



BREAKING THE SILENCE AROUND INFERTILITY

**A NARRATIVE REVIEW OF EXISTING
PROGRAMMES, PRACTICES AND
INTERVENTIONS
IN LOW AND LOWER-MIDDLE INCOME
COUNTRIES**

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome	PCOS	Polycystic ovary syndrome
ART	Assisted Reproductive Technology	POI	Premature Ovarian Insufficiency
ASRM	American Society for Reproductive Medicine	SRHR	Sexual and Reproductive Health and Rights
CoP	Community of Practice	STI	Sexually Transmitted Infection
CSE	Comprehensive Sexuality Education	tWE	the Walking Egg
DHS	Demographic Health Survey	UN	United Nations
ESHRE	European Society for Human Reproduction and Embryology	WHO	World Health Organization
FIGO	International Federation of Gynaecology and Obstetrics		
FLCIVF	Friends of Low-cost IVF		
GBV	Gender Based Violence		
HIC	High Income Country		
HIV	Human immunodeficiency virus		
HRP	Human Reproduction Programme		
ICMART	International Committee Monitoring Assisted Reproductive Technologies		
ICPD	International Conference on Population and Development		
ICSI	Intracytoplasmic Sperm Injection		
IFFS	International Federation of Fertility Societies		
IUI	Intrauterine insemination		
LGBTIQ	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer		
LLMIC	Low and Lower Middle-Income Country		
MDG	Millennium Development Goal		
NGO	Non-Governmental Organization		

1. INTRODUCTION

1.1. THE SHARE-NET INTERNATIONAL CO-CREATION CONFERENCE “ENGAGING IN KNOWLEDGE TRANSLATION TOGETHER”

Share-Net International (SNI), the Knowledge Platform on Sexual and Reproductive Health and Rights, will host its first annual Co-Creation Conference, “Engaging in Knowledge Translation Together” from 8 to 10 October 2019 at the Impact Hub in Amsterdam, the Netherlands. It will be a working conference in which participants will develop concrete and evidence informed knowledge products that will be used for influencing policy and practice at country level. The conference has two tracks: 1) Breaking the silence around Infertility and 2) Access to quality sexual and reproductive health and rights (SRHR) services for people affected by conflict, fragility and crisis. All participants of the conference, including researchers, practitioners and policy makers will engage in dialogues and work together for the creation of these knowledge products.

Members of Share-Net International in Netherlands, Jordan, Burundi and Bangladesh selected the topic of infertility as a neglected area in SRHR. The SNI Community of Practice (CoP) on Infertility was tasked to further develop the ideas for this track. SNI commissioned the University of Amsterdam to conduct a Narrative Review. This review aimed at identifying existing interventions related to infertility, and determining the main gaps in infertility policies, programmes and interventions, and in the integration of infertility in SRHR programming, with a focus on low and lower-middle income countries (LLMICs). The CoP identified four main issues as priorities: 1) breaking the silence on infertility in policy and practice, 2) prevention of infertility, 3) access to quality (in) fertility care, and 4) de-stigmatisation of infertility and childlessness. This report will present the findings of the narrative review¹.

1.2. NARRATIVE REVIEW METHODOLOGY

For this narrative review, a combination of methods was used. To find relevant articles around infertility prevention, accessibility to care, de-stigmatization and involvement of men, an academic database search (through Embase and Sociological Abstracts) and a Google search were used. Additionally, earlier research for a review on support groups for infertility was used (Bushee et al, 2018). Next to that, information gathered from key informant interviews and focus group discussion with Communities of Practice on Infertility from Bangladesh, Jordan and Burundi was used. Furthermore, results from a questionnaire directed to Share-Net members about existing interventions are part of the narrative review. Here we will summarise the methods for each methodology and reflect on these methods and their limitations.

Database search

For the academic database search, we developed search strings for each subtheme, together with the library of the University of Amsterdam. The CoP on Infertility provided feedback which was used to improve the search strings. All search strings covered the topics of infertility, intervention and low-income country

¹ The literature review yielded more examples of existing interventions in the field of infertility than could be presented in this report. An overview of all interventions can be found in Annex 3.

(LLMIC). There were separate search strings for prevention, de-stigmatisation and involvement of men, and access to care². Two databases were used, one more medical and one social science. Embase and Sociological Abstracts were chosen as the most relevant databases. This search led to 1649 relevant articles. After deleting articles that appeared more than once, 1527 articles were left. After removing articles that were not about interventions around infertility and that were more than twenty years old (and thus not considered relevant anymore), 156 articles were left. These articles were looked at more in-depth in order to see which ones were useful for the literature review. In the end, 86 articles were used for this narrative review.

Supplemental research

To complement the database research, online search engines were consulted including Google and Google Scholar, social media platforms including Facebook and Instagram, as well as app stores, to ensure an all-encompassing research strategy and optimise infertility-related findings. Search terms such as, but not limited to, 'access to infertility care intervention', 'initiative infertility prevention' and 'improving male involvement infertility implementation' were used. These supplemental research attempts yielded interesting information from NGOs, newspapers, blogs, and academic sources among others.

Results search for Jembatan project

In 2018, a search on support groups for infertility was conducted in preparation of the Jembatan project in Indonesia. These results were summarised by Bushee et al (2018), and was used for this narrative review.

Information key informants and CoPs

In addition to the literature review, 18 key informant interviews were held with key and recognised experts³ in the field of infertility as well as SRHR experts. They represented academia, global institutions, NGOs, medical practitioners/providers, and infertility societies, from different regions in the world. Focus Group Discussions were held with the Share-Net International Communities of Practice on Infertility in Jordan, Bangladesh and Burundi.

Reflections and limitations

Infertility encompasses medical, social, psychological, cultural, human rights, gender justice, economic, environmental and ethical aspects which the authors fully recognise. Due to time and funding restrictions, this narrative review was conducted based on certain choices that narrowed down the scope. The initial scoping identified the following key areas: gaps in policies and practices in relation to infertility prevention, access to (in)fertility care and de-stigmatisation. In addition, the narrative review maps existing interventions for addressing infertility in LLMIC. Some issues that are part of the reproductive justice spectrum, such as gestational carrying and the right to raise a family for same-sex couples, are less explored here.

Only two academic databases were used for the literature review. The use of more databases could have led to more possibly interesting articles, as every database contains different articles. Another limitation is

² The exact search strings can be found in Annex 1.

³ The list of key informants can be found in Annex 2.

the fact that not many concrete projects were found that were evaluated. For that reason, the narrative did not become an overview of good practices and tips and tricks, but became an overview of possible useful suggestions based on projects and research studies.

2. INFERTILITY, AN OVERVIEW

2.1. INFERTILITY: AN INTERCONNECTED, BUT NEGLECTED, PHENOMENON

Millions of people worldwide are affected by infertility. Every individual has the right to plan a family, to decide on the number, spacing and timing of their children and to have access to information and services that enables them to exercise these rights⁴. However, people suffering from infertility very often do not see these rights realised, even though information and services exist. It is a matter of reproductive justice, but it is not often seen this way. There are political, ethical, gender justice, inequality, visibility and knowledge gaps in addressing infertility.

Many governments in LLMIC are concerned with population growth and emphasise access to contraceptives. Global donors have funded large contraceptive programmes which emphasise the political discourse of encouraging people to have less children, instead of supporting people's right in deciding the number, timing and spacing of their children, including people who wish to plan a family but cannot (Inhorn 2009).

Governments that do facilitate access to ARTs often do this from a pro-natalist view. The advocacy for and provision of access to fertility care and ARTs are important to guarantee the universal right to health. However, a narrowed focus on access to fertility care and ARTs may emphasise the dominant norms on the importance of motherhood. It can increase stigma of people who are infertile and/or childless. Therefore, access to fertility care must be accompanied with advocacy and messages that address patriarchal and socio-cultural norms that undermine women's rights.

It is a concern that fertility care in LLMICs is mainly available through the private sector and rarely through the public sector. It involves the commercialisation of – mostly – women's bodies, who have every right to be able to have a family but need to pay exorbitant prices for ARTs and other fertility care. As a CoP on Infertility member from Bangladesh put it: *"Infertility is a huge booming business"*. While it is positive that infertile care is available, access is far from universal and equitable with only those who can afford the high costs obtaining it.

Involuntary childlessness is a social phenomenon and it affects different people in society; women, men, Lesbians, Gays, Bisexual and Transgenders (LGBT), (aspirational) single parents and people with disabilities. Infertility is sometimes classified as a disability, as an impairment of function generated by a disease (and infertility is clinically classified as a disease). While there are strategic reasons for that which will be presented in this paper, it can also be stigmatising to people who are not infertile and, in that sense, not

⁴ Recognised in the Convention on the Elimination of Discrimination Against Women (CEDAW) article 16E, and the International Conference on Population and Development Programme of Action, paragraphs 7.3 and 7.6.

disabled, but are involuntary childless nonetheless. Their right to have a family is surrounded by ethical and political deliberations, which impede their access to assisted reproductive technologies, including gestational carriers.

Infertility is an invisible and highly tabooed phenomenon and rarely discussed. While a large number of (mainly qualitative) studies have given ample insight in the socio-cultural and psychological dimensions of infertility and its impact in people's daily life (see e.g. Inhorn & van Balen, 2002; Van Balen & Bos, 2009; Van Balen & Gerrits 2001; Gerrits & Shaw 2010), limited quantitative data exist. Infertility has different impacts on men, women, people with diverse sexual orientation and gender identity and people with disabilities. As described above, there are political and ethical considerations that push addressing infertility into the margins. And lastly, there is lack of understanding on how cross-cutting infertility is as a topic and how it touches upon global concerns:

- Addressing infertility is about rights. It is part of the reproductive right to be able to decide freely and responsibly the number, spacing and timing of children and have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. (In) fertility implicates multiple human rights including the rights to plan the timing and spacing of children, to benefit from scientific progress, to health, including SRH, to non-discrimination, as well as informed consent and confidentiality.
- Infertility and unwanted childlessness occur everywhere in the world, regardless of gender, geographical location, socio-economic status, race, sexual orientation, disability, gender identity or (reproductive) age, but the response to it demonstrates huge inequities - which is often referred to as stratified reproduction (Colen 1995; Gerrits 2015). This is most evident in the wealthier people being able to obtain quality information and services at high costs, as well as inequitable laws that define who can have access to assisted reproductive technologies or third-party reproduction, and who cannot.
- Furthermore, even though both men and women can face fertility problems, the burden of infertility falls predominantly on women. This can result in violence and discrimination against them, perpetuating persistent gender inequality. Other inequalities are also persistent, with people facing infertility or childlessness being stigmatised, excluded or discriminated against in families and communities.
- Infertility is a public health concern, it is linked to maternal health and morbidity, to sexually transmitted infections and HIV and AIDS, to unsafe abortions, to menstrual health and discontinuation of contraceptive methods, to reproductive conditions and diseases such as endometriosis and cervical and reproductive cancers.
- Infertility also has economic dimensions: people facing infertility tend to spend much of their income on their search for adequate fertility treatments. Also, the burden on the health system is high, resulting in sometimes unnecessary surgeries and treatments and going from one provider to the next. Furthermore, childless individuals and couples face economic difficulties at an older age, without children taking care of them.
- Lastly, there is growing evidence that environmental (such as exposure to chemicals and pollution and hormonal intake) and life style factors (such as food, smoking and alcohol use) can lead to infertility.

- In conclusion, addressing infertility involves addressing structural issues such as patriarchy, dominant norms around gender and sexuality, privatisation and health, life style and environmental issues. Hence, responses to infertility require multidisciplinary approaches while being cognisant of the structural, social, cultural, medical, political and ethical dimensions that surround infertility and childlessness.

2.2. DEFINITIONS, FACTS AND FIGURES

Infertility definition

WHO defines clinical infertility as, “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse.” 180 Million couples worldwide are potentially affected by infertility, depending on estimates (Starrs et al 2018:7)⁵.

However, prevalence is very hard to measure as there are few national estimates of infertility prevalence and there is a variation in definitions and measurement of infertility across studies. Estimates are influenced by different definitions related to the population studied (e.g. women vs people vs couples) and the type of study as different fields use different definitions in the time spent trying to get pregnant (e.g. 1 year for clinical studies; 2 years for epidemiological studies; 3–5 years for demographic studies). In addition, studies can look at the ability to get pregnant versus the ability to carry a pregnancy to term. Lastly, a difference between primary and secondary infertility needs to be considered. Taking these different approaches into account, an estimated 48.5 million to 186 million couples are affected by primary or secondary infertility (Starrs et al 2018:9). Secondary infertility is more common than primary infertility (Starrs et al 2018:9).

The WHO/World Bank Report on Disability of 2011 estimated 35 million women with primary or secondary infertility, as a result of either infection due to unsafe abortions or maternal sepsis. The report also highlighted that infertility as a maternal morbidity represents the fifth largest global burden of all disabilities and that it is mainly found in developing countries (WHO 2011). It is also found that couples living with HIV in developing countries have higher rates of infertility or subfertility (WHO 2011).

Key definitions

Infertility: A disease characterised by the failure to establish a clinical pregnancy after 12 months of regular, unprotected sexual intercourse or due to an impairment of a person's capacity to reproduce either as an individual or with his/her partner. Fertility interventions may be initiated in less than 1 year based on medical, sexual and reproductive history, age, physical findings and diagnostic testing. Infertility is a disease, which generates disability as an impairment of function (Zegers-Hochschild et al. 2017).⁶

⁵ Starrs et al (2018) is the most recent publication thoroughly reviewing several aspects related with infertility, referring to a large number of seminal publications in this field and will therefore be extensively quoted in this report.

⁶ The AASRM ‘International Glossary on Infertility and Fertility Care’ (Zegers-Hochschild et al. 2017)

Secondary infertility:

- Female: a woman unable to establish a clinical pregnancy but who has previously been diagnosed with a clinical pregnancy.
- Male: a man who is unable to initiate a clinical pregnancy, but who had previously initiated a clinical pregnancy. (Zegers-Hochschild et al. 2017)

Assisted Reproductive Technologies (ARTs): All interventions that include the in vitro handling of both human oocytes and sperm or of embryos for the purpose of reproduction. This includes, but is not limited to, In vitro fertilisation (IVF) and embryo transfer, intracytoplasmic sperm injection (ICSI), embryo biopsy, pre-implantation genetic testing, assisted hatching, gamete intrafallopian transfer, zygote intrafallopian transfer, gamete and embryo cryopreservation, semen, oocyte and embryo donation, and gestational carrier cycles. Thus, ART does not, and ART-only registries do not, include assisted insemination using sperm from either a woman's partner or a sperm donor. (Zegers-Hochschild et al. 2017)

Fertility awareness: The understanding of reproduction, fecundity, fecundability, and related individual risk factors (e.g. advanced age, sexual health factors such as sexually transmitted infections, and life style factors such as smoking, obesity) and non-individual risk factors (e.g. environmental and work place factors); including the awareness of societal and cultural factors affecting options to meet reproductive family planning, as well as family building needs. (Zegers-Hochschild et al. 2017)

Fertility care: Interventions that include fertility awareness, support and fertility management with an intention to assist individuals and couples to realise their desires associated with reproduction and/or to build a family. (Zegers-Hochschild et al. 2017)

Gestational carrier: A woman who carries a pregnancy with an agreement that she will give the offspring to the intended parent(s). Gametes can originate from the intended parent(s) and/or a third party (or parties). This replaces the term 'surrogate.' (Zegers-Hochschild et al. 2017)

Medically assisted reproduction (MAR): Reproduction brought about through various interventions, procedures, surgeries and technologies to treat different forms of fertility impairment and infertility. These include ovulation induction, ovarian stimulation, ovulation triggering, all ART procedures, uterine transplantation and intrauterine, intracervical and intravaginal insemination with semen of husband/partner or donor. (Zegers-Hochschild et al. 2017)

2.3. CAUSES OF INFERTILITY

Infertility occurs for 20-30% in males, for 20-35% in females, for 25-40% in both the male and the female, and in 10-20% of the cases infertility is unexplained⁷.

⁷ ART Factsheet, ESHRE, July 2014. <https://web.archive.org/web/20160304060954/https://www.eshre.eu/Guidelines-and-Legal/ART-fact-sheet.aspx> (accessed on 26/08/2019)

The most common causes of female infertility are:	The most common causes of male infertility are:
<ul style="list-style-type: none"> • Tubal factors, which could be a result of STIs, post-partum infections, unsafe abortions and tuberculosis • Ovulation disorders, such as polycystic ovary syndrome (PCOS) and premature ovarian insufficiency (POI) • Uterine abnormalities, such as endometriosis and fibroids • Age (after age 35, fertility in women declines rapidly) • Behavioural and lifestyle aspects such as psychologic stress, drug addiction, drinking too much coffee and alcohol, smoking, obesity, extreme weight loss, and physical stress (competitive sports). 	<ul style="list-style-type: none"> • Age • Environment factors (chemicals) • Behavioural and lifestyle aspects such as psychologic stress, drug addiction, drinking too much coffee and alcohol, smoking, obesity, extreme weight loss, and physical stress (competitive sports).

Over the past decades, semen quality has decreased. Semen quality is affected by genetic factors, lifestyle, and environmental factors (Perheentupa 2019).

Several causes of infertility are preventable, such as infertility caused by STIs, post-partum infections and unsafe abortions, lifestyle factors if good quality sexual and reproductive health and rights information and services are available. However, PCOS, POI, male factors, uterine and tubal abnormalities, endometriosis, repeated miscarriages, immunological issues are all unpreventable. A focus on prevention of infertility is much needed, however, it also needs to be recognised that not all infertility cases can be prevented. For people affected by these causes, there needs to be proper, counselling and management and treatment of infertility.

2.4. CONSEQUENCES OF INFERTILITY

Infertility can have a devastating impact on individuals and couples. The Lancet-Guttmacher Commission summarised research findings indicating that infertility can cause psychological distress, intimate partner violence, marital instability, risky sexual behaviours, economic hardship, stigma and exclusion (Starrs et al 2018). It cuts across gender, class, race, age, geographical location, disability, sexual orientation and gender identity. It is a truly universal issue, which relates to public health, human rights, gender justice and environment.

In the majority of LLICs, it is culturally expected to procreate and become a parent (Inhorn and van Balen, 2002; Van Balen & Bos, 2009; Van Balen and Gerrits 2001; Gerrits and Shaw 2010; Pennings et al., 2009; Hammarberg and Kirkman, 2013). Those who fail to meet this expectation are often stigmatised and experience stress, a loss of identity and grief, and in some cases even ostracism, violence and abuse.

It is acknowledged that women and poor people carry the greatest burden. Access to quality information and infertility care is generally only accessible for the wealthy who can afford expensive treatments or travelling abroad for infertility services. Women are often the ones blamed for a failure in getting pregnant, even when it is male infertility that causes these problems. The views of womanhood and motherhood are deeply enshrined in patriarchal norms and women are seen as “gender non-performers” (Sarojini & Marwah 2016) when they are non-conforming due to their infertility or childlessness. Key informants confirmed the idea that women mostly carry the blame, that it is her fault, that she does not deserve to stay in the marriage, that she is seen as carrying a bad omen. There are many cases of men leaving the wife to remarry, of intimate partner violence and even marital rape.

Key informants have shared appalling stories of women feeling devastating guilt and humiliation. In many contexts, women obtain status in their societies by bringing children into this world. Men often still have other ways to obtain status, through e.g. wealth or employment. Infertile/childless women can feel isolated, are ostracised, and discriminated against. The stigma is exacerbated if infertility is resulting from an STI or an unsafe abortion. Infertility is referred to as a silent tragedy, especially for women.

Stigma can also be on the man with fertility problems, it is often seen as if he is losing his masculinity (Hörbst 2010). In order to save the face of the husband, the woman will sometimes say that the fertility issues are with her instead of him. In other instances, she finds someone else to make her pregnant. As one key informant said: “Sometimes it is easier to deal with infidelity than infertility.”

In many contexts, getting children is an extended family affair. There is social pressure on the couple to get pregnant. For example, according to a key informant, in the context of Benin, a baby is a sign of richness. There is even a proverb indicating this: “babies are the benefit of the trade of marriage” implying that without a baby the marriage is not worthy. In the absence of a pregnancy, families and in-laws step in, pressuring the man to take another wife. This is seen as the “simpler” solution. As a focus group discussion participant in Jordan put it: “Taking another woman is less expensive than paying for an infertility treatment.”

In Bangladesh, ideas about femininity and masculinity in relation to infertility differ per context and social class (Nahar and Richters 2011). The CoP in Bangladesh observes that in the working class and rural areas, old stereotypical ideas about men and women exist. There the burden of infertility falls on women and it is common practice that men will keep remarrying. However, in the upper class, in case of male infertility, women seem not to want to carry the blame. The man and his infertility will be exposed, and he will be stigmatised for being “unmanly”.

Key informants also highlighted the economic impact of infertility and childlessness. They note infertility as a catastrophic cause of poverty: due to ostracisation, exclusion, and women being pushed out of their community. In addition, couples and individuals spend a lot of resources to get diagnosed and treated, which often includes unnecessary surgeries. People take loans to pay for the high costs.

Young women may feel the need to prove their fertility to be considered “marriageable” and therefore have unprotected sex with the risk of getting pregnant at an early age, contracting STIs, or even terminating the pregnancy (unsafely) once they have proven that they can get pregnant.

In many countries in LLMICs, (young) people don't use contraceptives because they fear it will make them infertile. In addition, long acting contraceptives has resulted in young women not taking checks for STIs.

In addition, there are discriminatory ideas about fertility. For example, one informant working in reproductive justice explained that black women are often seen as "hyper fertile". If a black woman is infertile, it does not fit the narrative, which can lead to increased stigma.

In conclusion, as Daar & Merali (2001) put it:

"Infertility does transform a potentially private, individualised health problem into social suffering. Infertility has the potential to disrupt peace, exacerbate poverty, and devastate communities. The harms caused by infertility are pervasive, socially embedded and serious, precisely because infertility interacts with a complex network of social relationships, social expectations and social needs."

3. THE SILENCE AROUND INFERTILITY: THE MISSING PIECE IN SRHR POLICY AND PROGRAMMES

3.1. GLOBAL DEVELOPMENTS IN ADDRESSING INFERTILITY

For the last 40 years, there has been a global consensus that addressing infertility is an integral part of addressing reproductive health needs. This was recognised at the 18th World Health Assembly and as a result, a unit was created within WHO dedicated to human reproduction. A special research programme was established in 1972: The Human Reproduction Programme that has ever since addressed reproductive health with a focus on both fertility regulation, which includes contraception and fertility problems (Poel 2012).

At the ground-breaking International Conference on Population and Development (ICPD), held in Cairo in 1994, the international community agreed that reproductive rights *"rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly on the number, spacing, and timing of their children, and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion, and violence."* (ICPD PoA, para 7.3) The Cairo consensus also defined reproductive health care to include family planning, maternal health care, safe abortion where not against the law, education on sexuality and reproductive health, reproductive tract infections, and sexually transmitted diseases, including HIV and AIDS, and prevention and appropriate treatment of infertility (ICPD PoA, para 7.6).

In 2000 the Millennium Development Goals were established, with goals to end poverty in 15 years. One of the goals was to improve maternal health but it was not until 2007 that the target MDG 5b 'achieve, by 2015, universal access to reproductive health' was included. In that same year, the European Society for Human Reproduction and Embryology (ESHRE) initiated a meeting in Arusha to bring together stakeholders to discuss the issues in terms of access to ARTs especially in developing countries (Ombelet et al 2010; Poel 2012). It was one of the first initiatives that put infertility in LLICs on the agenda, including its socio-cultural

dimensions. Over the years, tools have been developed addressing access to infertility services, such as the ICMART Tool Box for monitoring ART practices⁸, the IFFS Surveillance Reports⁹, the UIT-IFFS Resource Centre¹⁰, and the FIGO Reproductive Medicine Committee's FIGO Fertility Tool Box¹¹. In 2017, The International Glossary on Infertility and Fertility Care was published by ICMART and partners, which updated the 2009 Glossary (Zegers-Hochschild, 2017).

Despite these global developments, infertility has remained a neglected area as part of reproductive health and rights policies and programmes, especially in lower income settings. In 2016 a special Lancet-Commission on SRHR was established to develop a comprehensive, evidence-based, bold and actionable agenda for key sexual and reproductive health and rights (SRHR) priorities globally. In its comprehensive report the Commission recognised that “access to services for prevention, management, and treatment of infertility” is an essential component of SRHR (Starrs et al 2018:10). The Commission presents an integrated definition of SRHR which reaffirms that “achievement of sexual and reproductive health relies on the realisation of sexual and reproductive rights, which are based on the human rights of all individuals to:... decide whether, when, and by what means to have a child or children, and how many children to have;”. It further expresses that “essential sexual and reproductive health services must meet public health and human rights standards” and that these services should include: “.... prevention, management, and treatment of infertility” (Starrs et al 2018:11 and 45). Yet, the Commission argues that some components of SRHR have attracted more attention and domestic and international funding than others and that attention and funding for infertility has been scarce (Starrs et al 2018: 16-17).

In December 2018, the WHO convened a Global Summit on Safety and Access to Fertility Care from which a Call to Action is to be published in the near future. Currently, WHO is developing global guidelines for infertility diagnosis, management, and interventions for treatment. In addition, WHO, commissioned a research on jurisprudence on human rights and infertility, which will yield a publication expected to be released at the end of 2019.

Share-Net International and Infertility

In November 2017, Share-Net International and the University of Amsterdam convened a Roundtable Discussion on Infertility. Researchers, WHO, ESHRE, NGOs and providers participated and discussed the main issues and barriers in addressing infertility¹² (Gerrits et al 2017). Three main topics were identified: (1) prevention of (sub)infertility, (2) addressing stigma, and (3) access to quality (in)fertility care. Out of this roundtable discussion the Share-Net Community of Practice (CoP) on Infertility was born. The CoP's mission

⁸ <http://www.icmartivf.org/toolbox/toolbox-main.html> (accessed on 26/08/2019)

⁹ <https://www.iffs-reproduction.org/page/Surveillance> (accessed on 26/08/2019)

¹⁰ <http://ru.iffs.elsevier.cc/tags/iffs> (accessed on 26/08/2019)

¹¹ https://www.figo.org/sites/default/files/uploads/wg-publications/reproductive-medicine/FIGO_Fertility_Tool_Box.pdf (accessed on 26/08/2019)

¹² The Round Table meeting was the final activity of an intervention-research project funded by Share-Net International, aiming to generate new insights about the views, needs and experiences regarding infertility and fertility care and to increase knowledge and awareness about infertility, childlessness and possible interventions among relevant stakeholders and institutions in Kenya and Ghana.(Gerrits et al 2017).

is to generate, share and promote the use of knowledge for successful integration of infertility within SRHR policies, plans and programmes. It looks at infertility holistically and promotes the prevention of infertility, the importance of destigmatising female and male infertility and childlessness, of having access to a broad range of quality (in)fertility care and involving men. Activities include research and disseminating research results, organising roundtables and conferences, and supporting collaboration between groups of people affected by infertility and organisations focusing on SRHR. As a first concrete activity the CoP participated in the 2018 SheDecides campaign, by producing a brochure on the importance to include infertility in the SRHR agenda¹³.

In 2018, through the support of a Small Grant of Share-Net International, the CoP launched a pilot project to support the integration of (in)fertility issues into SRHR programming in Indonesia. The Jembatan project – ‘jembatan’ means ‘bridge’ in Indonesian – aimed at facilitating collaboration, engagement, dialogue, sharing of experiences and knowledge amongst NGOs working in SRHR, an infertility support group and medical professionals, in Yogyakarta, Indonesia. The project intended to ‘bridge’ the distance between these stakeholders having a shared interest but who were not used to reach out to each other. The pilot project gave input to a ‘Stepping Stones’ document with tips and tricks for integrating (in)fertility in SRHR programmes, based on the lessons learnt and results from the Jembatan project (Radyowijati et al, 2019).

In June 2019, the CoP co-organised a session on Infertility at the Women Deliver Conference in Vancouver, with WHO and the Centre for Reproductive Rights. Currently, the CoP is strongly involved in the organisation of the Share-Net International Co-Creation Conference “Engaging in Knowledge Translation Together” to be held in Amsterdam in October 2019.

3.2. GAPS IN INTEGRATING INFERTILITY IN SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS POLICIES AND PROGRAMMES

“It gets me thinking: why are we not working on infertility? It is kind of hypocritical if we claim that we work on sexual rights and reproductive justice.”

Key informant working for an SRHR organisation

Lack of accurate data

Key informants recognise that there is a lack of accurate data on infertility and that there are severe challenges in measuring it. There are some global estimates – based on different methods of measuring (see Starr 2018) - but very few national estimates. In addition, there is no to limited data on specific groups such as same-sex and disabled women. There is a methodology to look at DHS data for infertility. Contraceptive calendar data can be used to estimate infertility rate. It was developed by Polis et al (2017)

¹³ <https://share-netinternational.org/wp-content/uploads/2018/03/SheDecides2.pdf> (accessed on 26/08/2019)

and got interest by WHO. Key informants acknowledge that infertility is a difficult issue to study, but contend that the lack of data is contributing to the invisibility of infertility.

There are no indicators for measuring infertility as such. A key expert in infertility suggested to use the indicator “Unmet need for infertility care” as that would include all people who want to build a family, but are unable to do so for various reasons, such as lack of information, lack of access to care, and stigma faced.

Infertility not a priority of governments, or from a pro-natalist point of view

Governments in LICCs have not prioritised infertility. Governments face competing public health priorities which are life threatening, such as malaria, tuberculosis, cancers, etc. At the same time, governments are more inclined to address population growth and invest in contraceptives – which is heavily resourced by the international community. In addition, there is a general idea that investing in addressing infertility is costly. There is a lack of clear guidelines on how to address gestational carrying and access to fertility care to disadvantaged groups such as same-sex couples. This lack of guidance discourages governments to develop policies on infertility.

There are LLMICs that do have policies around infertility and provide fertility services in the public health system. Often these countries have under replacement fertility rates and offer services from a pro-natalist view. While more equitable access to fertility services in these pro-natalist countries is positive, it may also exacerbate norms around motherhood and families and add to increased stigma of those who are childless.

Lack of priority for SRHR organisations

Despite the fact that preserving fertility and avoiding infertility is part of many people’s sexual and reproductive health life concerns, choices and behaviour, these topics are largely ignored. It is a taboo topic, and even grossly ignored by sexual and reproductive health and rights information, education, policies and programmes. Despite obvious linkages of infertility to other SRHR themes, such as HIV and AIDS, maternal health, STIs, abortion, contraception, gender-based violence and menstrual health, amongst others, these linkages are rarely made by SRHR policy makers and implementers.

Access to (in)fertility information, counselling, management and treatment is an integral part of reproductive rights. It being neglected by the SRHR community can do harm to its legitimacy, if SRHR policy makers and organisations only focus on one spectrum of reproductive rights (the right to delay or prevent a pregnancy), but not on the other spectrum (the right to the means and information to have children in case of infertility).

Key informants have felt that the right to be able to have a family has been left behind. Even now, when we speak about SRHR in its widest spectrum, the emphasis is still on maternal health and family planning (to be read as the provision of contraceptives). Abortion, female genital mutilation, adolescent SRHR, comprehensive sexuality education (SE), HIV and AIDS, discriminatory practices in SRHR services, some forms of maternal morbidity (e.g. fistula) are considered sensitive, but these issues are talked about nonetheless. Infertility on the other hand, is neglected and tabooed. A key informant who has worked on infertility globally for the last 20 years, claims that within the SRHR spectrum there is not a single topic as

taboo as infertility. As one key informant said: *“People come out to say that they are HIV positive or that they are gay. Most people do not come out in saying that they are infertile.”* Infertility is related to deeply rooted norms around femininity, masculinity, motherhood, patriarchy and sexual orientation.

SRHR organisations may also believe that addressing infertility involves high costs (for ARTs). They may assume that providing fertility services would always involve investments in equipment, professionals (gynaecologist, embryologist, infertility nurses), a lab and a surgery room and complicated accreditation procedures. SRHR organisations are not-for-profit organisations, meaning that such investments would be big for them and the competition with private clinics is stiff. However, key informants also acknowledged that SRHR organisations can lack understanding on how infertility connects to other SRHR issues and what can be done with limited investments, including more low-cost ART options, and different sort of interventions (for example to de-stigmatize infertility). The Lancet-Guttmacher Commission on SRHR in 2018 (Starrs et al 2018) recommended it to be part of the SRHR information and services continuum. They call for more action to raise awareness about infertility and its prevention, to research and make available low-cost fertility interventions, and to invest in equitable access to (in)fertility care (Starrs et al 2018).

Lack of institutional / technical / donor champions and a ‘convening space’ for infertility

Several key informants expressed that there is no institutional or technical champion or convener for infertility. The work of WHO/HRP is appreciated, however it was raised that this leadership does not trickle down to countries. Global guidelines need go together with engagement, training and advocacy at the national level. It was mentioned that currently there is no convening space that brings stakeholders working in the field of infertility from different disciplines and backgrounds. Stakeholders (researchers, providers, societies, advocates, data specialists) tend to work in silos.

Key informants have claimed that there is no funding for infertility. Donors tend to say that there are no partners to fund. This vicious cycle is not easily broken. Research in Bangladesh showed that various stakeholders are pointing to each other to ‘justify’ the neglect of addressing infertility (Nahar 2012).

Narrowed narrative and framing around reproduction

The narrative around SRHR needs changing, reflecting a more holistic, gender transformative and inclusive approach. Key informants have shared that we need to move away from the idea that reproduction is a “female thing”. One key informant working on reproductive justice wondered why the SRHR field is still sticking to the narrative around access to family planning only, as the emphasis on contraceptives was born out of concern for overpopulation, out of white male supremacy and out of patriarchal control of women’s bodies. Furthermore, the narrative around infertility is often concerning married heterosexual couples. A focus on disadvantaged people is needed, or people who are not in conformity with dominant norms.

The definition of infertility is failing to get pregnant while trying for one year with regular sexual intercourse. However, depending on the context this definition can be very narrow: how about couples with one of them working far from home? Or what if couples are unaware of their fertility window? In some places people may be considered to have a fertility problem if the woman does not get pregnant within one year after marriage, or when she only gives birth to a female child or subsequent children are not being born (Gerrits et al 1999). In different contexts the definition can be problematic and stigmatising.

In places where there are many forced and early marriages, early pregnancy should be discouraged: it is problematic when a young woman is declared to be infertile after one year. In addition, some key informants feel an uneasiness with infertility being labelled as a disability. Key informants have called for contextualising the definition of infertility.

A key informant shared that policies and laws on ARTs are highly influenced by the language used in relation to infertility, which are often based ideas people have around infertility and fertility. These can be religiously or morally influenced and it can have severe consequences for laws and policies. The International Glossary on Infertility and Fertility Care (Zegers-Hochschild et al. 2017) recommends using the term “gestational carrier” instead of “surrogate”, because, as the key informant explained, surrogate is connected to “mother” which opens the Pandora’s box about the question about who is believed to be the “mother’. In many countries, commercial gestational carrying is believed to be exploitation of the gestated carrier. Some people do see uterus transplantations as a good alternative. However, these transplantations are very costly. “Conception” is a loaded term as well and not medically sound, but does carry connotations impacting policy. One key expert in the field of infertility therefore urges those working in this field to apply neutral and medically sound language around infertility, to ensure that policies and programmes enhance access to accurate and quality infertility information and services.

Integrating infertility into SRHR programming - Indonesia

In 2018, through the support of a Small Grant of Share-Net International, a pilot project was launched to support the integration of (in)fertility issues into SRHR programming in Indonesia. The Jembatan project – ‘jembatan’ means ‘bridge’ in Indonesian – brought together the non-governmental organization PKBI DIY, the PH Infertility Clinic and the PTPH Support Group in Yogyakarta, Indonesia. The project intended to ‘bridge’ the distance between stakeholders with a shared interest in issues of (in)fertility, but who are not used to reach out to each other and engage. As a result of this initiative, several activities were conducted jointly to improve fertility awareness, to strengthen the support group and to improve the fertility services provided by PH Infertility Clinic:

- PKBI DIY dedicated a special radio programme to raise awareness about infertility in the communities, in collaboration with the PH Infertility Clinic and the PTPH Support Group.
- PKBI DIY established a referral system for people who visit their clinics, in collaboration with the PH Infertility Clinic.
- The PH Infertility Clinic established a formal communication channel for the PTPH Support Group. This is to facilitate regular and formal communication so members of the support group can provide their input on how to improve the services of the clinic. Some of the treating physicians and nurses chose to become advisors to the PTPH Support Group, and some joined the group. This implies that information, such as treatment and consultation scheduling, becomes more accessible for members of the PTPH Support Group.
- The PH Infertility Clinic helped to link the PTPH Support Group with the Department of Health Promotion of the Dr. Sardjito Hospital.

Source: Radyowijati et al 2019

4. INFERTILITY PREVENTION

4.1. PREVENTING INFERTILITY: AN OVERVIEW AND IDENTIFIED GAPS

Prevention of infertility can begin by reducing risk factors for the condition. Interventions include comprehensive sexuality education and counselling that incorporates information on STI prevention and fertility awareness to address, for example, menstrual irregularities and optimal timing of sexual intercourse to achieve pregnancy. Health education could also target other modifiable factors, such as tobacco, alcohol, nutrition, and occupational exposure to certain chemicals. Local providers working in health centres and communities could educate people, counter some of the myths and misperceptions surrounding infertility, and refer affected couples to the appropriate services at the district or regional hospital levels. Secondary infertility, the inability to become pregnant after an earlier birth—which has largely preventable and treatable causes—is more common worldwide than primary infertility (the inability to conceive a child at all). Secondary infertility could be reduced by access to safe delivery and safe abortion care; availability of contraceptive options to prevent unintended pregnancy; and prevention, detection, and treatment of infections.

Source: Starrs et al, 2018: 9

There is a plethora of possible causes of infertility and while the exact proportion of infertility cases arising from preventable causes is unknown, it is estimated to be substantial (Macaluso et al., 2010; Starrs et al 2018). Particularly the early diagnosis and treatment of underlying conditions may prevent infertility or lead to effective restoration (Macaluso et al., 2010: p. 16.e3). The Accelerate progress—sexual and reproductive health and rights for all: report of the Guttmacher–Lancet Commission (Starrs et al 2018) summarised possible ways for intervening (see above box).

Hence, many academics, policy makers and medical professionals suggest that more attention and resources should be devoted towards infertility prevention, particularly in resource-poor countries (Hammarberg and Kirkman, 2013; Dhont et al., 2010: p. 2024; Starrs et al 2018). Moreover, with the limited health resources available, infertility prevention is sometimes referred to as more cost-effective than infertility treatment and would benefit a larger number of people (Okonofua and Obi, 2009: p. 10). While a focus on prevention is very necessary, especially in settings in which infertility is largely caused by preventable causes such as STIs, post-partum infections and unsafe abortions, it needs to be acknowledged that many cases of infertility are unpreventable. Infertile and childless couples and individuals will always exist, implying the continuous need for fertility care and addressing stigma.

Several key informants mentioned that knowledge about menstruation cycles and fertility awareness is very low, in all regions of the world. Many women do not know when their more fertile days are and when it is the optimal timing of sexual intercourse to achieve pregnancy.

In addition, there are many myths around infertility, for example connected to the use of contraceptives. Part of the difficulty of encouraging use of contraception to avoid STIs - and thus avoid infertility - is the fact that in some contexts the use of contraception is seen to be a possible cause of infertility, which may lead women to avoid the use of contraception out of fear of infertility (Upton, 2002; Ikeme et al 2005; Williamson et al 2009; Hyttel et al 2012; Maharaj 2012; Izale et al 2014; Daniele et al 2017; James 2019). One infertility expert mentioned that there needs to be better communication from contraceptive providers about the fact that menstruation cycles can be disrupted for a while after removing long lasting methods. This will normalise after a while, but without this information, women will soon fear they are infertile when they cannot get pregnant immediately.

According to research by Friedman et al. (2010) among young women in the United States, attention paid to infertility is seen as an important motivator to seek screening for chlamydia. This shows that if infertility is explicitly made part of STI screening or prevention, it might increase people's determination to prevent STIs or seek treatment for it. Research on the effects of an educational programme aiming to increase fertility awareness in teenage girls in Japan also suggest that making infertility education part of sex education is important to make young people aware of infertility and infertility risks (Nagaoka, 2014).

The lack of awareness about fertility potential - and the decrease of this over time - is a major factor that accounts for the increasing incidence of subfertility worldwide (Mahey et al.2018: p. 2). Recent trends of postponing the age at which people have their first child as well as the accelerated development and use of medical technology to overcome such limits, reveal that awareness about age related fertility decline (ARFD) is low and that overconfidence tends to be placed in the potential of assisted reproductive technologies (ARTs) (García et al , 2018; Mahey et al., 2018). García, et al (2018) stipulate that the most effective ways to inform people about age-related fertility decline is through primary health care providers, mass media and social media. Even with small-budget campaigns – as the ASRM campaign shows below ¹⁴ - large audiences can be reached. This also applies to websites and apps.¹⁵

In addition to a cross-cultural awareness of differing policies, norms, beliefs, customs and ethics, it is also important to be aware that the causes of infertility differ socially and geographically. An example of this is the prevalence of schistosomiasis in African countries, including coastal Kenya, which may lead to infertility. (Miller-Fellows et al., 2017: p. 2-3). In this context preventing schistosomiasis may thus prevent infertility (Van Niekerk et al., 2017: p. 57; Steinmann et al., 2006).

Creating awareness about male infertility

Awareness about male infertility is limited (Hsiao et al, 2011; Leung et al, 2018). According to Leung et al (2018), in the United States 20% of those websites fail to mention male infertility entirely and less than 25% of websites mention referral to a urologist. In a study by Onyango, Owoko and Oguttu (2010) in Kenya, the

¹⁴ <https://www.asrm.org/resources/patient-resources/pyf-documents/protect-your-fertility/> (accessed on 01/08/2019).

¹⁵ Examples are FertiSTAT: <http://www.fertistat.com/> Your Fertility and "Beat Infertility" (1K+), "Infertility Treatment" (1K+) and "Hidden Secrets of Infertility" (10K+)

majority of participants argue that men and women are approached separately when creating awareness, as they then would feel freer to share stories and ask questions, and men might be more likely to get involved.

Identified gaps related to infertility prevention

Overall, the literature search and the key informants confirmed that hardly any explicit attention is paid to the prevention of infertility in LLMIC. More in particular, the gaps identified in addressing prevention related to infertility can be summarized as follows:

- Awareness about menstruation cycles and fertility is very low, including knowledge about when is the best time to achieve a pregnancy, lifestyle factors influencing fertility and age-related infertility.
- There is a lack of context specific data and knowledge on causes of infertility.
- There is a lack of understanding on newer risk factors, such as environmental factors and hormonal intake.
- Fertility awareness is not included in comprehensive sexuality education curricula.
- There is lack of adequate investments to prevent, diagnose, and treat sexually transmitted infections, to prevent and manage unsafe abortions, to provide safe abortion services and to ensure safe motherhood, which are main causes of infertility, especially in certain LLMIC contexts.
- There is limited attention to and awareness raising of male infertility.

4.2. EXISTING INTERVENTIONS IN INFERTILITY PREVENTION

The literature/web search showed that there are few infertility prevention initiatives in LLMIC.

Globally, one of the biggest and most successful infertility prevention campaigns - Protect Your Fertility - to date was led by the American Society for Reproductive Medicine (ASRM)¹⁶ in 2001 in the United States. With the assistance of Hauser Group, a strategic communications firm, the campaign targeted men and women between the ages of 18 and 40 and focused on four themes: smoking, body weight, sexually transmitted diseases and reproductive aging (Soules, 2003: p. 295). This small, self-funded campaign ended up becoming an internationally recognised media campaign receiving wide coverage in the mass media. The success of this campaign has been attributed to its controversial nature (see poster) and the debates these sparked during the ensuing media blitz (Soules, 2003: p. 297).

¹⁶ <https://www.asrm.org/> (accessed on 07/08/2019).



Similar to the 2001 ASRM campaign, other infertility prevention programmes also focus on the preservation of fertility through lifestyle choices. Of primary concern are individuals' smoking habits, food consumption, caffeine consumption, drugs intake, body mass index (BMI), stress levels, physical activities (e.g. engagement in sports) and environment. An example of an online tool that was created for the evaluation of such infertility risk factors is *FertiStat*.¹⁷ Developed by Cardiff University in the United Kingdom¹⁸, *FertiStat* was designed as a self-administered tool for women to increase awareness and knowledge of risk factors and how these may negatively affect their fertility and ability to achieve a pregnancy (Bayoumi et al., 2018). In a study on the cross-cultural comprehensiveness, feasibility and acceptability of *FertiStat* in the Middle East Bayoumi et al. (2018) found that the use of a tool to improve fertility awareness was accepted and perceived to be feasible; yet, the authors underlined the need for cross-cultural adaptation of fertility prevention-related measures, content, wording, dissemination and targeted audiences (Ibid 2018: p. 10).

The SRHR organisation Pro Familia in Colombia offers preventative services in their clinics, with a focus on fertility preservation. Pro Familia service providers inform people about preservation, STIs, lifestyle and nutrition. The clinics offer a comprehensive package that support infertility prevention such as access to contraceptives, diagnosis and treatment of STIs and safe abortion. Pro Familia also runs a Facebook Live page that contains information about preventing infertility.

¹⁷ <http://www.fertistat.com/> (accessed 12/08/2019).

¹⁸ <http://psych.cf.ac.uk/fertilitystudies/projects/> (accessed on 12/08/2019).

Main gaps in policy and practice in infertility - Burundi¹

“It is necessary that the taboo is broken, and that the veil around the infertility falls.”

The Burundi Government has a Reproductive Health policy in which infertility is included. The political will is there, which is also demonstrated by the First Lady’s personal involvement in and advocacy for the issue. Burundi however faces systemic challenges in delivering on this reproductive health policy. There are not more than 25 gynaecologist largely operating in the capital Bujumbura without much specialised equipment nor a specialised centre for fertility care in Burundi. Health insurances do not cover infertility care, not even diagnosis such as sperm count. People need to pay out of pocket.

A main challenge in Burundi is the taboo to talk about infertility. People affected by infertility then wallow in silence and seem to live in hiding because their problem cannot be expressed. There is no emotional or social support. The stigma faced by predominantly women without children alters their quality of life and exposes them to the violation of their rights. It is quite normal in Burundi for the male spouse to have extramarital relations in trying to have children elsewhere.

Another challenge is convincing sexual and reproductive health and rights (SRHR) organisations active in Burundi not leave infertility behind. Currently the Association Burundaise pour le Bien-Etre Familial, a SRHR service provider, is the only organisation that addresses infertility in Burundi. They collect testimonials from people affected by infertility which they use for advocacy for policy change.

There is lack of data and research. Students have conducted research on the psycho-social experience of couples without children and the self-image of elderly women without children.

Lastly, there is a great need for increased fertility awareness. The taboo needs to be broken in a way to address stigma, prevent infertility and encouraging people to seek care. Public education campaigns stressing that public education campaigns need to counter negative images and harmful gender stereotypes. The First Lady in collaboration with the Ministry of Health, is sensitising people on infertility. She went to all the provinces of the country, where she sensitised religious leaders, doctors and nurses.

5. ACCESS TO QUALITY INFERTILITY CARE

“Infertility care is more than IVF.”

Key infertility expert

5.1. ACCESS TO QUALITY INFERTILITY CARE: AN OVERVIEW AND IDENTIFIED GAPS

Lack of services to address quality infertility care

In many places, affordable and accessible infertility care (e.g. in term of costs, geographical reachability and availability) is lacking. Infertility services, including diagnoses are not offered in a systematic way in public health systems and the range, quality and availability of services including various fertility treatments varies (Gerrits and Shaw 2010). All key informants agreed that (affordable) quality infertility care is nearly non-existent. Even low-cost care options in the primary health care level are rare, such as diagnosis, counselling, and provision of information on infertility.

Access to fertility care is subjected to devastating inequities: infertility cuts across socio-economic status, but only the ones who can afford the often-expensive diagnosis and treatments (in the private sector) have access. Costs are often exorbitantly high and in lower-income countries in particular (Ombelet, 2009a; Gerrits 2012). Infertility diagnosis and treatment are rarely part of national insurance schemes.

Ombelet argues that the right to fertility treatments, particularly when faced with infertility issues, constitutes a human right that should be acknowledged and facilitated (2011). However, a lack of what Inhorn refers to as the ‘political will’ to include infertility on the public health agenda persists (2003). Consequently, access to infertility treatments and ARTs is often only possible through private fertility clinics, which is generally inaccessible for the majority of populations in lower-income countries (Inhorn, 2003).

The costs and the public funding and provision of health insurance for ARTs and specifically IVF treatments vary highly among countries, but in general the costs of IVF are high, which prevents many people from using this technology in order to help them conceive. LLMICs, publicly funded treatments are rarely available and, in some countries, non-existent. IVF is generally only available to the few people who can cover the costs themselves (Teoh and Maheshwari, 2014). According to Collins (2002, in Hammarberg and Kirkman, 2013), the costs of a treatment cycle is never less than half of an average individual’s annual income in any lower-income country.

Access to care is about care being available regardless of socioeconomic status and distance to a hospital (Serour and Dickens, 2001). Access to care is furthermore about having access to good quality care. Sallam suggests that to improve infertility care in low-income countries, three levels of infertility services have to be established: a basic infertility clinic (offering diagnostic tests and simple forms of infertility treatment), an advanced clinic (offering IVF and more advanced diagnostic procedures) and a tertiary-level infertility clinic (offering specialised assisted reproduction and surgical procedures). Part of this improvement is training the staff, equipping the clinics, educating the public and running the services (Sallam, 2008). Key

informants have mentioned that at the primary health care level, still a lot can be done with little investments.

Lack of available low-cost treatments

One way of offering affordable fertility treatments and ARTs is through offering low-cost options. Low-cost infertility treatments do not necessarily lead to worse results of treatments (Makuch and Bahamondes, 2014). In 2001, the WHO stated that research on low-cost ARTs is necessary (Cooke et al., 2008; Cooke, 2015). However, as key informants working in the provision of fertility treatment have shared, low cost IVF interventions are difficult to introduce in countries. Private institutions seem to work against these interventions as it can jeopardise their business. It needs back up from governments but they are often heavily lobbied by the commercial parties.

Lowering the costs of infertility care does not only include lowering the costs of IVF, but also refers to using lower-cost ARTs, such as Intrauterine insemination (IUI) (Ombelet et al., 2008a; Ombelet et al., 2010). Research in Jamaica also suggests that IUI is a cost-effective and safe option for treating subfertility in LICs (Christie et al., 2011). Part of lowering the costs of other ARTs is substituting expensive equipment, simplifying the laboratory processes and finding lower-cost ways of incubation (Asemota and Klatsky, 2015; Ombelet and Campo, 2007). In Gabon, a study was done into the effectiveness of a low-cost alternative in preparation of semen samples (a simplified sperm swim-up method) for IUI procedures. This method requires limited resources and there are no centrifugation steps needed, but is nevertheless an effective method for preparing semen samples for IUI (Moungala, 2015). A study by Franken (2015) also shows that lower-cost methods for semen analysis for IUI are possible.

Further, Richard Kennedy, president of the International Federation of Fertility Societies (IFFS), has suggested that one way of reducing costs of fertility care is through removing the 'add-ons' (ranging from antioxidants to endometrial or womb 'scratching' to preimplantation genetic screening). Instead of helping the chance for patients to become pregnant, 'add-ons' mainly raise the costs of treatments and thereby decrease the accessibility of them. Furthermore, they sometimes even increase risks to patients. Kennedy therefore suggests to go back to the basics of fertility treatments.¹⁹

While initiatives to lower the costs of ARTs and low-tech treatments may potentially be interesting to be used/reproduced in other places, a key informant working in low cost ARTs argued that an overview of efficacy, safety and cost-efficiency of the different methods is currently lacking and greatly needed.

Lack of fertility specialists

There is a general lack of fertility specialists in many low-income countries, largely as a result of the 'brain drain' of trained health and fertility physicians who move away to high-income countries (Serour, 2009). Infertility is lucrative: gynaecologists often also work in private clinics. In some LLMIC countries, public health system basic diagnosis is done. Key informants working in fertility care mentioned that patients

¹⁹ https://www.bionews.org.uk/page_134885 (accessed on 18/07/2019).

waste a lot of money to get bad or ineffective treatments. Providers do not do systematic diagnosis and give proper information on what the treatment options are. This results in people shopping around, from one sort of clinic to another sort of clinic. People are carrying around their medical dossiers without knowing what their problem is. Often there is not a good referral system (see also Gerrits and Shaw 2010).

Lack of regulatory frameworks

National regulation of ARTs and guidelines for their use in daily practice are missing in many LLMIC, which include lack of patient safety standards, frequent misconduct in providing third party assisted reproduction (gamete donation & gestational carrying) and lack of clarity on the ethics of assisted reproduction for same sex partners, single individuals and of non-medical sex selection. Laboratory standardisation and quality assurance is also an important issue that is fundamental to patient safety and cost-effective treatment outcomes. According to Fleetwood and Campo-Engelstein (2010), the lack of legal regulation is part of the reason ARTs are expensive in some countries. They say that because there is no legal regulation of ARTs (for example in the United States), doctors are allowed to set the prices for fertility treatments themselves, making the price a lot higher than the cost of services. In order to protect patients from costly care and to ensure their safety, part of improving fertility care should be regulation of fertility treatments (Murage, Muteshi and Githae, 2011). While legal regulation will not make the costs of ARTs cheap, it can make sure doctors cannot ask any price people are willing to pay.

A key informant of a global institution shared that governments are asking for guidance related to infertility treatment for LGBT couples and single parents and gestational carrying, which raise additional ethical questions it. There are no clear definitions and guidelines on these issues, which – according to the key informant - could result in not only a reluctance by governments to ARTs, but also to address infertility, even in the areas of prevention and low-cost care.

Social-cultural barriers to access

In order to increase patient-centeredness and accessibility of infertility care, several potential barriers have to be considered. Barriers may result from limited knowledge and concerns about how infertility treatments work: women in Indonesia, for example, were worried and felt embarrassed about undergoing vaginal examinations (Bennet et al, 2012). Language barriers may exist as well, for example with immigrant groups in the country they have moved to (Inhorn and Fakih, 2006). Different cultural ideas about the body and about infertility can also cause difficulties in accessing and delivering fertility treatments (Ethics Committee of the ASRM, 2015; Inhorn and Fakih, 2006), or cause frictions in (genetic) counselling appointments (Karbani, 2002). It is therefore good to have multilingual staff or interpreters to help with this issue (Ethics Committee of the ASRM, 2015), to have 'culturally skilled counsellors' (Karbani, 2002: p. 207) and to have information (whether a website, a booklet, or a video) available in multiple languages (created with involvement of people from minorities) (Culley et al., 2004). It is also important to be sensitive to other preferences from (minority) communities, such as women preferring a female physician (Inhorn and Fakih, 2006).

Other barriers in getting access and receiving care can be related with race, ethnicity or religion (Inhorn and Fakih, 2006). Karmon et al. (2011) found that African-American women in their study were more likely not

to know the cause of infertility than white American women, which they state can be because physicians have a different attitude towards infertility with different ethnic groups.

Stigma might also play a role in differences in accessing infertility care between ethnic groups, with some groups possibly having more difficulties discussing infertility in their private lives and facing more stigma (Missmer, Seifer and Jain, 2011). For couples living with HIV wanting to access infertility care stigma can also play a role. These patients can feel stigma from both family and society (and possible health care providers) for wanting to have children while being HIV positive (Volks, 2013). Additionally, Missmer, Seifer and Jain (2011) found that African-American women in their study were hesitant about accessing infertility care, as they associated this with having twins (in terms of health risk and economic and social costs). 'Social marketing' of infertility treatment may encourage hesitant people to seek medical infertility care. For example, information can be provided at religious or community centres, or on the radio/television or online (on blogs or forums for example) (Culley et al., 2004). In a workshop with fertility patients in Kenya, some participants highlighted the importance of engaging religious leaders in raising awareness for infertility (treatment) and de-stigmatisation of it (provided said religious leaders are not against ARTs) (Gerrits et al., 2017).

Lack of involving men in infertility care

While men are responsible for half of fertility impairment (Agarwal et al., 2015), responsibility (and blame) is generally put solely on women (Inhorn and Patrizio, 2015). In order to improve infertility care and accessibility and reduce stigma, it is necessary to involve men as well (Bashed et al, 2012). Otherwise, women not only unfairly get blamed for all cases of infertility, and moreover half of infertility cases will not get treated.

Male participation in infertility care

According to evaluation of various programmes in Cambodia²⁰, focusing on and providing information to both men and women increases male participation in reproductive health programmes compared to when there is no specific focus on men. Therefore, initiatives specifically addressing men are necessary if one wants to involve men in reproductive health and specifically in infertility care, prevention and de-stigmatisation.

A first step in involving men in infertility care is (the requirement of) taking a medical history and performing medical tests on both women and men in a clinic or hospital when fertility is tested (PATH, 1997). Women are recommended to come with their spouse and for health care providers to make an effort in making men come to the clinic (Kerubo Ondieki, 2012; Parrott et al., 2015). The fact that fertility is seen as 'women's business' by both men and women struggling with fertility and by healthcare professionals, discourages men to get involved (Grace et al., 2019; Onyango et al, 2010). In Kenya, it was

²⁰ http://www.policyproject.com/pubs/brochures/CAM_MaleInvolveEng.pdf (accessed on 21/07/2019).

found that the few times men did accompany their partner to the clinic, the staff would not allow them to enter the consultation room with their partner (Onyango et al, 2010).

It is important to look at the gaps of male infertility treatments and coverage, in order to find ways to improve those. According to Barratt, De Jonge and Sharpe (2018), there is a lack of progress in developing possible treatments for male infertility. They argue that ICSI is the ‘most transformative example’ for management of male infertility, but that with ICSI the burden of treatment is still on the woman, and that is thus not directly treating male infertility. They argue for the development and implementation of the ‘Male Reproductive Health Ecosystem’. This ‘Male Reproductive Health Ecosystem’ consists of: identifying and prioritising research gaps, developing a plan for closing these gaps, mobilizing strategic funding schemes, and formulating and implementing policy changes (Barratt, De Jonge & Sharpe, 2018). Considering the gaps in research on male infertility and on policies relating to male infertility is thus important in order to be able to improve those gaps and make male-factor infertility better and more accessible.

According to Joshi (2008), it is important to involve men in reproductive health because they are often key decision-makers in the lives of women in low-income countries. Having support from involved male partners is thus important for some women, both to be able to have or continue infertility treatments and to lower psychological stress through having a support system.

Health care coverage

A way of making fertility care and treatments more accessible is to include these in health insurance coverage, meaning patients do not solely pay out of pocket but that the state covers (part of) infertility treatment. According to Adamson (2009), there is improvement internationally in coverage for ARTs. Still, in most low- and middle-income countries this is not yet the case.

When infertility is classified as a disability in national laws, it could increase people’s access to fertility care. Fourie and Botes (2017) argue that if infertility would be seen as a disability in South Africa, this would require employers to “reasonably accommodate infertile employees”. This means for example providing leave for those pursuing gestational carrying or adoption. In South Africa, a disability is seen as something substantially limiting someone in his or her employment, and infertility is therefore not seen as a disability. However, WHO does classify infertility as a disability. This is also the case in the United States and Zimbabwe, where in the latter “a person is considered to be disabled when a physical disability gives rise to physical, cultural and social barriers”. Classification of infertility as a disability would thus be in line with the WHO and make sure infertile parents who choose adoption or gestational carrying to have children get the same amount of time off work as other parents.²¹

In various countries in the Middle East, there are many IVF centres, which is said to be related to the governmental support for infertility care, and treatments are fully or partially covered by health insurance. The costs of treatments are generally lower than for example in the United States or the United Kingdom,

²¹ <https://theconversation.com/why-south-africa-should-redefine-disability-to-include-infertility-71117> (accessed on 03/08/2019).

making treatments more accessible (though still not cheap compared to local incomes) even when not (fully) covered by health insurance (Sadeghi, 2015) or provided in the public sector. This is for example the case for Egypt, partly because the country has pro-natal policies and the government is eager to encourage their population to procreate (Inhorn 2009). According to Inhorn (2009) additional reasons for Egypt to subsidize ARTs, are that Egypt hosted the 'Cairo conference' in 1994 where infertility was mentioned as an important issue, and because Egypt has many highly trained IVF physicians (two of which have been president of the International Federation of Gynaecology and Obstetrics) (Inhorn, 2009). Having accessible infertility care in a LLMIC is thus possible, as Egypt proves. Recently, in various contexts more coverage of infertility treatments has been enacted, including the State of New York,²² and some African countries are offering ARTs (partly subsidized) in fertility centres in the public sector, such as in Ethiopia.

Non-Western Medicine

In some contexts and for some people collaboration between biomedical and traditional or alternative health care may have an added value. For example, it has been suggested that one way of improving infertility care is through including Chinese Medicine as complementary therapy for female infertility. Xia et al. (2017) say that 'A large number of researches have reported that CM [Chinese medicine] could alleviate or even cure female infertility' (p. 249), but that this research and evidence is not in line with those approved by Western medicine. They suggest combining Chinese and Western medicine to treat female infertility. Furthermore, they argue that Chinese medicine might help with the psychological aspect of infertility and its treatment (Xia et al., 2017: p. 249; ¹³.²³). While those solely adhering to Western medicine might not see the use of alternative medicine in treating infertility, it is valuable to consider that for some people non-Western medicine can help them feel more confident in the treatment of their infertility.

In general, the involvement / use of local healers and medicine and sociocultural beliefs (such as witchcraft for example) should be considered when aiming to treat infertility in lower-income settings. As in many countries infertility care is not only sought out from formal medical health care but also from traditional healers, traditional healers and sociocultural beliefs need to be considered in family planning, awareness, education and de-stigmatisation around infertility as well (Dhont et al., 2010; Galaa, 2006; Moyo and Muhwat, 2013; Ombet and Campo, 2007).

Psychosocial care and counselling

In addition to improving the medical-clinical aspects of infertility care, ample attention should be given to the psycho-social needs and needs for information and counselling of fertility patients (Gerrits and Shaw 2010; Ezabadi et al., 2017; PATH, 1997) Patient-centred care is seen as a practice that can improve the quality of infertility treatment, as it can improve well-being and treatment compliance (Li, Liu and Li, 2014).

²² In New York State for example, due to advocacy and negotiation, access to fertility treatment coverage was established. People in the state of New York will from 2020 have access to IVF insurance coverage and to fertility preservation before undergoing treatment for cancer or other medical treatments.

<https://resolve.org/get-involved/advocate-for-access/current-legislation/state-bills/fair-access-fertility-treatment-act-toolkit/> (accessed on 18/07/2019).

²³ <https://beingfertileprogram.com/male-factor-infertility-sl> (accessed on 22/07/2019).

Patient-centred care requires that individual circumstances and needs and social contexts are considered in the way services are offered and organised.

Peer support groups

Peer support groups are - often informal - groups of people affected by infertility that seek support and information from peers. Peer support groups can exist offline and online with people meeting face-to-face to talk about fertility issues. Support groups can be part of a larger organization or clinic or be professionally facilitated, but can also be peer-to-peer only. The level of formal organization may also vary highly, as fertility patients may not give priority to running an organization, while having to spend much of their time to fertility treatment (Radyowijati et al 2019). A recently conducted literature review on the functioning and value of (infertility) support groups showed that contact with peers through support groups can be an important part of dealing with infertility (Bushee et al, 2018): peer support can bring comfort, information, relieve feelings of distress and stigmatization. Further, Bushee et al (2018) came up with suggestions on how best to find and keep members for a support groups: having health care providers refer patients to the support group, advertise the support group, have written documentation on the emotional aspects of infertility, and create face-to-face sessions. When organizing face-to-face sessions, gender issues have to be considered: some people may prefer single-sex support groups. Furthermore, it is important that support groups are safe spaces to discuss fertility issues. Fundraising and advocacy, such as wanting to decrease the stigma of infertility in society, can also be part of a support group activities (Bushee et al 2018).

Identified gaps related to access to quality infertility care

The gaps identified in providing access to infertility care can be summarised as follows:

- In many places, affordable and accessible infertility care is lacking. Access to infertility treatments and ARTs is often only possible through private fertility clinics, which is generally inaccessible for the majority of populations in lower-income countries.
- There is a lack of availability of low-cost treatments.
- Even low-cost care options other than treatments in the primary health care level are rare, such as diagnosis, counselling, and provision of information on infertility.
- Infertility services, including diagnoses are not offered in a systematic way in public health systems and the range, quality and availability of services including various fertility treatments varies.
- Infertility diagnosis and treatment are rarely part of national insurance schemes.
- An overview of efficacy, safety and cost-efficiency of the different treatment methods is currently lacking.
- There is a general lack of fertility specialists in many low-income countries
- There is a lack of regulation, guidelines and standards for infertility treatments and care in various contexts.
- There is limited attention to male infertility and involving men in the diagnosis and care of infertility.
- Research about male infertility treatments and methods is limited and there are gaps in service coverage for men.

- Understanding and addressing of socio-cultural barriers and stigma in accessing fertility care and the added value of non-biomedical medicine in local contexts are missing.
- There is limited attention to psycho-social needs and needs for information and counselling of fertility patients, including through peer-support groups.

5.2. EXISTING INTERVENTIONS IN ACCESS TO QUALITY FERTILITY CARE

The main objectives of infertility care interventions concern the provision of low-cost infertility treatments and the training of physicians to become fertility specialists. Furthermore, a number of successful fertility care initiatives are undertaken that do not specifically aim at low-income countries, but that are nevertheless relevant to consider when thinking of how to achieve and improve access to good infertility care.

Setting global guidelines, standards and tools for providing infertility treatments

ESHRE developed guidelines for providing infertility treatment in lower-income countries. As summarised by Inhorn and Patrizio (2015), these include: "

- (i) increasing attention to infertility prevention, partly through national investments in reproductive health and sex education;
- (ii) research to improve the cost-effectiveness of infertility diagnosis and treatment, with technologies adapted to local conditions;
- (iii) modified ovarian stimulation protocols, using simplified and mild stimulation procedures or controlled natural cycles, to reduce the risks of ovarian hyperstimulation syndrome;
- (iv) single-embryo transfer to reduce multiple pregnancies;
- (v) efforts by international organizations to fund research and organise infertility diagnosis and treatment training courses in low-resource settings and
- (vi) support to governments to regulate ART practice by licensing providers, monitoring clinical activities and verifying success rates of low-cost approaches (ESHRE Task Force, 2009)."

FIGO, the International Federation of Gynaecology and Obstetrics, developed the Fertility Toolbox, which is a tool for providers of women's health care meant to increase accessibility to infertility management and prevention.²⁴ It is mainly meant for lower-income countries and can be adapted to different environments. The tools in the toolbox deal with putting infertility on the agenda, prevention, diagnosis, treatment, overcoming personal and societal barriers to infertility care and referral/termination of treatment (Adamson, 2012). The toolbox is being developed, reviewed and tested in Chile, India and South Africa in order to improve it (Adamson, 2012).

²⁴ <http://www.fertilitytool.com/> (accessed on 03/08/2019).

Provision of low-cost ARTs

The Low-Cost IVF Foundation was established independently in 2007 (Inhorn and Patrizio, 2015). Their goal was to encourage low-cost ART possibilities and to demonstrate that it is possible for the material costs for a cycle of IVF to be less than 200 euros (Vayena et al., 2009). Furthermore, the WHO developed a Rapid Assessment Tool that countries can use to evaluate what resources are required to establish a national infertility management programme (Cooke, 2015).

Another organisation is the non-profit organisation the 'Walking Egg Project' (Inhorn and Patrizio, 2015). It was founded to increase global access to infertility care, as mentioned in the Arusha project (Dhont, 2011). One of their aims is to simplify techniques of diagnosis of infertility, by introducing a system for 'one-day diagnosis' (Ombelet, 2014). The Walking Egg Project – gynaecologist. Ombelet and embryologist Van Blerkom - has also developed a simplified IVF laboratory technique to fertilise eggs (the 'tWE laboratory method') (Ombelet, 2014). With this simplified method, the IVF laboratory is reduced to an aluminium heating block containing one pair of test tubes for each embryo (inside a shoebox-sized container).²⁵ Costs related to building an IVF laboratory would be decreased by at least 80% when using the tWE lab system (Ombelet, 2015). Trials suggest that this low-cost method does not compromise IVF outcomes (Klerkx et al. 2013; Van Blerkom et al., 2014). Training local staff – embryologists and IVF-doctors – forms part of the tWE plan of action. The plan was to introduce this tWE in a number of low-income countries, including for example in Ghana (Gerrits, 2016). However, the successful introduction of the tWE method is hampered by a number of reasons, including countering forces in countries that see low-cost ART interventions threatening their business. Currently tWE is developing and testing a new methodology and designing a mobile fertility truck/ satellite system, in the hope to reach more couples.

Another initiative is the North American-based non-profit organisation 'Friends of Low-cost IVF' (FLCIVF) founded in 2011. The charity aimed to establish high-quality infertility care in public hospitals, train local medical staff to provide low-cost IVF services and monitor the success rate of low-cost IVF (Hammarberg and Kirkman, 2013). The non-profit organisation developed a simplified ovarian stimulation protocol without the use of injectable gonadotrophins, which can be used together with simplified IVF techniques. In 2015, programmes from the FLCIVF had been successfully implemented in Mexico, and later on in Sudan and Trinidad (Inhorn and Patrizio, 2015).

An organisation aiming to encourage health professionals to develop and use simplified ART protocols is the British International Society for Mild Approaches in Assisted Reproduction (ISMAAR). This society was established in 2007. They promote education, training and research on the topic of simplified ARTs and argue that simplified approaches to ARTs furthermore tackle concerns around high costs, multiple birth and long-term health risks for women who undergo treatment (Vayena et al., 2009).

A solution that is both low-cost and low-tech is the approach to IVF by Kevin and Kathy Doody from the United States, who developed a device called INVOcell. Doctors combine the eggs and sperm inside this

²⁵ <https://www.bbc.com/news/health-27814124> (accessed on 18/07/2019).

device (which is about the size of a wine cork and made of clear polystyrene), and is then inserted into the patient's vagina. The device stays here for around five days, after which the device is removed and the fertilised egg is placed in the woman's uterus. The FDA approved this technology in 2014. In the United States the INVOcell cuts IVF expenses in half. Furthermore, it gives patients more of a sense of control over the process, reduces clinic visits and might lead to missing fewer workdays. INVOcell might be a useful way to reduce costs of IVF and offer IVF to people not being able to visit a clinic or hospital as frequently as with IVF normally.²⁶ Huyser (2008) suggests that once INVOcell is tested and accepted in HIC's, this might be a useful low-cost solution for LIC's as well.

Other initiatives relate to mobile IVF-ICSI clinic and laboratory to the Beka'a Valley in Lebanon as part of the LCIVF Movement. The Beka'a Valley is an area of Lebanon with limited electricity supply and road access, and many Syrian refugees have come to this part of Lebanon. While the mobile clinic acknowledges that the success rates of mobile care are lower than those of Beirut-based laboratories, he argues that these lower success rates are better than those patients having no access to IVF-ICSI at all.²⁷

At the fertility clinic of the Tygerberg Academic Hospital in South Africa, Thabo Matsaseng (Head of the Reproductive Medicine Unit at Stellenbosch University) has initiated offering IVF for less than a quarter of the price of the treatment at most private clinics. He has achieved this by lowering clinic and administration fees, lowering hormone doses (to stimulate ovulation), using local anaesthetic instead of more expensive and complicated general anaesthetic and through having optimum utilisation of trained personnel (De Beer et al., 2016).²⁸

Involvement of men in infertility care through hotlines and mHealth solutions

Hardee, Croce-Galis and Gay (2017) suggest that having a family planning hotline (a telephone helpline) is a promising way to involve men in reproductive health. Both in India (Malde, 2005, in Hardee, Croce-Galis and Gay 2017) and Congo (Kasongo and Ligne Verte, 2016, in Hardee, Croce-Galis and Gay 2017) the large majority of calls to the existing family planning hotlines comes from men, and one of the topics often asked about is infertility. In Myanmar a reproductive health hotline was established to provide reproductive health information with both men and women calling in equal proportions. Medical doctors answered the calls and infertility was the most asked about topic. The majority of callers asking about infertility were women (Ko-Ko-Zaw et al., 2011). These and mHealth programmes, such as the Russian initiative mentioned before, are reproductive health initiatives where a large percentage of participants are male (Hardee, Croce-Galis and Gay, 2017) and might thus be an interesting and relatively low-cost way to involve more men into reproductive and infertility care.

²⁶ <https://www.dmagazine.com/publications/d-ceo/2019/january-february/from-north-texas-a-low-tech-fertility-solution-goes-viral/> (accessed on 18/07/2019).

²⁷ <https://journalofethics.ama-assn.org/article/lower-quality-clinical-care-ethically-justifiable-patients-residing-areas-infrastructure-deficits/2018-03> (accessed on 21/07/2019).

²⁸ <https://bhekisisa.org/article/2018-05-09-should-government-health-schemes-pay-for-infertility-treatment/> (accessed on 21/07/2019).

The initiatives mentioned earlier that provide (low-cost) at-home testing for male infertility (such as ExSeed and the one designed by Harvard Medical School) are also ways to include men in fertility management. The obstacle of visiting a clinic is avoided, and men are encouraged to assess their own fertility status. Another initiative which could “empower men to take control of their fertility” is Dadi. With this service, men receive a kit for \$99.99 (which includes a cup and a preservative), for sending sperm to test at a lab. They receive results within a few days. It educates people about male infertility and aims to normalise the conversation on reproductive health of men and for men to test their fertility in convenient way.²⁹ While the price is likely too high for many people to access it in LICs, a similar lower-cost initiative might be possible to develop in order to involve men more in fertility testing.

Provision of alternative and natural treatments

A possible alternative when medical care is not available, or not accessible for either for financial or ethical reasons (as procreating through medical technologies instead of through sexual intercourse is not in line with some religions) is the use of natural therapies. These can include lifestyle changes (e.g. losing weight, reducing stress, acupuncture), tracking one's menstrual cycle and time of ovulation, and taking fertility medications and hormone injections. In Singapore, for example, one can sign up for a 'natural fertility programme' at a (private) clinic to achieve pregnancy without ARTs. While this private clinic probably is not low-cost, natural therapies might provide an (albeit not equally effective) alternative for those not able to access medical treatments.³⁰

Access to at-home alternatives (digital)

Other initiatives of low-cost testing or infertility treatment are solutions that bring treatment to people's homes. They often are not specifically designed for LICs, but the fact that the costs of these tests or treatments are relatively low and the fact that less distance needs to be travelled (and thus time to be spent) to access them makes them potentially interesting for people in low-income countries. Many of these low-cost test and education options depend on smartphones. While this means these tools are not accessible to everyone, according to Grace Health's Ms. Mannheimer “1.9 billion women in low to middle income countries own their own phone, making the phone a tool for freedom”, making them perhaps more accessible than treatment options at clinics and hospitals.¹²

At-home alternatives to test and track one's fertility (male and female) with smart phone apps are – among others - made available by Harvard Medical School³¹, the company ExSeed³², BluDiagnostics,³³³⁴ and Grace Health³⁵.

²⁹ <https://www.psfk.com/2019/02/interview-dadi-male-fertility.html> (accessed on 21/07/2019).

³⁰ <https://www.straitstimes.com/lifestyle/couples-go-for-natural-therapies-instead-of-ivf> (accessed on 21/07/2019).

³¹ <https://www.mobihealthnews.com/content/harvard-researchers-develop-low-cost-smartphone-based-male-fertility-test> (accessed on 18/07/2019).

³² <https://www.exseedhealth.com/> (accessed on 18/07/2019).

³³ <https://uxdesign.cc/bludiagnosics-a-ux-case-study-df3a7dd54998> (accessed on 18/07/2019).

³⁴ <https://www.bludiagnosics.com/> (accessed on 18/07/2019).

³⁵ <https://www.raconteur.net/healthcare/femtech-africa> (accessed on 18/07/2019).

Grace Health is particularly relevant as it is an organisation targeting LICCs in combining smartphone usage and women's health and awareness and understanding of fertility issues (so-called 'femtech'). This company provides period and fertility tracking via the Facebook Messenger platform. Users of Grace Health can ask questions about their own health and can track and monitor their symptoms, feelings and energy levels in order to track their period and fertility. Grace Health is meant for both those trying to get pregnant and those trying to avoid pregnancy. They started their service in Ghana but have spread to fifteen more countries since their launch.³⁶

A similar tool is Dubai-based Nabta Health. This was the first initiative dedicated to targeting women's reproductive health across North Africa and the Middle East.¹¹ In China, one of the most popular apps to track the ovulation and menstruation is Fengkuangzaoren ('Crazy for making babies'). This app also has an algorithm-powered IVF assisting tool, which predicts the total cost and success rate of IVF, and it functions as a broker for clients with local and overseas clinics.³⁷

In Australia, the website YourFertility is a national public education programme funded by the Fertility Coalition. On the website, information can be found about fertility and how to improve chances of having a baby (for example related to age, weight and lifestyle).³⁸ These websites and apps can be a low-cost option for providing education and advice on infertility.

Other initiatives that aim to offer infertility services outside of hospitals and clinics are the Kindbody's 'Fertility Bus' in the United States. The mobile clinic offers women a free blood test for the anti-Müllerian hormone (AMH) to assess one's ovarian egg reserve and then advises women to go their brick-and-mortar clinic and undergo a full fertility assessment where they may end up freezing their eggs (for \$6,000 per egg-freezing cycle). While Kindbody's 'fertility bus' has been criticised as "capitalising off women's fear of infertility", the idea of bringing initial fertility testing to the people instead of people having to go a clinic can be seen as an interesting way to improve accessibility of fertility treatments.³⁹

Another initiative is making contact between physician and patient possible through phone or through the Internet (telehealth). In Australia's region New South Wales, for example, patients can have a phone or video consultation with IVF Australia's fertility specialists. This is particularly for patients who live in remote or rural areas, and aims to reduce travel time and expenses and thereby improve access to fertility care.⁴⁰

³⁶ <https://www.raconteur.net/healthcare/femtech-africa> (accessed on 18/07/2019).

³⁷ <https://edition.cnn.com/2018/05/07/health/china-infertility-intl/index.html> (accessed on 21/07/2019).

³⁸ <https://www.yourfertility.org.au/> (access on 06/08/2019).

³⁹ <https://techcrunch.com/2019/04/16/kindbody-raises-15m-will-open-a-fertility-bus-with-mobile-testing-assessments/?guccounter=1> (accessed on 18/07/2019).

⁴⁰ <https://www.ivf.com.au/fertility-treatment/regional-online-fertility-consult> (accessed on 18/07/2019).

Training of medical personnel

Merck's More Than A Mother aims to improve quality of fertility care.⁴¹ Merck Foundation is the philanthropic arm of Merck KGaA Germany.^{42,43,44} Their More Than A Mother campaign attempts to break the silence around infertility and destigmatise infertility, but furthermore attempts to "improve access to quality and safe fertility care across the African continent".⁴⁵ Part of this goal is the clinical and practical training of embryologists and fertility specialists, and health care providers in general, in Asian and African countries, to create local experts on fertility care.^{46,47,48} The Merck More Than A Mother campaign started in Kenya, but has now been introduced in various countries, such as Guinea⁴⁹, Burundi, Ghana and Mali, where the first ladies of said countries are ambassadors of Merck More Than A Mother.⁵⁰ Merck also aims, in collaboration with IFFS, to provide more basic fertility services in public hospitals across Africa, such as removing fibroids or treating infections.⁵¹

Over time various partnerships have been created between health and training institutes from HICs and LICs, mainly to train professionals working in infertility care. For example, such collaboration exists between health professionals from Zimbabwe and ARTs experts from Australia and Italy. The health staff from Zimbabwe also acquired some new equipment, and they are currently offering treatments (Hammarberg et al., 2018).⁵² A similar partnership programme for maternal and reproductive health research more broadly between the Gambia and Norway has existed since 1993, leading to improvement in health care (Sundby and Cham, 2009). The Department of Obstetrics and University of Stellenbosch in South Africa have since 1997 offered five-day hands-on semenology workshops to 87 health care workers from 16 African countries, in conjunction with WHO's Special Programme of Research, Development and Research Training in Human Reproduction. (Franken and Aneck-Hahn, 2008). Another programme aimed at improving the quality of gynaecology care in lower-income countries is the evidence-based structured training programme for health care workers 'Essential Gynaecological Skills' of Royal College of

⁴¹ https://www.merck-foundation.com/MF_MainPage?startURL=%2FServlet%2FServlet.FileDownload%3FURL%3D%252Fapex%252FMF_NewsReleases%253Fshowall%253Dtrue%26file%3D00Pw000001MAELBEA5%2B- (accessed on 19/07/2019).

⁴² <https://www.merckgroup.com/en/expertise/fertility.html> (accessed on 19/07/2019).

⁴³ <https://www.africanews.com/2019/04/18/merck-foundation-with-african-minister-of-health-defines-interventions-to-break-infertility-stigma-at-international-federation-of-fertility-societies-iffs-world-congress-in-china/> (accessed on 19/07/2019).

⁴⁴ <https://www.businessdailyafrica.com/lifestyle/society/Rasha-Kelej--An-Infertility-Advocate/3405664-5035860-mfxlap/index.html> (accessed on 19/07/2019).

⁴⁵ <https://www.kbc.co.ke/merck-unveils-safe-fertility-training-for-africa/> (accessed on 18/07/2019).

⁴⁶ <https://www.youtube.com/watch?v=uEla4dAiEzW> (accessed on 19/07/2019).

⁴⁷ <https://stories.for-africa.com/merck-foundation-partners-strongly-with-malaysia-after-success-stories-in-india-and-indonesia-441fd8a69ec1> (accessed on 29/07/2019).

⁴⁸ <https://www.bizcommunity.com/Article/196/342/141890.html> (accessed on 19/07/2019).

⁴⁹ <https://www.businesstoday.in/pti-feed/merck-foundation-partners-with-the-first-lady-of-guinea-to-build-healthcare-capacity-and-break-infertility-stigma-in-the-country/story/356031.html> (accessed on 18/07/2019).

⁵⁰ <https://www.thesierraleonetelgraph.com/merck-foundation-to-help-build-healthcare-capacity-in-senegal/> (accessed on 19/07/2019).

⁵¹ <https://www.klcc.org/post/merck-wants-empower-infertile-women-africa-can-music-videos-help> (accessed on 19/07/2019).

⁵² <https://ivfzim.com/> (accessed on 07/08/2019).

Obstetricians and Gynaecologists (Fawzi, 2018).⁵³ In Eritrea, with the support of Hammer Form, a German NGO, two one-week intensive training courses for physicians on gynaecological endocrinology and reproductive medicine were given at the Orotta National Referral Maternity Hospital in Asmara (Gnoth, Kaulhausen and Marzolf, 2013). In Brazil, a study was done to improve patients' self-medication performance with the help of nurses. Educating nurses on helping patients with their daily treatment injection might be a useful way to improve healthcare and reduce patients' anxiety (Costa et al., 2014).

Provision of Equipment

Next to training (new) fertility specialists, what helps in improving infertility care as well is having access to better or more equipment. Research by Omer (2009) suggests that a new gynaecological laparoscopy unit in Omdurman Maternity Hospital in Sudan is a real addition to the improvement of gynaecological surgery. Laparoscopy is possible with basic equipment and skilled staff from the country itself, making it a lower-cost alternative to IVF and embryo transfer (Badejoko et al., 2013). In Nigeria there was also a successful attempt to establish a low-cost hysteroscopy unit. Despite being low-cost, the hysteroscopy unit works well, and thus suggests that it is possible to replace expensive equipment with lower-cost innovative alternatives in low-income countries (Okohue and Okohue, 2018).

The University of Benin Teaching Hospital infertility management programme in Nigeria was implemented with a grant of the WHO. The pregnancy outcomes of the IVF treatments are similar to the rest of the world. Part of the programme's way to save costs is batching, which means that the menstrual cycles of patients in a specific batch (consisting of about 30 couples) are made to begin within 4 to 5 days of one another. This way, multiple patients can be treated at the same time, making purchasing fresh drugs in bulk possible, making having low staff possible and making inviting an experienced consultant embryologist for the week of treatments possible (Orhue et al., 2012).

Health records

Furthermore, in the last decade some initiatives have been developed to improve, health record systems, in order to have better insights into patient's information and into infertility data from a whole clinic or country. Reporting of treatment outcomes, complications and effectiveness rates are relevant for patients to make informed choices about infertility treatments and clinics (Van Zandvoort, De Koning and Gerrits 2001). Since 1989, an international reporting system exists on ARTs, organised by the International Committee Monitoring ART (ICMART). The data come from clinics, and then go to national, regional, and the world registry (Vayena et al., 2009). In South Africa steps have been taken to design and introduce a user-friendly electronic health record system for infertility clinics, as part of South African Register of Assisted Reproductive Techniques (Coetsee, Kruger and Vine, 2014). An initiative such as this is also relevant in order to improve international reporting and surveillance of ARTs.

ANARA, the African Network and Registry for Assisted Reproductive Technology, led by Dr. Silke Dyer, also

⁵³ <https://www.rcog.org.uk/en/global-network/centre-womens-global-health/our-work/essential-gynaecological-skills/> (accessed on 26/07/2019).

aims to collect data from ART centres. All ART centres in Africa are invited to be part of the initiative. The goal is to know more about the extent and outcomes of ARTs in Africa. Currently 18 countries and 72 clinics are included.⁵⁴

Provisions of psychosocial care and counselling

“Counselling is always essential”, irrespective of “how wide or how limited a clinic’s treatment options may be” (PATH, 1997: p. 5). Even when a limited number of patients (can) become pregnant, counselling helps couples understanding and coping with infertility. ESHRE has developed a guideline for fertility staff for providing routine psychosocial care. These guidelines address needs for care both before, during and after treatment. The needs addressed can be behavioural, relational, emotional and cognitive. Various studies point to the positive effect of counselling, group therapy or (partnership) support programmes on psychological well-being (Chegedekova, Khismetova and Turgambayeva, 2017; Mosalanejad and Koolee, 2013; Ramezanzadeh et al., 2011; Terzioğlu and Özkan, 2017), marital relationship and/or sexual satisfaction (Asazawa, 2015; Khoramabadi, 2015; Vizheh et al., 2013; Vizheh and Pakgohar, 2013), and some studies even argue that there is a connection between counselling or psychiatric interventions and pregnancy rates for infertile patients (Maleki-Saghooni et al., 2017; Ramezanzadeh et al., 2011).

A number of studies report on the results of professional training programmes in infertility counselling, respectively in Hong Kong, to create awareness about sensitive issues patients are confronted with during their fertility treatments (Chan et al., 2013); in Turkey, to improve nurses’ and midwives’ knowledge of infertility and enable them to offer emotional support and counselling (Isbir and Ozan, 2018); and in Brasil, to identify infertility patients in need of extra psychosocial support (Franco et al., 2002), or are directed to appropriate psychological care (Li, Liu and Li, 2014).

Other studies reviewed the effect of self-help interventions - including mindfulness and Traditional Chinese Medicine - for psychological well-being of women undergoing IVF treatment in Hong Kong and China (Wong et al., 2016; Wong, Chan and Tam, 2017; Bai et al., 2019; Hu et al., 2016; Li et al. 2016). These - seemingly - effective self-help interventions are relatively low-cost and flexible, and do not require much training or time from the staff of the clinic. ‘Support cards’ as used in Japan for women to handle feelings after a miscarriage, may also be an interesting tool to be adapted for women - and men – confronted with problems to conceive (Fukushima et al. 2014). An alternative support card with information on emotions and ways of dealing with those emotions after getting the infertility diagnosis might be useful.

Peer Support (Groups)

Next to counselling there are other ways in which infertile patients are offered support. An example of support where attention to mental and physical health is combined is the Russian initiative 'mHealth programme' for people undergoing ARTs. In this programme, there are opportunities for interaction with both peers and experts through social networks, online and offline seminars with reproductive health specialists at clinics and text messages to participants’ mobile phones. Online contact is thus an important

⁵⁴ <http://anara-africa.com/> (accessed on 07/08/2019).

way of being able to get both support and information, from both experts and people who are in a similar situation.⁵⁵ There are various initiatives worldwide that focus on creating an online community to discuss infertility and collect research, education, resources, and training. Examples are BeiBei Haven Foundation⁵⁶ in Nigeria, Joyce Fertility Support Centre⁵⁷ in Uganda, ACCOG⁵⁸ in Ghana, FFF⁵⁹ in Kenya and PTPH Support Group (Radyowijati et al 2019) in Indonesia. With some of them religion is a key factor of the community, such as with the Muslim Fertility Project⁶⁰ and Project Pomegranate⁶¹.

Main gaps in policy and practice in infertility - Jordan¹

“When a tree does not produce, we should cut it.”

In Jordan there is limited awareness on infertility. It is not part of a public debate or part of information provision by medical providers. The government does have policies around planning families, but these are only focusing on access to contraceptives. The constitution of the Government of Jordan does not contain the right to health. The government fears that they will be obliged to provide (high-cost) services, once they develop laws and policies related to infertility.

Infertility care is offered in Jordan, but not in the public sector through the Ministry of Health. There is an injustice in who can access the services and who cannot. Some insurance companies cover assisted reproductive technologies, however only for one round and for couples without any children. If a couple already has one or more children, access to ARTs is not covered. Services also tend to be gender-biased, with female patients being less informed by providers than male patients.

The stigma is heavy on the women. “When tree does not produce, we should cut it.” It is assumed that the woman is the main cause of the inability to have children. The man will find another woman, or is pressured to do so by his family. This is considered to be “the less expensive option”. Couples are suffering and there are cases of divorce and intimate partner violence.

For couples that will not have access to infertility care or when the treatment has failed, alternative options need to be sought, including foster children and adoption. However, in Jordan’s cultural and religious context, adoption is not socially acceptable.

Finally, a main gap is the lack of data. There is a general lack of understanding about infertility, its prevalence and its impact. Data and research will help in provoking public debates and advocate for policy change.

⁵⁵ <https://www.healthynewbornnetwork.org/blog/russian-ngo-launches-mhealth-infertility-support-program/> (accessed on 18/07/2019).

⁵⁶ <https://www.beibehaven.org/> (accessed on 25/08/2019)

⁵⁷ <https://www.facebook.com/pg/JoyceFertilitySupportCentreUganda/about/> (accessed on 25/08/2019)

⁵⁸ <https://www.facebook.com/accog.ghana> (accessed on 25/08/2019)

⁵⁹ <https://footstepsforfertility.org/> (accessed on 26/08/2019)

⁶⁰ <http://www.muslimfertilityproject.com/> (accessed on 18/07/2019).

⁶¹ <http://projectpomegranate.org/> (accessed on 18/07/2019).

6. STIGMA RELATED TO INFERTILITY

6.1. STIGMA RELATED TO INFERTILITY: AN OVERVIEW AND IDENTIFIED GAPS

The value attached to parenthood and having children is of great importance for many women and men worldwide. In many low and lower-middle income countries, cultural expectations to procreate and continue the family lineage exist and, as pointed out by Hesari et al., infertility is a significant multidimensional issue that can affect individuals' and couples' physical, emotional, sexual and social health (Hesari et al., 2019: p. 119).

The failure to meet these expectations is commonly seen as a mark of disgrace and infertility carries much social stigma in many communities. Individuals who are infertile and/or remain childless may experience discrimination, a loss of identity, isolation, assault, ostracism and/or physical as well as psychological violence (Hollos and Larsen, 2008: p. 162). Hence, depending on one's socio-cultural context, the inability to achieve pregnancy is often coupled with low confidence, depression, sexual problems, feeling of shame and/or guilt, a lack of communication with friends and family members and occupational challenges (Jafarzadeh-Kenarsari et al., 2015: p. 82). Moreover, infertility is often accompanied by financial stress as the costs of infertility treatments tend to be high and because many families in low-income countries depend on their children for economic survival (Hammarberg and Kirkman, 2013: p. 191). Hence, infertility is not just a medical problem but also a social, gender and public health matter.

Due to an increasing awareness of the repercussions of stigma of infertility in LLMIC, more and more authors are calling for de-stigmatisation efforts. Suggested activities include, but are not limited to, education and awareness raising, counselling, support groups and campaigns.

In a different vein, Inhorn and Patrizio (2015) underline the importance of access to ARTs, as a means to destigmatise infertility in LIMCs and to change gender relations in a positive (see box).

In many developing countries, the introduction of ART has created new hope for infertile couples, encouraging them to remain together. Overall, access to ART appears to be changing gender relations in several positive ways through: (i) increased knowledge of both male and female infertility among the general population; (ii) normalisation of both male and female infertility problems as medical conditions that can be overcome; (iii) decreased stigma, blame and social suffering for both men and women; (iv) increased marital commitment as husbands and wives seek ART services together and (v) increased male adoption of ART, especially for male infertility problems.

Source: Inhorn and Patrizio (2015)

Stigma around male infertility

One element that discourages men from being involved in fertility awareness and care is the stigma around male infertility. Men need to become part of infertility care in order for male infertility to become less stigmatised (Inhorn and Patrizio, 2015; Kamau, 2011). Inhorn and Wentzell (2011) see this as a form of

'emergent masculinities': "ongoing, context-specific, embodied changes within men's enactments of masculinity, particularly as they encounter emerging health technologies" (p. 802). This concept contrasts with Connell's (1995) 'hegemonic masculinity', the ideal form of masculinity in a particular context that men attempt to adhere to. New ways of engaging with reproductive health and reproductive technologies are thus connected to new ways of 'being a man' and challenge existing social norms (Inhorn and Wentzell, 2011; Inhorn and Birenbaum-Carmeli, 2009).

According to Inhorn (2012a) learning from attitudes on male infertility in the Middle East is helpful. Efforts from the government (making infertility treatment more accessible through public financing), medical progress (offering advanced medical treatments and making male infertility a medical problem instead of a problem of masculinity), and religious permissions (Islamic clerics were some of the world's first religious leaders to approve of IVF) helped in making male infertility treatment more accessible in the Middle East.⁶² Many men in her studies acknowledge and take responsibility for their own reproductive impairments and are willing to seek treatments, instead of holding women responsible for fertility and conception (Inhorn, 2012a; Inhorn, 2012b; Inhorn, 2018). Furthermore, they are becoming increasingly open in telling family, friends and colleagues about their infertility problems. This openness about male infertility can lead to the de-stigmatisation of male infertility, which Inhorn argues other countries and areas can learn from.⁷

Identified gaps related to addressing stigma around infertility

The gaps identified in addressing stigma related to infertility can be summarized as follows:

- Infertility/childlessness stigma is silenced, key informants know of little interventions in LLMIC that address infertility stigma at community level, or interventions that challenge the dominant norms around fertility and motherhood.
- There is a lack of information and studies on the socio-cultural meaning of infertility that can inform policies and programmes.
- In addition, there are few infertility support groups that are supported in addressing the stigma in their communities.
- There are dominant norms about masculinity and stigma related to male infertility, which contribute to limited seeking of information and care by men, and to blaming and ostracising women.

6.2. EXISTING INTERVENTIONS THAT ADDRESS INFERTILITY STIGMA

Increasing awareness

An example of an initiative that aims to increase awareness around infertility is the *National Infertility Awareness Week* in the United States, which is organised yearly. The National Infertility Awareness Week has a different theme each year and is part of the organisation RESOLVE, the National Infertility Association

⁶² <https://www.nytimes.com/2017/10/21/opinion/sunday/male-infertility-middle-east.html> (accessed on 21/07/2019).

of the United States.⁶³ Another example is the American initiative 'Fertility For Colored Girls', an organisation that raises awareness of infertility issues and specifically targets black women and couples struggling with infertility.^{64,65} Fertility For Colored Girls offers an interesting combination of online and offline forums, where peers can meet each other but new people can also be introduced to the group and the topic.

Online communities, and social media platforms and tv programmes are important media to provide information to individuals struggling with infertility but also to raise awareness. An example of an influential TV programme is 'The UFO Fertility Show', which is a Chinese wildly popular television show set in a future when aliens have travelled back to Earth via UFO to explore why the human race is perishing. In a way, the show raises awareness of infertility and the first two episodes alone have attracted 46 million views altogether online.⁶⁶

Addressing stigma related to male infertility

An initiative that aims to do this is Merck (their More Than A Mother project was mentioned earlier). Through the 'Fertility is a Shared Responsibility' initiative Merck wants there to be acknowledgement in society and from men themselves about male infertility and the role of male partners in a couple's infertility. As women tend to be seen as responsible for the couple's infertility, raising awareness about male infertility might correct this idea and the stigma that comes with it for many women.⁶⁷

The male initiator of the Association of Childless Couples of Ghana (ACCOG) referred to the stigma decreasing effect of his television appearances (Gerrits 2015).⁶⁸ Various male celebrities have spoken out about their struggles with infertility open up the discussion, create awareness and decrease stigma.⁶⁹

Working with role models and influencers

Moreover, influential people sharing their personal infertility stories also helps normalise the prevalence of infertility, the use of ARTs and involuntary childlessness and consequently aid de-stigmatisation efforts. Examples of prominent influencers who have shared personal infertility stories are former First Lady of the United States Michelle Obama,⁷⁰ First Lady of Namibia Monica Geingos,⁷¹ infertility blogger Vanessa Haye,⁷²

⁶³ <https://resolve.org/> (accessed on 20/07/2019).

⁶⁴ <https://www.fertilityforcoloredgirls.org/> (accessed on 18/07/2019).

⁶⁵ <https://www.oprahmag.com/life/health/a22799911/infertility-support-groups-black-women/> (accessed on 18/07/2019).

⁶⁶ <https://edition.cnn.com/2018/05/07/health/china-infertility-intl/index.html> (14/08/2019).

⁶⁷ <https://africanexecutive.com/article/read/8481> (accessed on 19/07/2019).

⁶⁸ <http://accog.com.gh/vision-mission/>

⁶⁹ https://www.huffpost.com/entry/male-celebrities-help-destigmatize-male-infertility_b_594bee3ae4b07cdb1933c06d?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2x1LmNvbS8&guce_referrer_si_g=AQAAAGdw7eZ_f0Yna9Vx-xDmZjyBQY13GzpzRnr4uEJhkPba3GeumOyTIFOXxeYe6saQOBMMynqvs-S4l80nMgl-y-O-EykEOcTVjxf6ina5kb4S5zR_Xqx9Wc4mKZe1100VQXOHDIO6o5BqNcb7NDiV7HA9vpAzbVPsQsqzDJJCmTWt (accessed on 06/08/2019).

⁷⁰ <https://www.washingtonpost.com/politics/2018/11/09/michelle-obama-is-one-millions-who-silently-struggled-with-infertility-heres-why-her-broken-silence-could-matter> (accessed on 06/08/2019).

⁷¹ <https://www.namibian.com.na/189681/archive-read/Break-infertility-stigma-%E2%80%93-Geingos> (accessed on 06/08/2019).

⁷² <https://www.bbc.com/news/av/health-48227027/blogger-there-is-a-stigma-around-infertility> (accessed on 06/08/2019).

and American television host Jimmy Fallon.⁷³ Their stories have gone on to touch many and helped break the silence on infertility.

The one organisation that actively seeks to fight the stigma of infertility in LMIC is the *More Than a Mother Project* by the Merck Foundation, a non-profit foundation founded by Merck - a pharmaceutical company that develops and offers infertility treatments.⁷⁴ The project addresses the need for interventions to reduce stigmatisation and social suffering of infertile women as well as the necessity for a team approach to family building among couples.⁷⁵ On their website, they offer a wide range of resources that are useful when trying to raise awareness and break the stigma of infertility. These resources include brochures, posters, a theme song, videos, publications and news updates. Particularly the video interviews with women who share their personal infertility stories and speak of the range of struggles they face - and in some cases overcame - are powerful⁷⁶.

Using art for awareness raising

Through art projects, large audience can thus be reached - both offline and online. This can be very influential when trying to break with the stigma of infertility. The Walking Egg collaborates with the famous artist Koen Vanmechelen, who has produced the symbol of The Walking Egg – an enigmatic glass egg with chicken legs – lithos of which can be bought to support the Walking Egg⁷⁷.

Various artists from the United Kingdom have used art to break the silence around infertility. Examples of their work include the embroidery of symbols of fertility on gowns worn during IVF treatment (Tabitha Moses), a photography project called *Photos I'll Never Take* where traditional family photos are made with a doll instead of a child (Tina Reid-Peršin), and the photographic project *SEED* where photographs are taken of crucial moments of infertility treatment (Sophie Ingleby).

The works of these artists were on display at Fertility Fest.⁷⁸ This is an arts festival dedicated to fertility and infertility. The goal of the festival is to use arts (theatre, dance, music, visual art, film and literature) to improve understanding of the emotional struggles of people having fertility issues, to improve the public conversation on infertility and reproductive science, and to improve fertility education.⁷⁹ Another example of an art project aiming to raise awareness around infertility is the United States based 'The ART of Infertility' with similar aims.⁸⁰ It travelled around the world with exhibits on the topic of infertility as well as

⁷³ <https://www.businessinsider.com/jimmy-fallon-reveals-fertility-struggle-2013-8?international=true&r=US&IR=T> (accessed on 06/08/2019).

⁷⁴ <http://www.merckmorethanamother.com> (accessed on 25/07/2019).

⁷⁵ http://www.merckmorethanamother.com/about_merck_more_than_a_mother.php (accessed on 9/08/2019).

⁷⁶ However, on a critical note: one of the videos showing the stigmatization of an infertile woman, ends with the 'happy end' that she gets pregnant by means of medical treatment. This questions the core message of the Merck campaign: is she really more than a mother?

<https://www.youtube.com/watch?v=bbNoawQlcBg>

⁷⁷ <https://thewalkingegg.com/sponsor>

⁷⁸ <https://www.stylist.co.uk/life/meet-the-artists-exploring-the-invisible-struggle-of-infertility-fertility-fest-2018/205895> (accessed on 15/08/2019).

⁷⁹ <https://www.fertilityfest.com/> (accessed on 15/08/2019).

⁸⁰ <https://www.facebook.com/artofinfertility/> (accessed on 14/08/2019).

offers innovative healthcare curriculums incorporating oral histories and artwork, and organised art and writing workshops for those suffering from infertility or reproductive loss.⁸¹⁸² Part of their goal was to facilitate conversations between physicians and patients (Walker and Novotny, 2016). Similarly, 'Infertility Illustrated' is an art project by Christine McDonough who sketches and illustrates the 'average day in the life of someone dealing with infertility'.⁸³ Her work has a following of nearly thirteen thousand users on Instagram.⁸⁴

Using art for expression

In addition to reaching large audiences and breaking with the silence around stigma, artistic activities can also serve as a form of expression to address and understand people's infertility experiences. *DrawingOut*, for example, is a participatory visual research method that entails a one-day metaphor-centered drawing workshop to collect visual and textual data about health-related topic, among which infertility (Gameiro et al., 2019: p. 3; James 2019). In a study by Gameiro et al., participants struggling with infertility found the drawing appealing and enjoyable, making it easier for them to talk about such a commonly stigmatised and distressing topic (2019: p. 9). While all these projects and initiatives are wonderful and help break the silence on fertility in ways that extend beyond borders, they are all located in and generally focused on people in Western countries. Very few initiatives are undertaken to do the same in LLMICs, though in several places – e.g. in Kenya – churches address the issue of infertility (Kamau, 2011; Gerrits et al 2016).

⁸¹ <http://www.artofinfertility.org/> (accessed on 18/07/2019).

⁸² <https://medhumdosis.com/2018/10/17/feature-the-art-of-infertility-a-community-project-reimagining-reproduction-advocacy/> (accessed on 18/07/2019).

⁸³ <https://infertilityillustrated.com/> (accessed on 15/08/2019).

⁸⁴ <https://www.instagram.com/infertilityillustrated/> (accessed on 15/08/2019).

Main gaps in policy and practice in infertility - Bangladesh¹

“Even the simplest questions like “When will you have a child?” can be stigmatising.”

In Bangladesh, not being able to have a child after many years of marriage affects both the husband and wife. However, the effect on the wife is comparatively more because it is in the Bangladesh culture to put blame and burden on women. In many cases, men remarry either by abandoning their wives, or in the presence of the wife, with the hope of having his own children. This puts women in an economically vulnerable position as it is very difficult for women to be financially independent, especially outside Dhaka. In the upper class, there are cases of women not accepting to carry the blame. The male’s infertility will be exposed. Due to patriarchal ideas around masculinity, he will not be considered a man anymore, which places a big burden on him.

Many believe that not being able to have a child is a curse or the result of their sin. People don’t realise that constantly asking a couple about having children can result in mental trauma. Thus, it is important to sensitise general people about infertility, its causes and the associated trauma. In Bangladesh, often the doctors are the ones who contribute to the mental humiliation faced by the couple by making insensitive comments. It is important to train doctors on how to talk to couples who have come to them expecting medical help.

Health centres that cater for infertility care are not available outside the capital Dhaka, and those inside Dhaka are not up to the mark and very expensive. It is affordable only for the rich, not the poor, middle class, or the ones who live outside Dhaka. It is common for many people to go to Kolkata (India) to seek treatment, which indicates that the treatment in Dhaka, even if expensive, is not effective. There are no treatment protocols or ethical guidelines. Some alternate solutions of infertility such as sperm donation and surrogate pregnancy are not available in Bangladesh. Moreover, infertility is not seen as a public health concern.

In Bangladesh, there is an urgent need for country-based research on infertility as there is no data available. It is known and understood that there are many men and women suffering from infertility, but there is no data or statistics to prove it. Research is needed addressing a the clear concept of 'Infertility'; demonstrating current statistics of infertility among men and women all over Bangladesh; and finding the correlation between infertility and other factors such as climate change, food habits, food adulteration etc.

Infertility should be part of the larger SRHR package in Bangladesh. There are many SRHR programmes that focus on maternal health, menstruation, contraception, but there is no intervention that focuses on infertility.

The desire to have children by third genders and people with diverse sexual orientation and gender identities community, either biological or non-biological, should not be ignored. For example, the adoption laws in Bangladesh only provide for married couples that are financially well off to adopt children. Thus adoption laws are not friendly for single people and transgenders. If the adoption laws are revised, and if campaigns are carried out to make people realize the beauty of adoption, then many people can experience the beauty of parenthood and many children can have parents.

There are misconceptions that 'Menstrual Regulation is one of the causes of Infertility'. However, menstrual regulation carried out by skilled professionals poses no risk. However, in Bangladesh, due to many factors women often have the procedure done by unskilled workers. It are the unsafe abortions that pose risks. Therefore, it is important to train skilled professionals not to discourage anyone, especially unmarried girls from approaching their services.

7. CONCLUSION / WAY FORWARD

Breaking the silence around infertility

- Infertility information and services should be integrated in SRHR policies and programmes. Linkages need to be made to comprehensive sexuality education, safe abortion and maternal and reproductive health services, menstrual health, contraceptive counselling, screening and treatment of STIs, GBV services, gender equality and non-discrimination.
- There is a need for a convening space, and a collaborative spirit among networks (media, patients, politicians, providers, advocates, data registries) across levels, to avoid silos.

- The infertility narrative needs to be developed avoiding language that supports moral or religious conceptions around fertility, and frame infertility within reproductive justice
- The definition of infertility (achieving pregnancy after one year of trying) can be problematic in some contexts and add to the stigma faced by people that are infertile or childless.
- Infertility needs to become more visible: infertility indicators and data generating systems should be established, and clarity on definitions and guidelines provided. Being infertile or childless should no longer be a taboo.
- Awareness needs to be raised about infertility and its impact and the idea that addressing infertility is a luxury problem and involves high costs needs to be tackled.
- There is a need to create interest with funders and donors to include infertility in the sexual and reproductive health and rights continuum.
- Men need to be involved in prevention, care and de-stigmatisation of infertility. Programmes that involve men should not do harm to women, women's autonomy or take away resources from women's services.
- The structural systemic issues that impact infertility and access to infertility care should not be ignored: sexism, racism, capitalism.
- Research gaps and priorities need to be established and funded, including ways to determine prevalence, social science research about the social impact of infertility and into the efficacy, quality and cost-efficiency of lost cost treatment alternatives.

Prevention of infertility

- Fertility awareness can be integrated in sexuality education programmes and other information provided by service providers. It should include information on menstruation cycles, fertility windows, lifestyle and protection against certain chemicals and pollution that affect fertility. Irregularities (such as unpredictable spotting or absence of bleeding and morbidities (such as fibroids, endometriosis or PCOS) associated with a woman's menstrual cycle often have an effect on (in)fertility. It is important that girls, boys, women and men know how to recognise abnormalities and seek medical support when needed, as well as not worry when unnecessary.
- Investments are needed in prevention, diagnosis and treatment of sexually transmitted infections, prevention and management of unsafe abortion and the provision of safe abortion and safe motherhood, which are main causes of infertility, especially in certain LLMIC contexts.
- The fear of infertility needs to be addressed, including through countering misconceptions about the use of certain contraceptives, which are believed to lead to infertility.

Access to quality infertility care

- Access to infertility care should become universal and equitable: the primary health care level should at the minimum offer diagnostic tests and 'simple' forms of infertility treatment, including proper counselling on the fertile window. At the secondary level IVF and more advanced diagnostic procedures can be offered. A tertiary-level infertility clinic would offer specialised assisted reproduction and surgical procedures.
- There is a need for more specialised fertility specialists (doctors, embryologists, nurses and counsellors) especially in the public health sector.

- Support providers to address infertility, in educating people, in dispelling myths and in referring people to appropriate services.
- Regulations, standards and guidelines need to be established to improve quality of care and counselling.
- Investments are needed in the development and availability of low-cost treatments. Advocacy at national level is needed for the introduction of those, while countering dominant privatised voices that may hinder its introduction.
- An overview of efficacy, safety and cost-efficiency of the different infertility methods is currently lacking and greatly needed.
- Advocacy is needed for the inclusion of infertility care and treatment in national insurance schemes.
- Non-Western medicine, traditional healers and sociocultural beliefs need to be considered in awareness raising, education and de-stigmatisation around infertility, as many people will seek help outside the medical sector.
- More research is needed in male infertility treatments and methods and gaps in service coverage for men need to be identified and addressed.
- Socio-cultural barriers in accessing fertility care needs to be considered and addressed, such as language barriers, a preference for a physician of the same sex, racial or religious barriers, and stigma felt due to an STI, being HIV positive or having had an (unsafe) abortion.
- Psycho-social needs and needs for information and counselling of fertility patients should be addressed.
- Women and men facing infertility may benefit from infertility support groups, that provide information of other ways of parenthood as well as showing “new ways” of shaping your life that does not include being a parent.
- Support and empower existing support groups, including in helping them to raise awareness on the issue and advocacy.

De-stigmatisation of infertility

- Public educational campaigns should counteract the negative public images and community reactions towards infertile women and men and clear messages need to be developed that are specific to local beliefs and framing.
- Gender transformative approaches need to be applied, to change dominant norms on masculinity, femininity patriarchy and motherhood. Women and men who are childless should not be perceived as inferior.
- Dominant norms about masculinity and stigma related to male infertility need to be addressed for the sake of the men and of the women. Stigma related to male infertility contributes to blaming and ostracising women.
- Affected people and community and women’s groups should be part of developing strategies that combat stigma against women and couples facing infertility and childlessness.
- Stakeholders should be brought together to find ways to address the infertility stigma and tackling the taboo and invisibility of the suffering of people facing infertility and childlessness.
- Partnerships should be built with NGOs working on gender-based violence and gender justice, as infertile women face high levels of violence and discrimination.

- LGBTIQ people and couples, HIV sero-discordant couples, and women with medical issues affecting fertility, such as cancer and disabilities need special support, if applicable, in their desire to become parents.

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