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Chapter 4

Fertility Problems and Fertility Care in Sub-Saharan Africa: The Case of Kenya



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4.1 Introduction

Although having children is important for the majority of people across the world, providing fertility care to involuntarily childless people is not a priority for many governments, and certainly not in sub-Saharan African countries. Reasons given for the neglect of fertility problems and treatment possibilities in these countries are concerns about the growing population size, scarcity of health care resources and infrastructure, and the heavy burden of other life-threatening diseases such as HIV/AIDS or higher priority health outcomes such as maternal mortality (Inhorn, 2009; Ombelet, 2012; Van Balen & Gerrits, 2001). Governments and NGO's are giving more priority to reproductive health programs in support of contraception and safe abortions. This is especially problematic as previous studies show that in highly pro-natalist settings the personal and social consequences of having fertility problems might have a devastating impact on the people involved (Daar & Merali, 2002; Inhorn & Patrizio, 2015).

Approximately eight to twelve percent of all reproductive-aged women and men worldwide are affected by infertility (e.g., Inhorn & Patrizio, 2015). It is estimated that around the world tens of millions of couples are dealing with primary infertility, which is the inability to conceive after 12 months of regular unprotected intercourse (Greil, McQuillan, Shreffler, Johnson, & Slauson-Blevins, 2011) and even more people are confronted with secondary infertility, which is the inability to conceive following a prior pregnancy (Inhorn & Patrizio, 2015). However, the prevalence of women and men who are confronted with primary or secondary fertility problems varies around the world. Infertility rates are especially high in Central and South Asia, the Middle East and sub-Saharan Africa (Inhorn & Patrizio, 2015). In sub-Saharan Africa, the prevalence of secondary infertility is much higher than primary infertility (e.g., Nachtigall, 2006), mainly due to poor maternity care and high rates of unsafe abortions (Inhorn & Patrizio, 2015). The high prevalence rates of fertility problems are also related to higher rates of sexually transmitted infections (STIs), and other infectious diseases such as lepromatous leprosy and malaria (Larsen, 1996; Saporta & Yuksel, 1994). In non-Western settings where parenthood is culturally mandatory (e.g., Donkor, 2008; Dyer, 2007) involuntary childlessness is also related to sexual risk behaviour as a result of attempts to conceive extra-maritally, and therefore infertility also increases the chance of being infected with STIs and HIV/AIDS (e.g., Inhorn, 2009; Inhorn & Patrizio, 2015).

Although at international fora and in various declarations, for example from the World Health Organisation (WHO, 2017), infertility is recognized as a major health concern especially in resource poor areas, it has led to few activities to address this issue in these countries (Ombelet, 2012). For example, few initiatives have been undertaken to inform and support people who are dealing with fertility problems or to prevent infertility (Ombelet, 2012). Also, diagnostic examinations are seldom offered in the public health system and treatments like in vitro fertilization (IVF) are only done in private clinics. Due to the limited availability and/or inaccessibility of proper information, diagnostics and treatments (Gerrits & Shaw, 2010; Ndegwa, 2014), many couples will remain involuntarily childless.

Not being able to have children is for most people a major life problem (See also, Peterson & Place, Chap. 2; Skvirsky & Taubman – Ben-Ari, Chap. 3 in this volume). A considerable body of research, mostly conducted in Western countries, has shown that involuntary childlessness has strong psychological and psychosomatic consequences in terms of, for example, depression, anxiety, lowered self-esteem, feelings of blame and guilt, and reduced sexual interest. Infertility has also been associated with increased risk of gender-based violence (Dyer, 2007; Van Balen & Bos, 2009). For only a small minority of involuntarily childless women and men in the Western world, these effects on their psychological wellbeing are at a clinical level (Greil, 1997), and in the West most involuntarily childless people are not excluded from being involved in the activities of their friends' and relatives' children (Wirtberg, Moller, Hogstrom, Tronstad, & Lalos, 2007). The limited quantitative research in sub-Saharan Africa, however, shows that in many countries involuntarily childless couples face severe negative psychosocial consequences. Childless women are frequently stigmatized, isolated, ostracized, disinherited and neglected by the entire family and even the local community (Daar & Merali, 2002; Van Balen & Bos, 2009). Research in Ghana, however, found that more highly educated infertile women felt less stigmatized than less educated infertile women (Donkor & Sandall, 2007).

4.2 Kenya and Infertility

In Kenya, a country of 38.6 million people, the prevalence of primary infertility is about 2%, while about 30% of all women and men of reproductive age are affected by secondary infertility (Ministry of Health Kenya, 2007). Although the few existing studies about the prevalence of infertility show that Kenya is grossly affected by the problem, little is known about how people who have to deal with fertility problems are experiencing their situation. The few studies that have focused on people's experiences with fertility problems in Kenya found that, as in many other low and middle income countries, women are traditionally blamed for infertility (Kamau, 2011; Kimani & Olenja, 2001). In this chapter we present findings from a research project carried out in Kenya in 2016. The aim of the project was to generate new insights regarding fertility problems and fertility care in Nairobi, Kenya.

4.3 Our Study

An interdisciplinary team from the Netherlands (University of Amsterdam) and Kenya (Technical University of Kenya) carried out the study, consisting of researchers from the fields of child development and education, public health and medical anthropology. The study was funded with a small grant from Share-Net International, which is the Knowledge Platform for Sexual and Reproductive Health and Rights (SRHR) initiated and funded by the Dutch Ministry of Foreign Affairs. A similar

study has been undertaken in Ghana. Ethical clearance and research permits were received from Institutional Review Boards (IRBs) at the University of Amsterdam, the National Commission of Science and Technology in Kenya, and the Kenyatta National Hospital from the University of Nairobi.

The study consisted of a quantitative component (a paper-pencil questionnaire) and a qualitative component (individual interviews and focus group discussions). The questionnaire study was conducted with patients facing fertility problems who were recruited from one private clinic and one government hospital in Nairobi. In addition, participants were recruited when they attended a patient support group meeting in Nairobi. A total of 75 women (and 2 men, but due to the limited number of male participants they were omitted from further analyses) facing fertility problems who were seeking help from health providers completed a paper-pencil questionnaire (further referred to as questionnaire), most of them on the spot when they visited a clinic or the patient support group meeting. Almost all questions that were used in the questionnaire were based on standardized instruments that have been used in Western and non-Western countries.

For the qualitative component, in-depth interviews were held with 21 individuals (20 women and 1 man) and 3 male-female couples. The participants were recruited from 2 private clinics, 1 government hospital, 2 churches in Nairobi or when they attended patient support group meetings in Nairobi. The participants were recruited when visiting these places and the criteria for participation was 'anybody that is trying or tried to conceive and faces or faced fertility problems'. The participants chose the place for the interviews. Most interviews took place either at participants' homes or at a clinic. Qualitative data were also collected by means of two focus group discussions in which a total of 19 women participated. The focus groups were held at one of the private clinics, selected because the private clinic participated in their organization. In addition, interviews were conducted with several key informants (3 gynecologists, 2 NGO founders, one person from the ministry of health, 4 pastors, etc.), who were working with people who have to deal with fertility problems. All interviews were recorded and transcribed for analyses.

The majority (93.3%) of the 75 women (mean age 34.0 years old, $SD = 4.99$) who completed the questionnaire had a partner and most of them (88%) also lived together with their partner (average period: 6 years) in Nairobi. All women who filled in the questionnaire had a job and most of them were working in the commercial sector, which meant they were not from the poorest socio-economic groups in Nairobi. Most of the women ($n = 55$) were struggling to get pregnant from their current partner for the first time. A minority ($n = 20$) of the participants with a partner had got pregnant from their current partner. However, 9 of these 20 did not give birth to a child and the remaining 11 of these 20 women were seeking help because they were having problems with getting pregnant for a second time. Two (of the 75) women had a child in a previous relationship and 12 (of the 75) women reported that their current partner had a child from a previous relationship. Sixty-four (85.3%) of the 75 women reported they knew whether the fertility problems had to do with them (81.3%), with their partner (7.8%) or with both of them (10.9%).

For the qualitative sample, the people who were interviewed or who participated in the focus groups were on average 37.2 years old ($SD = 6.22$) and all participants lived in Nairobi. Most of them were living with a partner and reported primary fertility problems.

4.4 The Absence of Male Participants

Finding male participants for a study on fertility problems is a well-known problem, both in Western and non-Western contexts (Becker, 2000; Sandelowski, 1993). The fact that it was very hard to recruit male participants for the current study, both for the questionnaires and the interviews, could be explained by the fact that people were recruited during their visit to a clinic, and most of the time these are women who seek help in medical centres on their own, or as one of the gynecologists who was interviewed said:

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 sexuality then they are not fertile. They don't seem to understand that, actually, that (if) you are sexually able (this) 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 (...).

The fact that we could find only a few men to participate in our study reflects what is called the “gendered medicalization of fertility problems” (Bell, 2014; Mumtaz, Shahid, & Levay, 2013).

In developing countries, the predominant perception is that infertility and fertility problems do not affect men and that women are the cause of infertility (Hörbst, 2010). One of the few male participants who was interviewed told us: “*To my opinion, women are pointed at, because most of the time they are seen as the ones with the problem*” (man, 42 years old). This is even the case when a medical check has already shown that there are no problems with the fertility of the wife and that the husband should be checked (Hörbst, 2010).

4.5 Knowledge of Fertility Problems

We assessed the knowledge of the 75 women who filled out the questionnaire about specific risk factors for lower fertility. This was done with the Fertility Knowledge Questionnaire, developed by a research team from Cardiff University, UK (Fulford, Bunting, Tsibulsky, & Boivin, 2013), which consists of 13 statements about knowledge on indicators for: reduced fertility (e.g. smoking, weight, history of STIs and mumps after puberty); misconceptions about fertility (e.g. woman fertile even without periods); and basic facts about infertility and its treatment (e.g., recommended

time limit for referral to a specialist). Participants could answer whether a statement was true, false or that they did not know the answer. A correct answer was assigned one point and an incorrect, do not know or missing answer with zero points. Points were summed, divided by the total number of questions and multiplied by 100 to produce a percentage ‘correct fertility knowledge’ score with a range of zero to 100%.

Table 4.1 shows for each statement of the fertility knowledge instrument the percentage of correct answers in our study. We found in our study among the 75 Kenyan women a ‘correct fertility knowledge’ score of 55.0%. We compared this score with scores measured using the same instrument in a multi-country study by Bunting, Tsublisky, and Boivin (2013). Bunting et al. (2013) investigated fertility knowledge in 79 countries (Kenya was not included). They used the 2010 Human Development Index (HDI) to categorize the countries’ levels of socio-economic development. The HDI is compiled by the United Nations Development Programme (UNDP, <http://hdr.undp.org/en/statistics/>) and combines life expectancy, educational attainment and income as a reference for social and economic development, and ranks countries into four categories of development (very high, high, medium and low). Based on the HDI, Bunting et al. (2013) categorized 32 countries (for example, the U.K. and U.S.A) as (Very) High Human Development (VHHD) countries, and 47 countries (for example, India and Brazil) as Medium or Low Human Development countries (MLHD). The overall fertility knowledge score that Bunting et al. (2013) found in the 32 VHHD countries was 64.3%, compared to 44.9% for the 47 MLHD countries (overall score for all countries: 56.9%). In our study the average fertility knowledge score was similar to this overall knowledge score, and relatively high compared to the MLHD group (Kenya is a MLHD country according to the HDI). Nevertheless, within the Kenyan group, the level of knowledge differed widely by question, with 8 (61.5%) of the 13 statements scoring less than 50% correct answers (Table 4.1). Many key informants who were interviewed stated that the little knowledge people have about infertility is due to the fact that (in)fertility is a taboo subject. In effect, the issue is silenced in the public arena. People in Kenya do not openly talk about issues related to (in)fertility, which contributes to their limited knowledge about the subject. In addition, access to information about infertility and fertility treatment is very limited in Kenya.

One of the interviewed gynecologists also referred to the low levels of fertility knowledge among his patients: “*People are not aware of how their body works*”. He linked this to the limited attention given to sexuality and reproduction in the curriculum of schools in Kenya, and stated that as a result people are not aware of the implications of STIs on someone’s fertility.

4.6 The Need to Have Children

Conceiving a child after you are married is very important for women in Kenya (Kamau, 2011) and this was also found in the answers of the women on the questions

Table 4.1 Fertility knowledge

	Correct answer	Percentage of women answering correctly
A woman is less fertile after the age of 36 years old	True	45.3
A couple would be classified as infertile if they did not achieve a pregnancy after one year of regular sexual intercourse without using contraception	True	26.7
Smoking decreases female fertility	True	82.7
Smoking decreases male fertility	True	86.7
If you have a healthy lifestyle you are fertile	False	45.3
About one in ten couples are infertile	True	29.3
If a man produces sperm he is fertile	False	81.3
These days, a woman in her forties has a similar chance of getting pregnant as a woman in her thirties	False	33.3
If a man has had mumps after puberty he is more likely to later have a fertility problem	True	44.0
A woman who never menstruates is still fertile	False	40.0
If a woman is overweight by more than 13 kilos (28 lb) then she may not be able to get pregnant	True	38.7
If a man can achieve an erection then it is an indication that he is fertile	False	84.0
People who have had a sexually transmitted disease are likely to have reduced fertility	True	77.3

that were related to their need to become a parent, measured in the questionnaire with the Need for Parenthood subscale of the Fertility Problem Inventory, developed by Newton, Sherrad, and Glavac (1999), see Table (4.2). Combining the answer categories “agree” and “strongly agree”, our study found that almost all participants, for example, reported that as long as they could remember they wanted to become a mother (94.4%), and that they saw this as a more important goal in their life than having a career (91.3%). Almost all participants also reported that they felt that they were born to become a mother (90.0%), that their marriage needs a child (84.5%), that they will do everything to have a child (80.8%), and that conceiving a child is one of the most important things in a couple’s relationship (79.2%).

While these figures may reflect the women’s views and wishes, some of the interviewed women also recognized the societal pressure affecting their ‘choice’. As one of the participants mentioned:

Okay, (...) in Kenya (...) when you get married, it is expected that you have children. Not having a kid is not something you decide, it is something that the society already decided for you (...) it is something that you just follow. (woman, 35 years old)

For almost all participants who filled in the questionnaire it was also very hard to accept that they would live a life without having children (Table 4.2). This was measured with the Rejection of Childfree Lifestyle subscale of the Fertility Problem Inventory (Newton et al., 1999). For example, only a minority (1.4%) reported to “agree” or “strongly agree” with the statement that there is a certain freedom regarding not having children that appeals to them, or “agree” or “strongly agree” that they see a number of advantages if they did not have children (4.3%).

The socialization of women and societal pressure to become a mother and women’s strong rejection of a childfree lifestyle, was well illustrated by one of the interviewees: “*The society prepared you as a girl (...) that one day you get married, you get kids of your own*” (woman, 33 years old). This woman also told us that she—as a young girl—had to take care of her younger cousins (she had to bath and dress them) because, as her mother used to say “*One day you will have kids of your own*”. However, not all interviewed women linked womanhood to being a mother: “*Being a women is not about having kids but it is about being courageous*” (woman, 33 years old).

4.7 Rejections from Society Because of not Having a Child

One of the interviewed gynecologists confirmed that women in Kenya who do not conceive are experiencing a lot of social pressure from Kenyan society: “*If you can’t have a family, you are deficient, you are not hundred percent, you have a problem*”. This was also reflected in the quantitative results when we investigated the experiences of stigmatization due to being childless and/or having fertility problems (measured the Perceived Stigma Scale developed by Donkor and Sandall in 2007 and consisting of 3 items) with answer categories 0 “does not apply to me” and 1

Table 4.2 Need of having children and rejection of child free lifestyle (percentages)

	Strongly disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly agree
<i>Need of having children</i>						
I will do just everything to have a child	4.1	1.4	6.8	6.8	24.7	56.2
I have often felt that I was born to be a parent	0.0	1.4	0.0	8.6	32.9	57.1
As long as I can remember, I've wanted to be a parent	1.4	0.0	0.0	4.2	31.0	63.4
Pregnancy and childbirth are the two most important events in a couple's relationship	1.4	5.6	4.2	9.7	29.2	50.0
My marriage needs a child	1.4	2.8	5.6	5.6	32.4	52.1
Being a parent is a more important goal than having a satisfying career/job	1.4	1.4	2.9	2.9	21.7	69.6
<i>Rejection on child free lifestyle</i>						
I could visualize a happy life together, without a child (or another child)	40.8	8.5	2.8	18.3	15.5	14.1
We could have a long and happy relationship without a child (or another child)	59.7	12.5	1.4	8.3	11.1	6.9
Having a child (or another child) is not necessary for my happiness	67.1	4.3	8.6	10.0	7.1	2.9
Not having a child would allow me to make time to do other satisfying things	68.1	18.8	5.8	1.4	0.0	5.8
There is a certain freedom without having children that appeals to me	76.8	15.9	0.0	5.8	0.0	1.4
Couples without children are just as happy as those with children	63.4	12.7	8.5	7.0	4.2	4.2

(continued)

Table 4.2 (continued)

	Strongly disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly agree
I could see a number of advantages if we didn't have children	77.1	14.3	2.9	1.4	1.4	2.9
A future without a child (or another child) would frighten me	7.6	4.5	9.1	4.5	30.3	43.9
I feel emptiness because of our fertility problems	2.9	5.9	1.5	10.3	30.9	48.5
Having a child (or another child) is not the major focus of my life	62.0	9.9	7.0	11.3	5.6	4.2

“yes, does apply to me”). About three-quarters of the women reported that other people treat them as inferior and look down upon them (74.3%) or that they felt that because of their situation (being childless or having fertility problems) people felt uncomfortable with them (74.3%). Almost two-thirds of the women (63.5%) reported that because of their childlessness or fertility problems other people in their environment avoided them. We also computed a sum score based on these three aspects of stigmatization which revealed that on average the participants reported a 2.12 out of 3.00 ($SD = 1.26$) on this stigmatization scale, with a majority (62.2%) reporting a “yes” on all three items.

One of the women who participated in the focus groups shared her experiences about stigmatization by saying that in her village it was very common for women to send other people’s children out for groceries but when she would ask someone else’s child to do this for her, people would tell her that she should first get her own child before she can ask other people’s children to do things for her. This was for her a very painful experience. Another woman also experienced something similar:

If another mother has a baby, other women are able to go there and hold that baby, but because I have no baby, I am not allowed to go there and hold the baby. (woman, 34 years old)

Other women told us that they were not allowed to touch other people’s children in their community, because the mothers were afraid that they [the participants] would cause bad luck to the children. Sometimes the women even experienced violence from other people in their community, they were segregated from the community or experienced other insulting and insensitive comments from people in the community in which they are living:

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’, things like that. In fact, when they see my husband coming from the shopping, they tell like ‘Why you need shopping when you have nobody to feed? You are tired, but you’re doing work for what’. Yeah, things like that. (woman, 42 years old)

One of the participants told us in an interview that her in-laws made a lot of comments about her inability to conceive. The in-laws told her that she wasted the resources of their son, which was very painful for her to be confronted with.

Not all participants, however, experienced such negative attitudes from people around them. Also from other studies carried out in non-Western countries it is known that in particular women and men from higher socio-economic backgrounds seemed to be able to protect themselves and their partners from negative familial and communal attitudes (e.g., Donkor & Sandall, 2007). One example in our study was a well-educated woman who had been able to protect herself from negative attitudes

related to childlessness by being and portraying herself as a “businesswoman”. As she had always been a woman who had found her study and career important and had also been seen as such by family and friends, they rarely asked her any questions about the absence of children in her marriage.

4.8 Fertility-Related Quality of Life

The agonizing experiences of having fertility problems and being rejected by other people had consequences for participants’ perceived quality of life. All interviewees referred to the grief they were feeling because of their impaired fertility. Some interviewed women told us that because they were not able to conceive a child they did not feel complete or—in the words of one of our participants—“*without a baby you cannot be called a woman*” (woman, 41 years old). One of the few men that participated in the interviews argued that the feeling of not being complete when you are not able to conceive a child is not exclusive for women and according to him in Kenya manhood is also largely dependent on parenthood:

Well ... for men, for those who are married, there is the idea that you cannot have problems with getting children, because then you are not a man. [...] As a man you cannot stand in front of people and talk when you do not have children, [...] because ‘who are you’?. You are nothing. (man, 48 years old)

In the questionnaire we included the Fertility Quality of Life questionnaire (FertiQoL; Boivin, Takefman, & Braverman, 2011) to assess the impact of fertility problems on social, emotional, mind-body and relational domains. Based on the participants’ responses, the raw scores were calculated and the scaled scores were computed in accordance with instructions available at <http://sites.cardiff.ac.uk/fertiqol/scoring>. For each domain the score can be between 0 and 100, with a higher score meaning a higher level of quality of life.

The earlier quotes, showing the feelings of isolation from the community, are reflected in the participants’ mean scores for the social domain of quality of life, or the extent to which the participants’ social interactions were affected by fertility problems. The minimum and maximum reported scores for this social domain of quality of life were 8.33 (low quality of life) and 100 (high quality of life). On average the women scored on this social domain 48.16. ($SD = 18.85$). For the emotional dimension, reflecting the impact of negative emotions such as jealousy, resentment, sadness and depression on quality of life, the minimum and maximum reported scores were 12.50 and 100 respectively, and on average the score was 42.44 ($SD = 20.38$). The mind-body domain shows the impact of fertility problems on physical health (e.g., fatigue, pain), cognitions (e.g., concentration) and behaviour (e.g., disrupted daily activities, delayed life plans). The minimum reported score on this scale was 12.50 and the maximum was 100, with an average score of 49.06 ($SD = 22.70$). The relational domain of quality of life is about the impact of fertility problems on the marriage or partnership (e.g., sexuality, communication, commitment) and the

reported scores for this aspect were between 20.83 and 83.33 with an average score of 51.97 ($SD = 14.50$). The wide range of impacts which fertility problems had on the relational domain of quality of life were also reflected in the interviews. One of the interviewees, for example, referring to the impact that not being able to conceive has on her relationship with her partner, stated:

At this moment (...) I don't feel close, close together, because I feel so tired, there is a problem that is supposed to be tackled, that is supposed to be managed. But we are finding ourselves in a different direction. I am on my own side, euhm, we no longer go for out, we no longer go for coffee, we lead a normal life, yeah, work, home, work, home, work, home. (woman, 35 years old)

On the other hand, there were also participants who told us that the whole situation of dealing with fertility problems had strengthened their relationship with their partner, which is also reported in the literature on infertility in Western countries (Gerrits, 2016), as illustrated by one of the participants who told us:

I think the relationship has become more closer, the time we are supposed to do the [pregnancy] test he is always on my toes: are you okay, do you need something? He wants to take me out, he just want to keep me happy. (woman, 34 years old)

4.9 Loneliness Versus Support and Sharing

Many participants expressed in the interviews their feelings of being alone in their experience of fertility problems, especially at the beginning of these problems. In one of the interviews, a woman described her first reaction when her gynecologists told her that she had damaged fallopian tubes:

It was bad, I cried a lot, like, for two months I spent 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. (woman, 34 years old)

An aspect that contributes to this loneliness is, according to many interviewees, the fact that people are not expected to talk about their fertility problems. Interviewees noted that in Kenya, issues related to sexuality and reproduction are seen as matters only discussed with the partner. One of the interviewed women mentioned that women and men are sometimes "counseled" by the church when they get married that "*you do not move bedroom matters to the public*" (woman, 35 years old). In the questionnaire we also found that 92.0% of the participants reported that they had not asked a friend or a relative for advice regarding their conception problems.

The fact that having fertility problems is a "silenced" topic in Kenya means people feel extremely lonely, do not have a lot of support, and are also unaware of other people facing similar challenges. This silence might also contribute to people in general having less knowledge about (in)fertility, as mentioned by a woman in one of the focus groups: "*the limited information about infertility is partly due to the fact that people do not share their stories*".

Following a clinic or hospital visit, however, this silence could change. More than three-quarter (78.2%) of the questionnaire participants mentioned that they sometimes or (quite) often asked other childless people for advice. As all participants were recruited with the help of clinics or patient support groups, it is obvious that they had met other people with fertility problems in the clinic. Interviewees also pointed to the importance of participating in a support group (as some of them did), to decrease the feeling of being alone, to find hope and also as a safe place to share one's feelings and get information from other people in a similar situation:

I feel very comfortable, because we are sharing problems. You see, you are not the only one, there are other people. Even when you see that someone is pregnant, you see that there is hope. Even though she may have not gone through the IVF, but you see there is hope. There is support, they can't abuse you, no, because you have met each other through this [support group], you talk, you share and pass information, I think that is good. (woman, 42 years old)

4.10 Fertility Treatment: Considerations and Experiences

Many factors might influence people's decision making about using medical treatment such as IVF (Boivin, Bunting, Collins, & Nygren, 2007). The questionnaire also included 27 statements to assess these factors. The statements are based on the "Treatment Uptake" instrument developed by Bunting and Boivin (2007) based on a literature review. Participants were asked to indicate the degree of importance they gave to each statement when they were considering using fertility treatment (see Table 4.3). When we combine the answer categories "very important" and "extremely important" the most frequently mentioned considerations were: (1) The success rate of fertility treatment (97.1%), (2) The opportunity of identifying why I could not get pregnant (97.1%), (3) Whether we could get fertility treatment where we live (92.9%), (4) How easy it is (or not) to get medical advice or treatment (92.2%), (5) The idea that we had tried everything to have a baby (91.0%), and (6) Whether health insurance could cover the cost of the fertility treatment (89.4%).

In the interviews, participants told us how hard it was to find information about causes of infertility and that it was also very difficult to find their way to a gynecologist who provided fertility treatment, or in the words of one of the interviewed women: *"It was not easy to find information out there about where IVF is done in Kenya"* (woman, 33 years old). One of the gynecologists also explained that due to the limited access to information about infertility and fertility treatment, people facing fertility problems postpone seeking help in the biomedical realm. This can lead to poorer treatment results, because women are often too old by the time they reach a gynecologist who provides assisted reproductive technology (ART) services. This gynecologist also emphasized the importance of educating people about visiting a doctor when they have not conceived after one year.

In the questionnaire we also asked people to respond to the statement that fertility treatment is too expensive and 85.5% did (strongly) agree with this statement. In Kenya there are 7 private fertility clinics (located in Eldoret, Mombasa and Nairobi)

Table 4.3 Considerations for treatment (percentages)

	Not important at all	Somewhat important	Moderately important	Very important	Extremely important
The success rate of fertility treatment	0.0	1.4	1.4	25.7	71.4
The opportunity of identifying why I could not get pregnant	1.4	0.0	1.4	24.6	72.5
My feelings about adoption	32.8	7.5	13.4	14.9	31.3
My partner's feelings about adoption	26.2	10.8	15.4	15.4	32.3
Our ability to pay for fertility medical advice or treatment	16.4	3.3	6.6	23.0	50.8
My beliefs and attitudes towards fertility treatment	29.9	10.4	1.5	25.4	32.8
My partner's beliefs and attitudes towards fertility treatment	32.3	6.2	4.6	26.2	30.8
Whether our health insurance covers the cost of fertility treatment	4.5	4.5	1.5	19.7	69.7
The idea that we had tried everything to have a baby	1.5	3.0	4.5	20.9	70.1
How easy it was to get medical advice or treatment	1.6	1.6	4.7	29.7	62.5
Whether we could have a happy future without having children	9.4	4.7	3.1	21.9	60.9
Fear that nothing could be done to help us have a baby	10.6	6.1	4.5	21.2	57.6

(continued)

Table 4.3 (continued)

	Not important at all	Somewhat important	Moderately important	Very important	Extremely important
Whether close family/friends could accept a child born as a result of fertility treatment	19.1	4.4	2.9	16.2	57.4
Whether I could accept a child born as a result of fertility treatment	12.9	2.9	1.4	15.7	67.1
Whether my partner could accept a child born as a result of fertility treatment	11.8	2.9	13.2	13.2	57.4
My religious or moral beliefs about fertility treatment	36.4	7.6	7.6	21.2	27.3
My partner's religious or moral beliefs about fertility treatment	32.8	10.3	5.2	29.3	22.4
The potential negative emotional effects of the fertility treatment	11.5	37.7	11.5	13.1	26.2
The referral or waiting time for the fertility treatment	7.4	7.4	13.2	14.7	57.4
The potential negative physical effects of a fertility treatment	4.5	33.3	16.7	16.7	28.8
Whether we could get fertility treatment where we live	4.3	1.4	1.4	20.0	72.9
Fear for being refused for treatment because of my (or my partner's) age, fertility history, lifestyle or because I (or my partner) already had a child	29.3	4.5	4.5	20.9	46.3

(continued)

Table 4.3 (continued)

	Not important at all	Somewhat important	Moderately important	Very important	Extremely important
Whether fertility treatment would be a strain on my relationship with my partner	39.4	4.5	12.1	21.2	22.7
Confidence that I could be satisfied putting my energy into other life goals	23.9	13.0	10.9	17.4	34.8
My partner's age	19.4	8.1	3.2	19.4	50.0
The reputation of the fertility clinic and its practitioners	9.4	6.3	6.3	17.2	60.9
My age	16.9	1.5	6.2	21.5	53.8

and they are providing about 1000 IVF cycles per year (Ndegwa, 2014). The costs of an IVF are indeed high, namely 4500 US dollar for one cycle (Ndegwa, 2014). The high costs of ART services, for example an IVF cycle, mean that the majority of people in Kenya, who are dealing with fertility problems, are not able to afford ART services, creating huge access inequalities to appropriate fertility care (see also: Gerrits, 2012; Inhorn & Birenbaum-Carmeli, 2008; Inhorn & Patrizio, 2015). In the literature this is described as ‘stratified reproduction’ (Colen, 1995, p. 5). Almost all interviewees told us that they had to borrow money to pay for fertility treatments such as IVF or Intrauterine Insemination (IUI). The CEO of an organization for education on reproductive health that was interviewed linked more affordable infertility treatment to de-stigmatization of fertility problems in Kenya:

So, for me, I want, I want a stigma free country on infertility. On how we are going to get a 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] needs 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.

This is exactly what Inhorn and Patrizio (2015) underlined as well: more affordable and accessible ARTs in developing countries are not only needed to treat fertility problems, but effective ARTs also decrease the (gendered) stigmatization of infertility.

In the interviews, people also shared the feeling that medical professionals are more preoccupied with earning money than with providing good health care and giving adequate information. One of the interviewees who underwent several IVFs and IUIs and still was not pregnant, found out later, when she went to another doctor, that the IVFs and IUIs could never have been effective because there was a septum in her uterus and she said:

It did not even bother them to put me through a single test before starting the procedures. The consequences are always for the patient and never for the doctors. It are the doctors who are going home with the money. (woman, 44 years old)

This is of concern because people starting the whole treatment procedure do so based on trust in the doctor’s knowledge, especially given the biomedical complexity of infertility and fertility treatment and the limited access to information about these topics in Kenya. In the words of one of the interviewees “*I did not consult any other doctor, because I just thought, yeah my doctor said I do this ... so, I do this.*” (woman, 26 years old)

Notwithstanding the many complaints, participants also had positive experiences with medical professionals. One of the interviewed women, for example, visited another clinic after several bad experiences with the first clinic. She got the address of the second clinic from a personal contact; this clinic was more specialized in infertility and its treatment and there she was diagnosed with blockages to the fallopian tubes,

which, according to the interviewee, needed to be removed before IVF could take place. In the second clinic she felt well informed, as the doctor took time to explain her medical condition and for the first time she felt “*this doctor is not just after the money.*” (woman, 33 years old)

4.11 Conclusion and Recommendations

Our study on infertility and fertility care in Kenya showed the various consequences of fertility problems and the difficulties people experienced with finding the right information and accessing fertility care. These findings are in line with findings in other sub-Saharan countries (Gerrits & Shaw, 2010). It should be noted that the participants mainly consisted of women living in Nairobi, and the majority of women who filled in the questionnaire were working in the commercial sector and did not belong to a low SES group. So there is still scarce information about women of low SES or women living in rural areas who face fertility problems, and very little is known about Kenyan men. The experiences of people living in rural areas might be different and are presumably likely to be worse compared to those who are living in large cities such as Nairobi.

Our study showed that knowledge regarding fertility varied widely among our research group and was on average limited on several topics. People were especially unaware of declining fertility with age, and the declining chance of getting pregnant when overweight, and had misconceptions about all sperm being fertile, and being fertile when not menstruating, as well as how many people face infertility. As also suggested by one of the interviewed gynecologists, informing people in Kenya through education in schools, clinics and other locations (such as churches) about (in)fertility and risk factors associated with impaired fertility, and also educating people about seeking medical advice on time, may improve their chances of fertility (see also Bunting et al., 2013). Several studies on other diseases have shown that increasing knowledge of signs, symptoms and preventable causes does reduce risk, reduce delay in seeking help, and improve health outcomes (Grunfeld, Hunter, Ramirez, & Richards, 2003; Oliveria et al., 1999). Bunting et al. (2013) emphasized that one could expect similar benefits from increasing fertility knowledge, although the high costs involved in fertility treatments may strongly reduce these benefits. Education might also lead to destigmatization of infertility (see also Gerrits et al., 2017).

Holmström and Röing (2010) emphasize that medical professionals should provide correct information to their patients about the success rates and possibilities of ARTs, so that their patients can make well informed and empowered decisions in their steps to undergo fertility treatment (or not). In our study, we found that according to the interviewees, professionals did not always provide appropriate information because they presumably also had a business to run (the private clinic). Elsewhere, two Sri Lankan IVF clinicians have drawn attention to the challenges practitioners in private IVF clinics (including they themselves) are facing (Palihawadana &

Seneviratne, 2015). On the one hand, they have an obligation to inform their patients realistically about the availability of ART facilities and the range of possible solutions for infertility problems; on the other hand, they have to advertise and promote themselves in the media, as ‘any private sector enterprise’ that can resolve people’s infertility problems (Gerrits, 2015, Palihawadana & Seneviratne, 2015). According to Franklin and Roberts (2006) the money-making focus may affect the trust that people have in the medical ART world. However, we should also mention that our participants also reported positive stories about some private clinics which do inform their patients very well and really want to help them.

In Kenya, like in many sub-Saharan countries, motherhood is considered imperative for womanhood. In our study, for example, this was reflected in the answers that most women gave about it often not being a choice to have a child but a “decision” made for women by society. Like in other studies in non-Western countries (see for an overview: Van Balen & Bos, 2009), we found that many women reported feelings of grief, incompleteness, loneliness and low scores on instruments measuring quality of life. To deal with these feelings some participants did mention the importance of patient support networks (see, for example, Peterson & Place, Chap. 2 in this volume). Many researchers have emphasized the importance of support groups for patients with particular health issues, such as HIV/AIDS, in sub-Saharan African context (Gillett & Parr 2010; Moyer, Igonya, Both, Hardon, & Cherutich, 2013). Little is known about the importance of support groups for people with fertility problems in these contexts, while they are known to play an important role in many Western countries (e.g., Van Uden-Kraan, Drossaert, Taal, Seydel, & Van de Laar, 2009) and lately have been set up in a number of Sub-Saharan African countries such as in Ghana (Gerrits, 2015, 2016).

Globally, ARTs have brought a solution for many infertile people and they are generally seen as highly desirable (Gerrits, 2015). It is therefore not surprising that ARTs are also seen as a welcome opportunity in a context in which there are a lot of socio-cultural and psychological consequences for unwanted childlessness, especially for women. Franklin (1997) described ART as a “technology of hope” when these technologies were initially introduced in Western contexts. Franklin (1997) also argued that this (gendered) medicalization of infertility can change from what users might experience as something to increase their reproductive agency into something which adds a new kind of pressure or obligation on women (and men) to use. In line with this we argue that it is not only important to make ART more accessible, but efforts should also be made to destigmatize infertility and unwanted childlessness, because only then childless couples will not be isolated and discriminated against (Ombelet, 2011). On the other hand, the use of ART can also be seen as a way for people to cope with societal pressure and negative attitudes around them (Bochow, 2015) and in itself may have a destigmatizing effect (Inhorn & Patrizaio, 2015).

Our study also showed that access to diagnostic information and treatment was very important for the participants; however, the access to these ‘technologies of hope’ is limited because of the costs and availability. In Kenya ARTs are only available in the private sector, and thus are very expensive, and so only accessible to some couples, and sometimes only after borrowing a large amount of money. Not

surprisingly almost all participants (even while most of them belonged to higher income groups) agreed with the statement that fertility treatment is too expensive. This leads to what the literature labels as ‘stratified reproduction’ (Colen, 1995). This ‘stratified reproduction’ is in contrast with international statements which have been made since 1948. In 1948 the United Nations (UN) Universal Declaration of Human Rights stated that: “Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to raise a family”. This statement was followed by a statement at the UN International Conference on Population and Development (ICPD) in Cairo in 1994: “Reproductive health therefore implies that people have the capability to reproduce and the freedom to decide if, when and how often to do so And to have information and the means to do so ...” (UN, 1998), and then in 2004 at the World Health Assembly: “the provision of high-quality services for family-planning, including infertility services” was once more confirmed (World Health Organization, 2004). These statements underline the right to have access to fertility treatments when couples are unable to have children (Ombelet, 2011). The ‘stratified reproduction’ resulting from unequal access to ARTs in Kenya (like in many other countries) contrasts with these international statements, and one of the remaining questions is “why would citizens of developing countries not have the right to have at least one child, especially if we succeed to simplify care and make them [ARTs] affordable for a much larger part of the population?” (Ombelet, 2011, p. 260).

Several initiatives have been undertaken in the last couple of years to simplify diagnostic procedures for fertility problems, to use less expensive ovarian stimulation medication and to use IVF procedures that are more affordable, but still safe and effective (Frydam & Ranoux, 2008; Ombelet, 2011, 2014; Ombelet, Cooke, Dyer, Serour, & Devroey, 2008). The project undertaken by the Belgian non-profit organization the Walking Egg (tWE) is an example of such an initiative. One of the main goals of the Walking Egg is to make infertility care universally available and accessible (Ombelet, 2011; Ombelet & Campo, 2007). As part of the Walking Egg initiative, a new simplified method of IVF culturing was developed, called tWE lab method (for more technical information see the tWE lab system: Klerck et al., 2014). Studies carried out at the IVF unit in Genk (Belgium) showed that the outcomes of this more affordable culture method were identical with those from a conventional IVF method (Ombelet, 2014; Van Blerkom et al., 2014), while the costs of this tWE lab method are between 10 and 15% of the costs of a conventional IVF (Klerck et al., 2014).

Nevertheless, it will take time until more people have access to fertility care; and even when they have access to fertility care, this will not always result in a pregnancy and a child. According to the Centres for Disease Control and Prevention (CDC, 2011), the success rate of a single IVF using a woman’s own ova is 30–40% for women below 35 years. The rate then decreases steadily thereafter to around 10% by the age of 43 years. Therefore, we contend—following the gynecologist Willem Ombelet—that it is important to not only focus on broadening access to

ARTs, but also on preventing infertility, for example by preventing sexually transmitted infections and infections resulting from unhygienic maternity care and unsafe abortion practices, and challenging existing negative attitudes regarding unwanted childlessness (Ombelet, 2011).

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