and men facing fertility problems seek for a solution, also in the biomedical realm. Through several media and networks, participants have found their way to the biomedical realm, in which they came to medicalize (Conrad 1992) their fertility problems. This process of medicalization is gendered, meaning that women are often the ones who first seek medical help and undergo fertility treatment. While this gendered aspect of medicalization may reproduce and legitimize the traditional beliefs in Kenya about infertility being a woman's problem (Kimani and Olenja 2001), I have argued that it can also function as a way to protect women from negative reactions from their husbands and, as Inhorn & Patrizio (2015) have also discussed, to oppose traditional beliefs about infertility being a woman's problem, as testing for fertility problems can indicate male factor infertility.

In addition, I have illustrated that despite the risk of failure, participants see IUI and IVF as 'technologies of hope' (Franklin 1997). These technologies provide participants with hope to overcome their fertility problems, which makes it easier for them to cope with external negative attitudes and personal feelings they face due to their impaired fertility, and also provide hope to conceive in secrecy. In correspondence to the findings of Bochow (2015)

in Botswana, I have argued that both the (gendered) medicalization of infertility and the use of ARTs could enhance the reproductive agency of women and men facing fertility problems in Kenya. This finding stands in contrast to the argument of Franklin (1997), a feminist scholar, who has critiqued the use of ARTs, as it can transform what might be seen by women themselves as agency into a new kind of oppression. In the Kenyan context, however, ARTs are not so much seen as means of oppression, but rather as means to alleviate societal pressure. The reproductive agency that the medicalization of infertility and use of ARTs can provide for women and men facing fertility problems in Kenya is, however, stratified (Colen 1995), as fertility treatment is limited to the private health care sector and only those people who are able to afford consultations, tests and treatment may gain reproductive agency.

The limited (access to) information about infertility and fertility treatment, I have argued, even furthers this stratification. In Kenya, information about infertility and fertility treatment is not readily available. In a context where (access to) information about infertility and fertility treatment – which are very complex issues – is limited, Holmström & Röing (2010) argue that medical professionals need to provide patients with adequate information in order for them to make informed choices about their treatment trajectory. Due to the lack of regulation in the field of fertility care and, as also illustrated by Palihawadana & Seneviratne (2015), the contradictory aims within private fertility clinics in Kenya – the medical aim (i.e. informing patients appropriately) versus the private-for-profit aim (i.e. selling their services to as many people as possible) – the provision of appropriate information by medical professionals is in some cases lacking. The lack of information provided by some medical professionals and their focus on “making money” have significant impact on the empowerment, financial situation and medical results of women and men involved as well as, as has also been illustrated by Franklin & Robert (2006) and Gerrits (forthcoming), participants’ trust in their medical professionals.

In this context, some of the participants decided to look for medical information about their fertility problem(s) and possible treatment options by themselves, which empowered them within medical encounters. However, participants’ increased biomedical knowledge, Gerrits (forthcoming) argues, may also increase their medicalized views, which has been highly critiqued in the Western context. I have, however, illustrated that in the Kenyan context – where ARTs are only provided in the private-for-profit sector – obtaining medical information about infertility and fertility treatment is important for women and men facing fertility problems to be able to outrun exploitative medical encounters. So, I have argued that, in Kenya, the risk of too little information (i.e. exploitation) is greater than the risk of

acquiring too much biomedical information (i.e. increased medicalized views), which illustrates the importance of what I have termed “informed medicalization” in the Kenyan context. Participants from lower socio-economic classes are, however, less able to inform themselves. In addition, even when they do have the information to empower themselves within medical encounters, they do not always have the financial resources to pay for treatment.

Through my research, I have thus found a contradiction in the way women and men facing fertility problems in Nairobi, Kenya experience the medicalization of infertility. On the one hand, almost all participants desire the medicalization of their infertility as this provides them, in contrast to what feminists have argued, with hope to conceive a child (in secrecy) and a way to gain reproductive agency. On the other hand, the limited access to ARTs and information makes the possibilities for reproduction among women and men facing fertility problems in Nairobi, Kenya highly stratified. While people who have the means to pay for treatment and the ability to actively search for information are able to fully empower themselves within medical encounters and gain reproductive agency, people who either don't have the means to pay for treatment or the ability to inform themselves are not able to do the same and can, especially when they lack the appropriate information, even be affected negatively by medicalizing their infertility.

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Annexes

Annex I: List of abbreviations

| | |
|------|-------------------------------------|
| AIDS | Acquired Immune Deficiency Syndrome |
| ARTs | Assisted Reproductive Technologies |
| FFC | Footsteps to Fertility Centre |
| FK | Fertility Kenya |
| GDP | Gross Domestic Product |
| HIV | Human Immunodeficiency Virus |
| ICSI | Intracytoplasmic Sperm Injection |
| IUD | Intrauterine Device |
| IUI | Intrauterine Insemination |
| IVF | In Vitro Fertilization |
| NGO | Non-Governmental Organization |
| PCOS | Polycystic Ovary Syndrome |
| PGD | Preimplantation Genetic Diagnosis |
| RTIs | Reproductive Tract Infections |
| STDs | Sexually Transmitted Diseases |
| WHO | World Health Organization |

Annex II: Table with some characteristics of the participants facing fertility problems

| Pseudonym participant | Age | Primary or secondary infertility | Cause of fertility problems | Years of trying to conceive (with or without fertility care) |
|------------------------------|------------|---|---|---|
| Abby | 33 | Primary infertility | Blocked fallopian tubes + fibroids | Five years, but has now succeeded |
| Alexandra | 35 | Primary infertility | Has no fallopian tubes | Ten years |
| Anne | 40 | Secondary infertility | Blocked fallopian tube | One/two years |
| Ashley | 37 | Secondary infertility | Hormonal imbalances | Two years, but has now succeeded |
| Brenda | 33 | Primary infertility | Unknown | One year |
| Cecile | 38 | Secondary infertility | Problems with fallopian tubes | Three years |
| Cheryl | 44 | Primary infertility | Septum in uterus | Four years |
| Clara | 35 | Secondary infertility | Could not hold a pregnancy (due to the muscles) + husband has low sperm count | Unknown, but has now succeeded |
| Daisy | 34 | Primary infertility | Damaged fallopian tubes | Around ten to thirteen years |
| David | 48 | Primary infertility | Partner has blocked fallopian tubes | One year |
| Esther | 33 | Primary infertility | Endometriosis + blocked fallopian tubes | Three years |
| Eunice | 41 | Secondary infertility | Blocked fallopian tubes | Sixteen years |
| Helen & Jeremiah | 26 & 33 | Primary infertility | Endometriosis + fibroids + cyst + damaged fallopian tubes | Two years |
| Lynne | 37 | Secondary infertility | Blocked fallopian tubes | Six years |
| Magy | 47 | Secondary infertility | Endometriosis + unknown | A few months |
| Mary | 41 | Secondary infertility | PCOS + removed fallopian tubes | Unknown |
| Morgan & Tanisha | 28 & 25 | Primary infertility | Hormonal imbalances | Two years |
| Nadia | 42 | Secondary infertility | Blocked fallopian tubes + no hair in tubes | Fifteen years |
| Nate & Wendy | 42 & 38 | Secondary infertility | Unknown | Five years |
| Rose | 35 | Primary infertility | Partner has low sperm count | Three years |
| Sabrina | 30 | Primary infertility | Endometriosis + fibroids | Two years |
| Sophia | 38 | Primary infertility | Blocked fallopian tubes | One year, but has now succeeded |
| Suzy | 46 | Primary infertility | Unknown | Six years, but stopped trying |
| Tara | 46 | Secondary infertility | Unknown | Ten years |

Annex III: Table with some information about the participants that are related to fertility care and/or policy

| Name participant | Profession | Institution | How related to (in)fertility |
|--|---------------------------|---|--|
| Cecilia | Founder and board member | Fertility Kenya (FK) | A NGO that focuses on providing support and knowledge to people facing fertility problems in Kenya. She herself also experienced fertility problems. |
| Constantine | Founder and CEO | The African Centre for Women, Information and Communications Technology | A NGO that focuses on providing education, including education about reproductive health matters. |
| Dr. Gichuhi | Gynecologist/obstetrician | Upper Hill Medical Centre | A private clinic that helps women and men facing fertility issues medically. |
| Dr. Mueke | Gynecologist/obstetrician | Mbagathi Hospital (maternity unit) | A public hospital unit where ante- and post-natal care for women is provided as well as consultations are held for women and men with other reproductive health issues such as infertility |
| Dr. Ndegwa | Gynecologist/obstetrician | Footsteps to Fertility Centre (FFC) | A private clinic that helps women and men facing fertility problems medically. |
| Representative of the Ministry of Health | Manager | Ministry of Health (Reproductive health department) | The reproductive health department of the Ministry of Health is involved in creating national policies around issues of reproductive and sexual health, including infertility |

Annex IV: Informed Consent Letter

INFORMED CONSENT LETTER

I have been informed about the benefits, risks and procedures for the research entitled “Women and Men with Fertility Problems: A Qualitative Study on the Experiences with Fertility Care in Nairobi, Kenya”. I have been given the opportunity to have any questions about the research answered to my satisfaction. I agree to participate in this study.

Date

Name and signature or mark of participant

If participant cannot read the form him- or herself, a witness must sign here:

I was present while the benefits, risks and procedures were read to the participant. All questions were answered and the volunteer has agreed to take part in the research.

Date

Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date

Name of person who obtained consent

Annex V: Topic guide for interview with woman and/or man facing fertility problems

1. Introduction of the research

Explanation of the research, discussing the aims of the research, issues of anonymity and confidentiality and the rights of the participants to not answer any question if not wanted as well as their right to stop their participation when wanted. After everything was discussed and the participant understood everything and agreed to it, informed consent was signed.

2. Personal data and personal life history

Could you maybe tell me something about yourself?

Prompt1: Age, religion, country/region of origin, ethnic group, marriage, children, family background, school/education, profession, economic status.

Prompt2: Where did you grow up? How was your childhood? What was your family like? How is the relationship with your parents and/or sisters and/or brothers? Where do you live now? What does your life look like?

3. Personal history with involuntary childlessness

Could you tell me something about your experience with fertility problems?

Prompt: When did you first encounter problems with your fertility? How do you experience the fertility problems? How was your first reaction? How did your partner react? Did you share this experience with family and/or friends? If so: How

did your family/friends react? How do the fertility problems influence your personal life? How do the fertility problems influence your marital relationship? How do the fertility problems influence your intimate relationship with your partner? How do the fertility problems influence your feeling as a woman/man? How does your experience with fertility problems differ from your partner's experience? Did your experience change over time?

4. Treatment seeking

When did you/who did decide to seek treatment?

Prompt: Why did you decide to start treatment? What kind of treatment did you start (e.g. faith healing, traditional medicine, biomedicine)? How has your experience been with the treatment you have undergone? How does treatment influence your personal life? How does treatment influence your marital and/or intimate relationship? How does treatment influence your experience of fertility problems? If no treatment undertaken: why did you and/or your partner decide not to seek treatment for your fertility problems?

5. Views on ARTs

What are your views on ARTs?

Prompt: Why do you view ARTs in this way? What do other people or institutions (e.g. church) think about you being treated with ARTs? Is the view of other people important in how you see ARTs?

6. Fertility care in Kenya

In general, what do you think about fertility care in Kenya?

Prompt: How is your experience with fertility care in Kenya? What do you think can be changed about fertility care in Kenya? How do you think this can be achieved?

7. Religion

How does religion play a role in your experience with fertility problems?

Prompt: How have you used religion in your experience with fertility problems? What role has the church played in your experience with fertility

problems? Does the church provide support for people with fertility problems?

8. Future

What are your plans for the future?

Prompt: How do you see the future in relation to your fertility problems? If treatment is not working out, would you be willing to try alternatives (such as adoption, sperm donation, egg donation, surrogacy)?

Annex VI: Topic guide for interview with NGO and Ministry of Health (Reproductive Health Department)

1. Introduction of the research

Explanation of the research, discussing the aims of the research, issues of anonymity and confidentiality and the rights of the participants to not answer any question if not wanted as well as their right to stop their participation when wanted. After everything was discussed and the participant understood everything and agreed to it, informed consent was signed.

2. Background of the NGO/Reproductive Health Department

Can you give me some background information about the NGO/Reproductive Health Department?

Prompt: Can you tell me something about the history of the NGO/Reproductive Health Department? When was this NGO/Reproductive Health Department set up? Who set up the NGO/Reproductive Health Department? Why was this NGO/Reproductive Health Department set up?

3. Role within the NGO/Reproductive Health Department

What is your role within the NGO/Reproductive Health Department?

Prompt: When did you start this function? Why/how did you end up at this NGO/Reproductive Health Department? What are your goals?

4. About the NGO/Reproductive Health Department

Can you tell me something about the orientation of this NGO/Reproductive Health Department?

Prompt: What are the goals of this NGO/Reproductive Health Department? What are the challenges? What are the dreams? What is the vision/mission of this NGO/Reproductive Health Department? Is there a difference between a short- and long-term vision? Have changes in the goals, dreams, vision and mission occurred over time? What kind of activities does this NGO/Reproductive Health Department do to reach the goals, dreams and vision? What is your focus? Why focus on this subject and not something else? What is the reaction of the society towards this NGO/Reproductive Health Department? Have you seen an impact as a result of your work?

5. Relationships

To whom is this NGO/Reproductive Health Department related?

Prompt: Does this NGO/Reproductive Health Department have a relationship with donors, other NGOs, governments, churches? If so: How do these relationships influence the work that is done? How do you inform people about your work? Is there a global involvement, or only focused on Kenya? Is expansion of relationships a plan for the future?

6. Infertility

How is this NGO/Reproductive Health Department related to issues surrounding fertility problems?

Prompt: Does this NGO/Reproductive Health Department work on issues related to fertility

problems? Why or why not? What have your experiences been with this topic? Is it something you would like to address in the future? Why or why not?

Annex VII: Topic guide for interview with gynecologist

1. Introduction of the research

Explanation of the research, discussing the aims of the research, issues of anonymity and confidentiality and the rights of the participants to not answer any question if not wanted as well as their right to stop their participation when wanted. After everything was discussed and the participant understood everything and agreed to it, informed consent was signed.

2. Background information

Can you tell me something about yourself?

Prompt: What did you study? Why did you decide to specialize in gynecology? Where were you trained? Where have you worked? How has that been?

3. History and development of fertility clinic/unit

Can you tell me something about this fertility clinic/unit?

Prompt: When was this fertility clinic/unit set up? Who set up this clinic/unit? Why was this clinic/unit set up? Do you provide ARTs? Why or why not? What are the difficulties you have faced in providing ARTs? Do you have any financial

support? If so: by whom? How do national or international regulations and policies influence your practice? Is anything covered by insurance? How does this influence your practice?

4. Patients

What kind of patients do you see?

Prompt: What kind of socio-economic background do your patients have? Are there mostly women or men coming to the clinic/unit? How is the communication with your patients? Do you talk to people differently depending on their background and gender? What are challenges you face with patients?

5. Quality of care in clinic/unit

How is the quality of care in your clinic/unit?

Prompt: Who sets the standards for your clinic? Are there medical criteria to offer ARTs? How do you assure that people get quality care?

6. Fertility care in Kenya

In general, what do you think about the fertility care in Kenya?

Prompts: What do you think about private versus public fertility care? What do you think can be improved? How do you think this can be done?