# Infertility in South Africa: A Neglected Issue in Need of a Public Health Response

An Exploration of Causes, Consequences, and Interventions

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# Infertility in South Africa: A Neglected Issue in Need of a Public Health Response. An exploration of Causes, Consequences, and Interventions

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Science in International Health by

Floor van Gorkom The Netherlands

#### Declaration:

Where other people's work has been used (from either a printed or virtual source, or any other source), this has been carefully acknowledged and referenced in accordance with academic requirements. The thesis Infertility in South Africa: a neglected issue that warrants a public health response. An exploration of causes consequences and interventions is my own work.

#### Signature:

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## Table of Contents

Li	st of Ta	bles	iv
Li	st of Fig	ures	iv
G	lossary.		v
Α	bstract.		vi
In	troduct	ion	vii
1	Вас	kground	1
	1.1	Demographic Information	1
	1.2	Socio-Economic Situation	1
	1.3	Health Problems	2
	1.4	Health System	3
2	Pro	blem Statement and Justification	4
	2.1	Infertility an Important Global Public Health Problem	4
	2.2	Reasons for Non-inclusion of Infertility in International Agendas of the SRHR Community	5
	2.3	Justification	6
3	Obj	ectives	6
4	Met	hods and analytical framework	7
	4.1	Search Strategy	7
	4.2	Conceptual Framework	9
5	Stud	dy Findings	10
	5.1	Magnitude of the Problem of Infertility	10
	5.2	Structural Determinants for Infertility in South Africa	12
	5.2.	Socio-economic and Political Context that Impacts Infertility	12
	5.3	The Social Determinants of Infertility	16
	5.3.	Socio-Economic Position	16
	5.4	Intermediary Determinants of Infertility	19
	5.4.	Environmental, Lifestyle, Biological and Psychological Factors in Relation to Infertility	19
	5.4.	2 Health System and Infertility	22
	5.4.	Social Cohesion and Social Capital	23
6	Disc	ussion	26
7	Con	clusion and Recommendations	30
	7.1	Conclusions	30
	7.2	Recommendations	31
Q	Rofe	prences	33

#### List of Abbreviations

AIDS Acquired Immune Deficiency Syndrome

AMH Anti-Mullerian Hormone

AP Adolescent Pregnancy

ART Assisted Reproductive Therapy

ATR African Traditional Religion

BMI Body Mass Index

CTOPA Choice of Termination of Pregnancy Act

CSW Commercial Sex Workers

DHS Demographic Health Survey

GII Gender Inequality Index

HAART Highly Active Antiretroviral Therapy

HIV Human Immunodeficiency Virus

HSG Hystero-Salpingo-Gram

ICPD International Conference on Population and Development

ICSI Intra-Cytoplasmic Sperm Injection

IFAASA Infertility Awareness Association South Africa

IUI Intra-Uterine-Insemination

IVF In Vitro Fertilization

LCIVF Low-cost IVF

LGBTQI Lesbian Gay Bisexual Transgender Queer Intersex

MAR Medical Assisted Reproduction

NDOH National Department of Health

NGO Non-Governmental Organization

NHI National Health Insurance

OI Ovulation Induction

PDOH Provincial Department of Health

PID Pelvic Inflammatory Disease

PLHIV People Living with HIV

PMB Prescribed Minimum Benefits

RSA Republic of South Africa

RTI Reproductive Tract Infection

SASREG South African Society Reproductive Medicine and Gynecological Endoscopy

SRHR Sexual Reproductive Health and Rights

SRHS Sexual Reproductive Health Services

SSA Sub Saharan Africa

STI Sexually Transmitted Infection

TFR Total Fertility Rate

TTP Time To Pregnancy

UHC Universal Health Coverage

WHO World Health Organization

### List of Tables

Table	Title	Page number
Table 1	Search Strategy	8
Table 2	Time to Pregnancy in Months	11

# List of Figures

Figure	Title	Page number
Figure 1	Districts of RSA	1
Figure 2	Top 10 causes of death and change 2009-2019 in RSA	2
Figure 3	Top 10 causes of death and percentage change 2009-2019 in RSA	3
Figure 4	Top 10 risk factors contributing to death and disability combined in	3
	RSA and percentage change 2009-2019	
Figure 5	WHO Conceptual Framework of Social Determinants of Health	9
Figure 6	Distribution of IVF Centers in SSA	23

#### Glossary

<u>Infertility:</u> WHO definition; infertility is a disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months of regular unprotected sexual intercourse (1).

<u>Primary infertility:</u> WHO is when a pregnancy has never been achieved in couple after 12 months of regular unprotected sexual intercourse (1).

#### **Secondary infertility:**

- Female: a woman unable to establish a clinical pregnancy, but who previously has been diagnosed with a pregnancy (2).
- Male: a man who is unable to initiate a clinical pregnancy, but who has previously initiated one (2).

<u>Assisted reproductive therapy (ART):</u> WHO definition: all treatments or procedures that include the in vitro handling of both human and oocytes and sperm or embryos for the purpose of establishing a pregnancy. This includes, but is not limited to, in vitro fertilization and embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donations and gestational surrogacy. It does not include assisted insemination using sperm from either a woman's partner or a sperm donor (1).

<u>Fertility care</u>: Interventions that include fertility awareness, support, and fertility management with an intention to assist individuals and couples to realize their desires associated with reproduction and/or to build a family (2).

<u>Medically assisted reproduction (MAR)</u>: 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 (2).

Fecundity: the ability to produce an abundance of offspring or new growth.

<u>In vitro fertilization:</u> a medical procedure whereby an egg is fertilized by sperm in a test tube or elsewhere outside the body (2).

<u>Intra cytoplasmic sperm injection (ICSI):</u> a technique or IVF in which an individual sperm cell is introduced into an egg cell with the intention of fertilization outside the body (2).

<u>Intra uterine insemination:</u> a procedure whereby semen is deposited in the uterine cavity of a female (2).

#### **Abstract**

This study about infertility in RSA identified the social determinants, consequences and interventions. The aim was to contribute to the development of context specific and evidence informed response. Infertility is a common yet neglected and understudied problem in RSA. The exact prevalence is unknown; estimates range from 15-20% in couples to 37% in women. The prevalence of male factor infertility is unclear. The main structural determinants are issues around the cultural value of children, gender and inequities within socio-economic position. These cross racial lines, gender and geographic location. The structural factors influence preventable determinants such as; environmental hazards, life style factors as obesity and smoking. And most importantly untreated chronic conditions such as diabetes, STIs and HIV as well as psychological factors due to high stigma and burden for individuals dealing with infertility. The health system is overburdened and understaffed and the cost for infertility treatment needs to be covered by the individuals themselves. There are many barriers in accessing fertility services of which costs and scarcity are the most important. The government did an excellent job in developing an integrated guideline for SRHR and a treatment guideline for infertility in 2019. Implementation and dissemination needs to be improved. The emphasis should be on a multisector and integrated approach with a focus on prevention, awareness and reducing stigma. As well as organizing psychosocial support for individuals facing infertility. The government should consider improving accessibility and coverage of costs of basic infertility treatment and low cost IVF.

Key words: Infertility, South Africa, Prevalence, Social Determinants, Public Health Response

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#### Introduction

Infertility or involuntary childlessness is a major public health problem. Working in Tanzania, Namibia and the Netherlands I have witnessed the magnitude of the problem and the often-devastating impact it has on people's lives. The effects can be disastrous and act at multifactorial level.

In developing countries an estimated 1 in 4 couples is affected by infertility(3). I find this an incredible high number which concerns me deeply especially because it received so little attention in the global agenda of Sexual Reproductive Health and Rights (SRHR), despite many efforts to address it (4)(5). It is a very pertinent issue which needs more attention and deserves a public health policy approach.

Besides having worked in low and middle-income settings, I also worked in a fertility clinic in The Hague, The Netherlands. This was a vastly different setting in which our patients were eligible for treatments known as assisted reproductive technology (ART) such as in vitro fertilization (IVF) and Intracytoplasmic Sperm Injection (ICSI), technically advanced health care services that remain out of reach for most couples worldwide. But unlike what many people think, there are many under-utilized ways to tackle the problem of infertility in low- and middle-income settings. Many strategies can and should be undertaken varying from preventive, diagnostic, supportive (financially and psychologically) treatment. Many more than ART only. In recent years there are developments towards both effective and low-cost ART options. The Republic of South Africa (RSA) is one of the few countries that has developed a guideline and therefore it is interesting to take RSA as example for my study.

In this thesis I hope to describe the magnitude of the problem, the impact it has on people's lives and asses the current response and propose recommendations for infertility care in RSA. I genuinely believe that we can identify sustainable ways to support couples in achieving their fertility goals (whether this is wanting more or less children). I hope this case study can be an example of how to approach infertility from a public health perspective in a middle-income country and that it contributes to increasing the knowledgebase of infertility in an African setting.

At last, it is my ambition that this thesis supports the growing international evidence and movement to advocate for the urgent need to place the problem of infertility in low- and middle-income (LMIC) countries higher on the international SRHR and health agenda.

#### 1 Background

#### 1.1 Demographic Information

In 2020 the RSA has an estimated population of 59,62 million citizens, of which 51,1% are female (6). The population is quite young with a median age of 27.6 years (7), and 28.6% of the population under 15 years. Life expectancy at birth is 62,5 for males and 68,5 years for females (2020) (6)(8), which has increased dramatically over the last years (51,6 years in 2005). In 2019, the total fertility rate was 2.1, declining from 2.9 in 1998 (8).

The country has 9 provinces, and 33% of the population is living in rural areas(9), as shown in Figure 1. The country has 11 official languages. The apartheid regime, which segregated and economically and politically oppressed the nonwhite population, lasted from 1948-1990 and its marks are still notable in society.

According to the last national population census (2016) 7.4% of the population declared itself black African, 9.2% as White, 8.8% as Colored and 2.6% Indian or Asian. Most of the population is religious Christian (81.2%), other (3.7%) and 15% are not affiliated to any faith (10). Many black South Africans believe in Christianity as well as African Traditional Religion (ATR) (11). The Gender Inequality Index (GII) is 0.406 and reflects inequalities in reproductive health, empowerment and economic activity, and ranks 93 out of 162 countries worldwide (7).



Figure 1: Districts of RSA (12).

#### 1.2 Socio-Economic Situation

RSA is an upper middle-income country according to the World Bank (13). The Gross National Income per capita (GNI) is \$12,129 (\$9,248 for female and \$15,095 for men). The country's wealth is unequally distributed and is reflected in the GINI coefficient of 0.63 which is the second highest in the world after Lesotho (14). The poorest 40% of the population holds 7.2% of its wealth, while the richest 1% holds 19.2% (7).

Fifty-six percent of the population lives below the national income poverty line. A large part of the population is unemployed (28.2%), especially youth (56% of youth 15-24 years)(7). According to the 2016 Demographic Health Survey (DHS) the general educational level is high, 28% of women and 24% of men have completed secondary school. And 12% of women and 11% of men continued advanced education. The literacy rate is 95% for men and 96% for women. The educational levels were higher in the urban areas, which also scored a higher household wealth (10).

#### 1.3 Health Problems

RSA deals with a quadruple burden of disease: communicable diseases (HIV/AIDS, TB, SARS-Covid-19), non-communicable diseases, maternal-and childhood diseases and injuries are the top 10 causes of death and burden of disease (15)(16)(17). Recently it became a quintuple high burden, with the emergence of SARS-Covid-19.

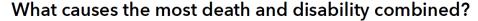
RSA faces the largest HIV/AIDS epidemic of the world with 7.5 million people living with HIV (PLHIV) in 2019 and an adult prevalence of 19% (men 12.9% and women 25%). Seventy percent of PLHIV is on Highly Active Anti-Retroviral Treatment (HAART) resulting in a 53% reduction of HIV infections since 2010 and reduction of deaths by 61% (18).

Contraceptive use among women aged 15-49 years is 55% (10). The unmet need for family planning 14.9%. Intimate partner violence experienced by women is 21.3% (7). The median age at first birth among women aged 25-49 is 21.3 years, and 18% of women gave birth by age 18 (10).

Figure 2 shows the top 10 causes of death in RSA, figure 3 the top 10 for death and disability and figure 4 provides the top 10 risk factors for death and disability, many of which are important for infertility (17). In 2019, COVID-19 was not yet existent, but now RSA is heavily affected. On the 23d of July the country counted 2.356.049 positive cases and 69.075 deaths (19).

#### What causes the most deaths? Communicable, maternal, neonatal, and nutritional diseases Non-communicable diseases Injuries 2009 2019 % change, 2009-2019 HIV/AIDS HIV/AIDS -44.9% Lower respiratory infect Ischemic heart disease 0.3% -6.2% Tuberculosis Stroke Stroke Lower respiratory infect -22.6% Diabetes 11.8% Ischemic heart disease Neonatal disorders Tuberculosis -40.0% Diabetes Road injuries -14.1% -13.6% Road injuries Interpersonal violence Interpersonal violence -31.3% Neonatal disorders Diarrheal diseases Diarrheal diseases -31.8%

Figure 2: Top 10 causes of death and change 2009-2019 in RSA (17)



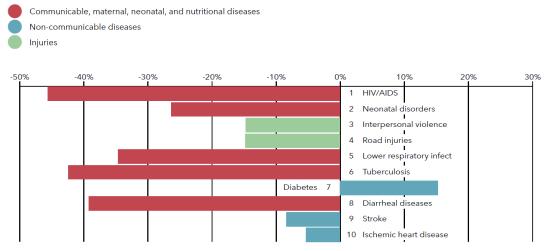


Figure 3: Top 10 causes of death and percentage change 2009-2019 in RSA (17)

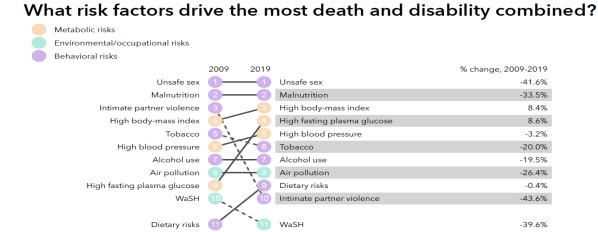


Figure 4: Top 10 risk factors contributing to death and disability combined in RSA and percentage change 2009-2019 (17)

#### 1.4 Health System

Basic primary health care is offered free to all citizens in the public health care system. Current health expenditure (% of GDP) is 8.1%, this is lower than the 15% agreed upon in the Abuja Declaration of 2001 (20). The total health expenditure per capita in 2018 was \$525,96 (7). Health programs receive the second highest concentration of government funds after education in 2021 (21). Expenditure in the public and private health system are roughly the same. The coverage however is very unequal. The private sector serves 16% and the public system 84% of the population who are largely poor and black (15). The private sector also employs 70% of the health workforce. Only 15% of the population is covered by medical insurance schemes, due to its high costs (20).

RSA has a decentralized health system. The National Department of Health (NDOH) is led by the minister of health and sets out national health policy. This federal health policy is implemented in 9 provinces by the Provincial Department of Health (PDOH) which supervises the District Departments of Health local

departments with a focus on provision of primary health care. The primary health care service is provided in the district hospitals and community-based health care centers. The hospitals are categorized into tertiary, regional, and district hospitals (20).

In 2019, the government launched the National Health Insurance plan (NHI), as a mechanism to facilitate Universal Health Coverage (UHC). It offers all citizens' access to a defined package of comprehensive health services, including SRHR. It aims to create a health financing system that ensures all citizens are provided with essential healthcare. The first phase of NHI is underway, with full implementation expected in the financial year 2025/26 (22)(23).

RSA faces multiple public health system challenges that were reported by stakeholders in a 2020 survey (24). The major ones are fragmentation of services, staff shortages and financial/cash-flow problems. The providers expressed a strong need to improve integration and address human and financial deficiencies (24). The DOH mentions the following systematic challenges: complex burden of diseases, quality concerns related to health care in general, ineffective and overburdened health care system resulting in inefficiencies in service delivery and inequalities in care delivery in both public and private sectors, and spiraling health care costs (23).

#### 2 Problem Statement and Justification

#### 2.1 Infertility an Important Global Public Health Problem

Infertility is a common problem for couples worldwide. The global population of infertile people is difficult to estimate due to inconsistent definitions of infertility and use of different methods in studies and limitations in design and sampling methods (4).

However, some data do exist and are commonly referred to. A study, based on multiple DHS (1995-2001) estimated that there are 186 million (ever-married) women of reproductive age that had primary or secondary infertility worldwide(25). Another study in 2007 extrapolated 72,4 million infertile women of whom 40,5 million were seeking medical care (26). The most recent study estimated that 48,5 million couples faced infertility, but they used a different definition (not being able to have a life birth after 5 years)(3). According to WHO, reducing this time frame from 5 to 2 year would increase the total number to 121 million. There are no global numbers on infertility amongst men. WHO estimated that over 10% of women worldwide are dealing with infertility. The numbers seem to be stable over the past 20 years (27).

Contrary to what many people believe, Africa suffers from remarkably high numbers of infertility. Central Africa is also referred to as the 'infertility belt' (28). In a survey that looked at secondary infertility in Africa, 60% of participating countries reported secondary infertility rates over 25%, and 30% of countries reported rates over 30% (25). This is mostly the result of preventable causes, such as poorly managed Reproductive Tract Infections (RTI) such as Sexual Transmitted Infections (STI), complications after childbirth or complications from unsafe abortions(28)(29)(30)(31).

Individuals dealing with infertility deal with numerous issues when the expectation of becoming a parent is not met (32)(29)(33)(34). The consequences of infertility are often more dramatic in LMIC (31) as women affected by infertility must deal with social consequences, ranging from stigma, isolation, ostracism, disinheritance and neglect by family or community members leading to high levels of psychological distress. Feelings of grief and loss of identity are common. Infertility also leads to marital instability, divorce, increasing risks of HIV and STI infections and even prostitution.

Moreover, persons affected by infertility also suffer economically due to high costs of treatment, divorce, and no one to take care of them in the absence of pension funds (4)(5)(28)(29)(30)(31)(35). Male infertility receives little attention. Recent research into experiences of men showed they face many struggles too. These are related to their position in community, loss of masculinity and bullying (36)(37). Women are often blamed and bear the most severe consequences, even if they are not the one causing it (28).

Approximately 33% of couple infertility is due to male, 33% to female factors and the remaining percent to a combination of both male and female, or unidentifiable factors (23). There is a lack of recent literature on causes of infertility in middle- and low-income country settings; no prospective studies were ever conducted.

Some authors, such as Sharma et al, divide the causes of infertility into two groups. Group one contains causes that have similar prevalence rates around the globe and include genetic, anatomic, hormonal, and immunological problems (30). The second group consists of preventable causes like reproductive tract infections (RTI). In sub-Saharan Africa (SSA) this is mostly due to STIs such as chlamydia and gonorrhea, for both men and women. According to Ombelet, in SSA 85% of women have RTI related causes of infertility, compared to 33% globally (31). In addition, HIV infections can lead to tubal damage and altered spermatogenesis in men. Other infectious diseases have been mentioned such as genital tuberculosis, leprosy, and schistosomiasis. Other preventable causes in LMIC are a result of poor-quality health care practices such as unsafe abortions, unhygienic obstetric practices, and inadequate treatment of infections. This is due to overall poor performance of the health system, lack of well-trained staff, poor laboratory and supportive facilities and unavailability of drugs. Indirectly these are amongst the reasons for secondary infertility (29)(30)(31).

Other factors are influenced by lifestyle, such as smoking, alcohol, tobacco use, insufficient diet, obesity, malnutrition, or environmental hazards. The socio-cultural factors influencing infertility include teenage pregnancies which both can lead to infections and secondary infertility (due to complications of labor and exposure to STIs and HIV), aversion to condom use, polygamy and in some areas the delay in childbearing, mostly highly educated women as seen in Western societies (30)(31).

In 2004 the World Health Assembly adopted the five core points of the WHO sexual and reproductive health package. One of these was the global need for provision of high-quality services for family planning, which includes infertility services (38). In 2018, the Guttmacher-Lancet commission on SRHR asked attention for the fact that infertility has not been prioritized by global public health policymakers and that it received far too little attention and funding compared to other SRHR programs(5).

# 2.2 Reasons for Non-inclusion of Infertility in International Agendas of the SRHR Community

There are different reasons why infertility has been neglected in international SRHR agendas. Firstly, particularly in Africa (4)(28), high HIV and STI infection rates and high rates of fertility and infertility coexist. Pregnancy rates in adolescents are high, asking in turn for contraceptive and safe abortions services (28). International policy makers have strived for getting these two issues on the international agenda and neglected the opportunity to include infertility in their strategies. Some argue that the international community has worsened the neglect of infertility, by not including this problem in their agenda setting(4).

Secondly, some argue that infertility is a solution to the problem of overpopulation and a tool to achieve demographic dividend (accelerate economic growth from declining fertility rates) (4)(28)(31). This is in line with Western views of population control and overpopulation in many SSA countries.

#### 2.3 Justification

In view of recent efforts to address infertility in an integrated approach addressing all aspects of infertility and other much needed SRHR services, it is important to understand the complexity of infertility (5)(27)(31)(39).

Infertility is not about bio-medics only. Socio-economic, cultural, psychological circumstances such as gender (in)equality and socio-economic status as underlying factors, are context specific and require a comprehensive response from the public health system.

RSA was chosen as a country in case, to illustrate how the conceptual framework on determinants of health can and should be applied to identify opportunities and gaps in a specific context.

RSA, a middle-income country with a very diverse population, is dealing with major public health concerns and has high numbers of infertility. The exact magnitude of the problem is quite unclear. There is no overview or deep analysis of the magnitude, determinants, and response to the problem. Policy makers need recent, context specific, detailed information about the problem of infertility for developing policies that realize positive outcomes for women and men with infertility and involuntary childlessness. These policies should be informed by international best practice.

This thesis aims at formulating recommendations for policy makers and key stakeholders on how to improve services for individuals and couples dealing with infertility. This then hopefully contributes to improving infertility care services for both women and men in RSA and serves as an example for other countries in similar settings.

#### 3 Objectives

The overall objective of this study is to contribute to improving preventive and supportive policies/measures for people dealing with infertility in RSA.

Specific objectives are:

- 1. To explore the magnitude of infertility as public health problem in RSA;
- 2. To describe the social determinants of infertility in RSA;
- 3. To identify and analyze the consequences of infertility for individuals, couples, and society;
- 4. To identify effective approaches to infertility in RSA and beyond, which could be implemented or scaled-up in RSA;
- 5. To formulate recommendations for policy makers addressing the issue of infertility in RSA.

#### 4 Methods and analytical framework

#### 4.1 Search Strategy

A comprehensive literature review was conducted of available peer reviewed, national, and grey data. Searches in international databases as well as snowballing methods were used. The search strategy is highlighted in table 1. The literature search gathered quite some country-specific publications. Reports of international organizations, NGOs and research institutes were used. If context specific data was unavailable international research was used to act as reference for gap filling t the local content specific factors.

#### **Table 1: Search Strategy**

#### Sources

Data base and search engines: PubMed, Medline, google scholar, google search engine

Institutional and Government websites: WHO, Guttmacher, World Bank, UNDP, Government South Africa, National statistic department South Africa, National Department of Health

**Literature:** published peer reviewed data, opinion statements by key players in the field (letters to peer reviewed journals etc.) grey literature and newspaper articles, videos on social media. Snowballing methods from references.

Limitations: English and Dutch language, Articles published between 2000 and 2021

	Step 1	Step 2	Step 3	Step 4	
Chapter	Broad key words for international and Sub-Saharan Africa literature	Additional key words (used in mixed combination for international literature)	Principle key words South African literature	Additional key words (used in mixed combination for South African literature)	Prioritized literature
Background	Fertility OR Infertility OR Childlessness OR Fecundity OR Barrenness	Cultural	South Africa  AND  Demographic health survey  National strategic health plan	Geographic and district Burden of disease Health indicators Economic situation/context Health system	Peer reviewed literature (international and South African) Institutional and government reports and surveys
Problem analysis	Fertility OR Infertility OR Childlessness OR Fecundity OR Barrenness	Public health problem  Consequences  Human rights based approach  Policies  WHO	South Africa  AND  Fertility OR Infertility OR Childlessness OR Fecundity OR Barrenness  Time to pregnancy		Peer reviewed published data  Reports from international NGOs  Government
Magnitude			South Africa  AND  Fertility OR Infertility OR Childlessness OR Fecundity OR Barrenness	Pertility rates  Department of Statistics South Africa  Demographic health survey	Government data  Local peer reviewed literature

			Time to pregnancy		
Consequences	Sub Saharan Africa	Consequences	South Africa	Consequences	Peer reviewed
		Social		Social	literature
	AND	Psychological	AND	Psychological	
		Economic		Economic	
	Fertility OR	Health	Fertility OR	Health	
	Infertility OR		Infertility OR		
	Childlessness OR		Childlessness OR		
	Fecundity OR		Fecundity OR		
	Barrenness OR		Barrenness OR		
	Time to pregnancy		Time to pregnancy		
Determinants	Sub Saharan Africa		South Africa	Social determinants of	Peer reviewed data
				health	
	AND		AND		International data
				Socio economic	on social
	Fertility OR		Fertility OR	Lifestyle	determinants of
	Infertility OR		Infertility OR	Smoking	health combined
	Childlessness OR		Childlessness OR	Obesity	with local data fron
	Fecundity OR		Fecundity OR	Alcohol	DHS
	Barrenness OR		Barrenness OR	HIV	
	Time to pregnancy		Time to pregnancy	Teenage pregnancies	
				STI	
				Non communicable	
				diseases	
Policies/		Strategies	South Africa	Patient groups	Institutional and
approaches		Policies		Insurance companies	government
		Interventions	AND	Fertility clinics	reports
		Integrated SRHR		SASOG	
		services	Fertility OR	SASREG	Patient support
		prevention	Infertility OR	IFAASA	groups
		Low-cost IVF	Childlessness OR	NGO	_ '
			Fecundity OR		Newspaper articles
			Barrenness		
					Social media
					campaigns

One key informant interview was done with Dr. Thabo Matsaseng, professor of infertility at Tygerberg Hospital in Cape Town RSA. The aim of the interview was to get a deeper understanding of the playing field and to gain expert opinion where context specific data was meager.

#### 4.2 Conceptual Framework

The conceptual framework for action on social determinants of health developed by Solar et al for the WHO was used to systematically assess the determinants of the infertility problem (figure 5)(40). The framework is designed to help policymakers when developing targeted interventions addressing underlying processes and to effectively tackle health problems and inequities. The textbox describes the definitions for the different factors as stated by Solar et al.

This framework fits the aim of this study to explore all determinants of infertility in RSA. The framework highlights those conditions and illnesses that impact on equity in health and well-being and "feedback" on an individual's social position.

The results chapter systematically assesses all factors of the framework in relation to infertility in RSA. The final recommendations are based on this review and could be used for improving infertility prevention and care in RSA.

# Definitions on the conceptual framework social determinants of health (40)

#### "Structural determinants of health:

**Context:** include all social and political mechanisms that generate, configure and maintain social hierarchies, including: the labor market; the educational system, political institutions and other cultural and societal values.

Structural mechanisms are those that generate stratification and social class divisions in the society and that define individual socio-economic position within hierarchies of power, prestige, and access to resources. Structural mechanisms are rooted in the key institutions and processes of the socio-economic and political context. The most important structural stratifies and their proxy indicators include: income, education, occupation, social class, gender, race/ethnicity.

Intermediary determinants of health: material circumstances; psycho-social circumstances; behavioral and/or biological factors; and the health system itself as a social determinant.

Social cohesion and social capital: cuts through and links both structural and intermediary dimensions. This is where the role of the state should promote equity and aim for cooperative relationships between citizens and institutions and developing flexible systems to facilitate access and participation on the part of the citizens. "

Solar et. Al., WHO 2010 (40)

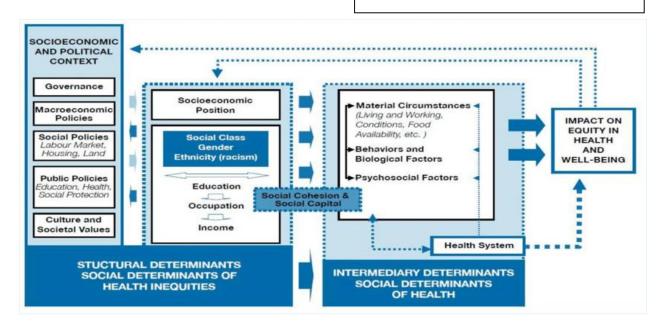


Figure 5: WHO Conceptual Framework of Social Determinants of Health (40)

#### 5 Study Findings

#### 5.1 Magnitude of the Problem of Infertility

The exact magnitude of the problem of infertility in RSA is not well studied and remains unclear. This chapter gathers data from multiple sources for understanding the magnitude of the problem.

The most recent DHS of RSA (2016) contains 627 pages, and the word infertility is not mentioned once. Chapter 5: Fertility, describes fertility, infertility or involuntary childlessness is not mentioned. Among women aged 25-49 years of age, 9% has never given birth. This can be due to numerous reasons, not related to infertility (10). The report states that the total fertility rate (TFR) is 2.6 per woman and has declined from 2.9 in 1998. TFR declines with increases in household wealth and education level and when residing in urban areas. TFR also varies by population group with black African women having the highest TFR of 2.7 children, colored 2.5, Indian/Asian 1.7 and white 1.5.

Garenne et al. analyzed trends and dynamics of marriage and infertility in RSA, based on data from four population censuses from 1996, 2001, 2007 and 2011 (41). The study defined primary infertility as being childless by age 40 and above, which is different from the WHO definition. It was calculated as the proportion of women with no life birth among women who responded to questions on childbearing. This is a very different definition and does not distinguish between voluntary or involuntary infertility neither marriage, union, nor celibacy. What they call infertility should be called childlessness.

Cooper et al (42) estimated that 15–20% of couples report difficulties with conception. This study is most widely referred to by government and other stakeholders when estimating the magnitude of the problem in RSA. She based this estimation on a study of Moore and Zimazi, from 1996. This study was not found on the internet, but has been quoted in many articles ever since, both peer-reviewed and grey literature <sup>1</sup>.

The only other study looking at infertility profiles at a public hospital dates from 1998 in Durban. It was a prospective study for couples visiting the infertility department. This research was not included in the analysis as it was older than the 20-years' time limit.

Stewart- Smythe et al stated that 20% of all women attending the gynecologist outpatient department present with infertility (43). A study published in 2003, at a public hospital in Johannesburg did retrospective analysis of hospital records of couples undergoing diagnostic tests due to infertility. It found that bilateral tubal obstruction was the most common cause of infertility (65% of women bilateral, unilateral obstruction in 16%). Ovulation problems did not seem common, but the authors reported technical problems in semen analysis and progesterone tests. This led to unreliable data regarding anovulation and sperm count (43).

Lince-deroche et al (44), studied women accessing reproductive health services in a public health facility in Johannesburg. She found that over a third (37.5%) of all women who tried to conceive in the last year (n=40) reported experiencing fertility problems (n=15). Roughly 80% of them also sought care for their

<sup>&</sup>lt;sup>1</sup> 84 Moore S, Zimazi D. Reproductive health problems. In: Goosen M, Klugman B (editors). South African Women's Health Book. Cape Town: Oxford University Press, 1996. p.446.p446

needs (44). This study does not give details of the self-reported fertility problems or what care was provided, but it suggests that the problem of infertility is common in this population.

Although there is a lack of reliable population-based data on the burden of infertility in RSA we do know that women present to the health facilities with problems and questions regarding infertility. The magnitude of male infertility is considered mostly hidden. This considered due to stigma and blame of the women(43)(45).

One other angle to look at the magnitude of sub- or infertility is the self-reported Time-To-Pregnancy (TTP). Bello et al studied this in 1,121 South African women (46). Table 2 6 shows that after 12 months 32% of women and after 24 months 17% were not pregnant yet. This data is mostly in line with the international definition of infertility (not conceiving after 12 months of regular intercourse)(46).

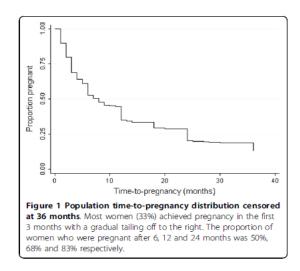


Table 2: Time-To-Pregnancy in months (46)

Another study of Bello from 2016, studied the TTP for more than a year in women amongst administrative-and domestic workers, and teachers. Within one year respectively 20%, 20% and 39% were not pregnant. This study does not report on the causes for these percentages (47).

Obtaining representative data on the magnitude of male infertility in RSA is considered notoriously difficult (28)(48). Botha et al. investigated sperm of healthy South African partners of women undergoing surgery for endometriosis-related infertility. Subfertility was found in 34.2% of these men, with 11.9% having a severe defect (azoospermia, double defects, or triple defects)(45). However, a sperm count on its own, depending on the results, is not enough to predict chances of pregnancy, since this is the outcome of multiple factors (49). In absence of other data these data are the most indicative for the prevalence of male factor infertility.

#### 5.2 Structural Determinants for Infertility in South Africa

#### 5.2.1 Socio-economic and Political Context that Impacts Infertility

#### **Macro-economic Policies**

According to WHO the largest share of global donor funding for SRHR in 2017 is allocated to HIV (70%). In contrast, investments in other key reproductive health care services (e.g., antenatal and postnatal care including delivery, prevention and treatment of infertility, prevention and management of complications of abortion, and safe motherhood activities) only accounted for 16% of all SRHR donor flows in 2017 (50). Within the SRHR community itself, the topic of infertility and provision of funding for it has been largely neglected (4)(5).

It was not possible to find data on budget allocation of the RSA government in relation to infertility nor any commitments in future. So far, ART services are not offered for free to all citizens of RSA.

#### **Governance**

Governance is not directly causing infertility. However, if the government is not taking care of its citizens it could lead to more infertility. This could be due to higher incidence of preventable causes, such as infections. Or due to weak health care systems which do not cater to the needs of couples dealing with infertility. Acknowledging infertility as a problem is the basis for the development of strategies and plans which are needed to curb the problem of infertility.

The government has listed infertility in the Medical Schemes act, NO 131 of 1998. It is one of the described diseases of 270 in the Prescribed Minimum Benefit Diseases (PMBs) list. This means that insurance companies should cover the infertility treatment, irrespective of the medical aid plan that one is on (51).

#### **Social Policies**

RSA has a basic set of social policies in place. These include free healthcare in the public health system, basic education and subsidized housing for the poor. In addition, there is universal provision of some basic services such as water, electricity, and sanitation. Old age grants are payable to citizens 60 years and over. Therefore, citizens are not solely dependent on financial support from their offspring in later life (52) (64). The occupational health and safety act requires employers to keep the workplace safe and protect their staff from exposure to environmental hazards including chemicals and toxins. This impacts infertility and is an especially important prevention factor (53).

There is a child support grant payable to poor households with young children(52).

There is no special social policy for individuals dealing with infertility.

#### **Public Policies**

South African reproductive health policies and the laws that underwrite them are among the most progressive and comprehensive in the world in terms of the recognition of human rights, including sexual and reproductive rights (54).

Public policies regarding education and social protection are not formally associated with infertility. They do have an indirect effect on individuals' position in society.

As described in the background section, RSA is working towards the implementation of a NHI to achieve UHC. The government has a national integrated sexual and reproductive health and rights policy from 2019 (23) and a national clinical guideline for safe conception and infertility(55).

#### Alignment with regional and international strategies and frameworks

#### The Constitution:

- Section 9: everyone has the right to equality, including access to health care services. This means that individuals should not be unfairly excluded in the provision of health care (18).
- Section 27: everyone has the right to have access to health care services: including reproductive health care.

#### Sustainable Development Goals:

- Goal 3: Ensure healthy lives and promote well-being for all at all ages (3.1, 3.3, 3.7).
- Goal 5: Achieve gender equality and empower all women and girls (5.1, 5.2, 5.3, 5.6).
- Goal 10: Reduce inequality within and among countries, relates to achieving SRHR for priority populations most affected by HIV, and fulfilling the right to development (19).

#### Signatory to following International Treaties:

- 1994 International Conference on Population and Program of Action
- 1995 Beijing Fourth Conference on Women
- SADC SRHR strategy
- 1995 Convention on the Elimination of all forms of discrimination against women (CEDAW)
- 2003 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa

#### The National Integrated Sexual and Reproductive Health and Rights Policy of 2019:

It states that: "This policy is a demonstration of the DOH's commitment to provide comprehensive SRHR services with a rights-based approach, to achieve health for all. Embedded in the principles of equity and equality, this policy emphasizes the autonomy and agency of clients seeking SRHR services. It is positioned to facilitate coordination between all stakeholders, guide decision makers, protect clients and providers, and provide a justification for allocation of resources - noting that implementation of SRHR services are not only restricted to the health sector. Its implementation is therefore the prerogative of all government departments, industry, and civil society(23)".

The objectives of the policy are: a) to have a rights-based approach for all people seeking SRHR; b) to align the different stakeholders; c) to improve and increase quality and uptake of services with a focus on priority groups; d) To strengthen the health system, in order to offer SRHR at all levels of the health care system. The policy is very detailed and speaks about all relevant SRHR issues related to infertility (STI, AP, HIV, health system, lack of data and M&E in broad terms).

Addressing infertility and subfertility is mentioned in the introduction as one of the emerging key issues in the SRHR landscape. The key focus area is to increase access to management and counselling for people seeking infertility treatment, in a uniform, standardized and cost-effective manner. It also refers to the 'safe conception and fertility management guideline' from 2019 which will be described in the next paragraph.

The policy further states that "Services for subfertility and infertility management are provided at the tertiary level and are not included in the free service for maternal and childcare package". It is unclear why the government decided to exclude these services from their free public health care.

A special objective is to promote SRHR services to males and male partners. Emphasizing shared responsibility, gender equality and active involvement in parenthood and reproductive behavior.

The policy actively seeks multi-sectoral engagement between government, civil society, private sector, and development partners with the aim of keeping the government accountable for the advancement of SRHR and to uphold human rights. They wish to develop innovative specific interventions to address economic-related structural factors among priority groups that hinder access to SRHR. And they seek integration of strategies of (non)-communicable diseases, also relevant to infertility.

The National Clinical Guideline for Safe Conception and Infertility
In 2019, the NDOH published a National Clinical Guideline for Safe Conception and Infertility. The aim of the document is stated as: "the document presents an approach to prevention, management and psychosocial care for people seeking infertility treatment, seeks to fill the clinical and policy gap in RSA, as outlined in 2019 integrated sexual and reproductive health policy" (55).

The guideline offers a basis for a multidisciplinary and multisector approach and can be used by advocates to lobby for prevention, care, and more social and medical cohesion amongst all the stakeholders. It also describes which professionals should use it, ranging from health staff to psychologists and specialists.

Different chapters look at: a) prevention, safe conception and ways to preserve fertility, including life-style factors, prevention of STI, health education; b) diagnosis and evaluation, including proper standard care, appropriate diagnostic workup, appropriate psychological and emotional support as a basis standard of care; c) counselling and psychological support of infertile couples, including coping with stress, stigma, social- and financial stress around diagnosis and treatment of infertile couples before, during and after diagnosis; d) treatment options, including specific mentioning of the LGBTQI community and PLHIV. Other chapters describe causes of infertility, different ART procedures, the laboratory and how to organize services at which level of clinic in the health care system.

The document states that infertility treatment should be offered by gynecologists and fertility specialists. But the initial assessment can be started by nurses, general practitioners, and urologist, who then refer patients to an appropriate treatment facility. There are details on what diagnostic and treatment components should be available at what level. This is clearly laid out in a flowchart. It is stressed that it is always necessary to assess the couple, and not just one of them, with the emphasis on gender equality and collective responsibility and engagement with the health system.

Connoly et al (56), estimated the government public economic benefit attributed to investing in ART in RSA using a framework analyzing infertility and fertility treatments and the policies that influence the accessibility to services. The authors conclude that ART could deliver a net positive outcome to the government under the set of parameters from the study. The authors advice to do single embryo transfers in government funded ART cycles, since multiple pregnancies lead to higher burden and costs on the health care system (56). The coverage of infertility treatment will then contribute to social cohesion and capital within the society.

#### **Cultural and Societal Values**

As stated earlier, RSA is a country with different ethnic groups and is a diverse society with many religions, cultures and believes. In SSA having children is of great value to individuals, couples and society. Successful procreation is celebrated on socio-cultural as well as personal level. Cultural, religious, emotional values and spiritual beliefs have a big influence on notions of childlessness (33).

African Traditional Religion (ATR) exists next to the Christian faith among many black South Africans. Black south Africans have a deep belief in the existence of God and a deep respect and reverence for ancestors which directly impact behavior and practice (57).

Traditionally in RSA, marriage is considered a communal affair, a marriage between two clans. Children are expected shortly after the union. Children ensure the continuation of generations and the clan's name through father's lineage (13)(33)(57)(58). In the context where 'lobola' (bride-price for a woman) is paid, women feel very pressurized by their partners' family members, society and religious communities to conceive (13)(33)(57)(59). If married couples remain childless, polygamy strategies are adopted. In some situations, women described having to sleep with family members of the husband trying try to conceive and prevent divorce or separation(11). It is unclear if this practice is still widely accepted, however it again underlines the importance of having children.

The importance of producing offspring is also described in the setting of adolescent pregnancies both in urban and rural communities. Young girls and boys first must 'prove' their fertility before they are eligible to marriage. Also, social pressure from peers is a factor for early pregnancies (11)(59)(60).

The blame of childlessness in marriage is directed at women, regardless of them causing the problem. This stems from patriarchal cultural and religious belief system that negatively portrays childlessness and puts men in superior position to women(11).

Urban Xhosa men living with HIV were asked about fatherhood. Children were considered a source of meaning, happiness, and fulfillment. Fatherhood was linked to notions of masculinity and social identity, especially for married man. Children give a sense of accomplishment and pride. Having children was a sign of their virility, thus enhancing social status and recognition. It confirms the dominant norms of masculinity (61).

Among Christians, ATR and Hindus (Muslims were not included in this study), children are considered a gift of God and the majority of these studies indicate infertility as a punishment for wrongdoing (11)(62)(57)(58). Within ATR, ancestors are seen as intermediaries who can link the individual with God. Couples from African communities that face infertility believe that seeking traditional forms of healing is necessary to make the ancestors happy and ask for their help or even fix their infertility problems (57).

#### **Social Security and Domestic Support**

A literature review of SSA countries showed that different values were attributed to children. Data from RSA, Mozambique, Zambia and Malawi show that children offer social security, assist with labor, confer social status and secure rights of property inheritance and provide continuity in clan name and family line(58)(63). In settings without the availability of pension schemes people mostly depend on their children to take care of them once they get older (33).

#### 5.3 The Social Determinants of Infertility

As described in the methods section the WHO framework considers health consequences a social determinant of health since it has a negative feedback loop on individuals' social economic position. Therefore, this chapter will not only look at social determinants leading to infertility but will also discuss the consequences of infertility on these domains, since these are important factors to consider when looking at health equity and policy design.

#### 5.3.1 Socio-Economic Position

#### **Social Class and Social Status**

In general infertility occurs in all layers of society and is not considered a direct result of low economic status on its own. However, some authors hypothesize that there is a clear relation, and it is important to consider it as indirect factor. Social status is linked to levels of education, occupation, and income. But as the model on determinants of health shows, is also directly related to the intermediary determinants.

Dyer et al, compared women with infertility problems at their infertility clinic in Cape Town to women who were coming for antenatal services. Women at the infertility clinic had significant lower levels of education and were less likely to be employed. Their hypothesis is that these women have higher risk behaviors due to lack of empowerment or inability to negotiate safe sex, lack of understanding of reproductive health and the possible consequences. They mention that this is not backed up with good regional or national data(64).

#### Consequences of Infertility on Social Status

The consequences of infertility on women's and men's social status have been studied in two different qualitative studies by Dyer et al at the public infertility clinic in Cape Town in 2002 and 2004 respectively (36)(65). Men and women were questioned how their infertility problems influenced their family relations.

About a quarter of the men felt comforted, they received advice and were encouraged to seek help. Just under half felt pressurized and uncomfortable about the continuing questions and jokes that were made. Some also mentioned how their families pressured their wives. When asked about their community, most men reported negative experiences due to their childlessness. They mentioned situations of talking behind their backs, scorning of their wives, and degrading jokes. They would hear comments such as: "Bring your wife, I can do it for you". They also mentioned that men without children were not respected, or considered an adult and not treated as a man from the community: "During ... meetings ..... others will say, what are you talking about, you know nothing, you don't have children, sit down, only those men with children can talk". These encounters led to feelings of embarrassment and hurt. It also led to men avoiding social contacts or pretending to not want children. Some did not feel the effects but were concerned about the impact these comments had on their wives (36).

Many men and women kept their problems regarding infertility a secret or openly lied about it. They felt the need to be careful in disclosing their problems, to prevent gossip. When they choose to speak out it was with women who faced similar problems. This secrecy can be a barrier to receiving support (65)(66).

Most women mentioned experiencing stigma and ridicule from their families and community. This was a major source of pain, to the extent that some did not want to visit their homelands. Many women also described having been sworn, shouted and cursed at. This made them feel like an outcast and inflicted pain, sadness and anger. Only few women could ignore these comments (36)(65).

Women's families would sometimes add to these hurtful experiences through abuse and additional pressure. Childlessness led to bad relations towards the larger family. For some the family would be a source of support and guidance, where older women could give advice how to deal with the problem. Family gatherings were often difficult as they had a different status being childless. Many avoided these gatherings altogether (65). The same phenomena are mentioned by Pedro et al, who interviewed married women dealing with infertility. They mentioned to socially isolate themselves from family and friends, because this was less painful then being confronted with other people's children and their questions (66).

#### **Education**

Globally, and especially in first world countries, highly educated and working women delay childbearing well into their thirties for career purposes. This can lead to infertility since a woman's fertility significantly decreases after 35 years (67). This phenomenon also exists in RSA. Masebe et al analyzed geographic data from the DHS and found that as education of women increases childlessness increases, and the total number of children decreases (68). This data does not distinguish between voluntary or involuntary childlessness.

Levels of education are strongly linked to health and determinants of health such as health and risk behaviors, and preventative service use (69). A study in RSA showed that respondents with higher education levels were more likely to seek healthcare (70). Health literacy also increases with levels of education (71). It is therefore not unlikely that highly educated individuals are more aware of health risks, risk reduction strategies, and are better in navigating through the health system and have the means to pay for the services they need.

#### **Occupation**

Occupation is tied to infertility in different ways. It can be a direct factor when individuals are exposed to risk factors at their workplace. These can be chemicals or toxins that effect fertility and STIs for commercial sex workers.

#### **Income and Economic Status**

In RSA access to quality infertility services beyond primary and secondary health care is determined by one's financial means. Therefore, lack of income or poverty, is an especially important factor impacting fertility as poor people have less access to infertility services and have less treatment options. Berga et al argue that poverty and low income, leads to major stress in individuals which in turn functions as stressor inducing pathophysiological reactions that can lead to amenorrhea and anovulation. The argument comes from observations in an ongoing cohort study in western setting, so no final proof as yet (72). In RSA this is not studied but this could well be the case.

#### Consequences of Infertility on Income and Economic Status

Infertility itself has major implications for an individuals' economic status at multiple levels. A study conducted by Lince-Deroche in 2019 in Johannesburg public clinics assessed the reproductive health needs and costs of individual women accessing different SRHS (44). Many women had out-of-pocket costs for accessing these so-called free services. These included travel costs (43.1%), consultations (8.8%), medications (19%) and childcare costs or others (9.9%). Forty percent of women visiting the clinic for fertility problems had to miss income from work. Of all SRH needs infertility led to the highest time investment for women. In the entire cohort there were two women with catastrophic expenditures, of which one was due to infertility and a positive HIV status. This woman spent 112% of her annual income (44).

A study from Dyer in 2013 analyses frequency of catastrophic expenditures and coping strategies to recover from it (73) in an urban public fertility clinic in Cape Town (Groote Schuur). This is one of the few clinics that offer subsidized treatment, although there is need for co-payment. The fees are tiered according to income (73)(74). The average direct cost for ART treatment was €1311 with indirect costs of €217. Forty-two percent of couples had to borrow money close to the total amount of direct costs. Thirty-nine percent lost income due to taking time off from work. Only 14.3% of the insured received some reimbursement covering less than 30% of direct costs. Twenty-two percent of couples faced catastrophic expenditures, with 51% in the poorest households and only 2% in richest tertile (p<0.01). Sixty-six % of couples were reducing their spending on basics such as food and clothing, and used their savings. Of the poorest patient strata 75% used all their savings. Some couples sold assets, and more than half took extra work. The poorest couples were significantly more likely to incur catastrophic out of pocket costs. All couples in the study were from relatively high socioeconomic status. The authors suggest that the poorest people have no access to ART even in the subsidized clinic due to the financial barriers(73).

A follow-up study in the same clinic with the same respondents was done 4 years later analyzing how households recover from out-of-pocket payments for ART (75). The recovery was below 50%. Complete recovery was reported by 13.7% households. With respectively 5%, 10%, 20% in lowest, middle and richest tertiles. The expenses for ART treatment had serious negative impact on the economic situation of these couples(75).

Evidence from other LMIC showed that remaining childless had many negative financial consequences such as not inheriting, missing children to work with on the field, leading to lower economic positions for people dealing with infertility(33).

#### Gender

Infertility cuts across gender and sex. However, the impact and implications of infertility can be different depending on one's gender in RSA. This is described by men and women in two studies of Dyer in Groteschuur Hospital in Cape Town through in-depth interviews (36)(65).

When asked about their relationships men and women had different experiences, clearly related to their gender. Many women saw infertility as a direct threat to their relationship and marriage. They were deeply worried about abandonment, divorce, or infidelity as a result. They felt they could do nothing to prevent that from happening. Some women experienced multiple break-ups with a partner, because of infertility. Some women from the Muslim communities worried that their husbands would get a second wife(65). Only some mentioned to receive support and sympathy from their husbands and referred to him as their only friend (65)(62).

In a study of Dyer et. al, women were asked about their experiences of abuse in relation to infertility. In total 44.4% affirmed experience of abuse because of their infertility and in 66% this involved their intimate partner. Fifteen percent of these women said their partners had used physical violence against them and in majority of cases this had happened on numerous occasions, the rest mentioned verbal and/or emotional abuse. Twenty-five percent of women also reported this abuse from others, particularly their in-laws (76).

Most men described their relationships to be good and loving. One admitted to an extra marital affair, and one physically abused his wife. Four (out of 27) said their relationship was taking a strain. None

expressed concerns that childlessness would lead to separation or divorce. When asked about the effects of infertility on relationships in general, they had a different opinion. They felt it would negatively impact relationships, leading to divorce or domestic violence towards women. Few also admitted that women suffered more than men. Men described situations where they would be drinking alcohol and abuse their women or their wife's children from previous relationships. Some men agreed that marriage creates expectations, and when not fulfilled the automatic reaction was to look for another woman (36).

#### **Ethnicity**

There is no evidence from literature that suggests that ethnicity is associated with infertility. However, in RSA it could well be an indirect factor. Due to the large income disparities and the apartheid history, it is largely the black South African community which has the lowest socio-economic status and therefore fewer financial means to access services.

- 5.4 Intermediary Determinants of Infertility
- 5.4.1 Environmental, Lifestyle, Biological and Psychological Factors in Relation to Infertility

#### **Material Circumstances and Living and Working Conditions**

In a study amongst informal traders at a junction in Durban women with exposure to biomass fuels used in cooking and dust were compared to women that did not have these exposures (cloth makers). Infertility was significantly higher (P=0.002) in those exposed. Exposed traders were almost 3 times more likely to be infertile compared to non-exposed traders (OR = 2.6; CI = 1.6-4.3)(77).

Sex workers are exposed through their work to HIV and STIs, which increases their risk of becoming infertile. Baral estimates there are 15,000 commercial sex workers in RSA with a HIV prevalence of 60% but says there are no reliable data. There is also an undocumented informal sex work industry that is not visible due to the criminalized nature of sex work (78).

#### **Behavioral and Biological Factors**

#### **Biological Factors**

Some biological factors can lead to infertility. In women, fertility decreases with age. Globally the most common cause is delaying of childbearing. In certain settings (mostly western societies), highly educated women delay childbearing until social and cultural norms are established (67)(79)(80). This phenomenon is not reported from RSA. However, as described earlier Masebe et al did see this trend in the geographic data, it is not clear if this is voluntary or involuntary (68)(73).

Other causes are hormonal, genetical, oncological and anatomic disorders that can occur both in men and women. There is no literature that describes the prevalence of these causes or that suggests that these causes are more prevalent in RSA than in other regions of the world. This is neither for certain racial groups nor population.

#### Body Weight and Body Mass Index

Low body weight and obesity (body mass index (BMI) >30kg/m2) in men and women contributes to disruptions to the endocrine system and therefore contributes to infertility (83). Obesity in women is associated with poor outcomes in ART. Women with underweight (BMI <18kg/m2) are at risk of ovulatory dysfunction and pregnancy complications (81)(82).

The DHS of 2016 shows that obesity in women is quite common (40%) amongst all ethnic groups in both urban and rural settings. Underweight is uncommon (3%) and mostly present in children and young adolescents. In men, obesity is less common with 10% (10). The DHS shows that by age 20, most women are either overweight or obese. Severe obesity increases with increasing wealth for both men and women(10).

#### Alcohol and Tobacco

Alcohol abuse in men induces testicular atrophy, impotence, reduction of libido and deterioration of sperm count. In women alcohol alters hormonal levels which can lead to anovulation, and higher risks of miscarriage. It is advised that couples trying to conceive abstain from alcohol use (79)(81)(82).

Tobacco use in men reduces sperm count, motility, and sperm volume. Women who use tobacco enter menopause earlier, have irregular cycles and spontaneous abortions. Smoking also affects ART outcomes (30)(79)(81)(82).

It is unknown whether couples in RSA are aware of the effects of tobacco and alcohol use on conception. There is no data or research analyzing these risk factors, but the policies and guidelines mention these.

According to the DHS 2016, 8% of women and 37% of adult men smoke tobacco products. Among women, smoking increases with increased wealth and decreases with higher education. Among men this pattern is not seen(10).

Both male and female respondents at the infertility clinic in Cape Town said that infertility would lead to substance abuse(36)(65). Due to frustrations of childlessness couples would start drinking a lot or taking drugs as a way of coping. This could in return negatively influence their general health but also their fertility chances.

According to the 2016 DHS, alcohol consumption is more common among men than women with 61% of men and 26% of adult women ever having consumed alcohol. Sixteen percent of men and 3% of women showed signs of problem drinking. Three percent of women reported consuming alcohol during the pregnancy of their last birth(10).

#### Sexually Transmitted Infections, Sexual Behavior and HIV

STIs are the most common cause of female factor infertility in RSA (23)(83). The 2016 DHS states that 12% of women and 7% of men either had an STI or symptoms during the 12 months before the survey (10). Wand et. al estimated overall STI prevalence at 20% and STI incidence at 15 per 100 person-years (84). Mostly Chlamydia Trachomatis and Neisseria Gonorrhea lead to tubal factor infertility (30)(85).

RSA is facing the largest HIV epidemic in the world. The relationship between HIV and subfertility is bidirectional and complex. Subfertility may precede HIV infection. For women, personal desire and cultural and social pressure to bear children can lead to repeated sex without condom and multiple bedpartners. This increases STI and HIV acquisition risks among women who are trying to conceive (58)(79)(86).

HIV infection is associated with reduced fertility. According to Basu 15-20% of HIV positive people suffer from infertility (not mentioned if these individuals were on HAART)(87).

Lyer et al, analyzed a cohort of HIV-affected couples in RSA for burden and determinants of infertility. They defined subfertility as not being able to conceive after 6 months of aimed conception. They found

that 66% of couples experienced sub-fertility. Predictors for subfertility were HIV-positive women and duration of anti-retroviral-therapy, failure to conceive for over 1 year prior to study enrolment, female partner age and HIV+ status of male partner. If women were HIV- and their partner HIV+, they were 31% more likely to be subfertile. Sero-concordant-positive couples had a 78% higher chance of infertility compared to sero-discordant couples with HIV- female partners (86).

In other studies, women and men mentioned that they would do whatever it takes to get pregnant also in other SSA countries. This potentially leads to both men and women having multiple partners trying to conceive or proving that the fertility problem is not theirs(11)(75)(36)(65).

#### **Psychosocial Factors**

Psychological factors are related to infertility on many different levels. First, there is growing evidence that stress is associated with negative reproductive outcomes and that it may also affect ART outcomes (72)(81)(82). Secondly, the fear of infertility on its own can lead to risky sexual behavior with multiple partners with increased exposure to HIV and STIs(79) (81), which in return increases the risk of infertility.

Infertility has many and quite severe consequences on an individuals' psychosocial health. Dyer et al performed 4 different studies in the public fertility clinic in Cape Town. Two in men and two in women using similar methodologies with the same objectives for men and women. Two studies measured psychological distress with the SCL-90-R checklist amongst men and women visiting the infertility clinic. The control groups consisted of women and their male partner visiting the ANC clinic. Male partners visiting the infertility clinic had significant higher scores for acute psychological symptoms compared to partners of pregnant women, but remained within the upper range of normal and therefore did not indicate disorders of psychological functioning (88). The women at the infertility clinic had significantly higher levels of distress when compared to the control group. Women who also experienced abuse scored worse on the scale for emotional distress. This was not investigated in the control group (89). The authors argue that this reflects the profound negative impact that involuntary childlessness has on the emotional, social, cultural, and economic realities for women in RSA (89). The difference between women at the infertility clinic and ANC was much bigger than between the men facing infertility and their control group. This suggests that women experience a higher degree of distress due to infertility than men.

The other two studies by Dyer et. al. performed in-depth interviews with each 30 respondents visiting the infertility clinic. A minority of men stated not to be affected by infertility at all. The majority of men reported feelings of sadness, pain, and emptiness. They mentioned to feel down, guilty towards their partners and family, felt left out, and heart broken by the situation. Many also felt inadequate. Thirty percent of men described to also feel angry and frustrated. "You see; you are a man because you have children. But if you don't have children some other guys will say you are a woman" (36). All women interviewed articulated intense emotions when speaking about their childlessness, such as burning pain, anger, deep sadness, bitterness, guilt, loneliness, and desperation and 2 of them had suicidal thoughts. The general opinion was that all men and women want children. Many mentioned that wanting a child is their only wish in life, and without it there would be no purpose in life. These finding are confirmed by Pedro et al. in the Western Cape in 2015 (90). The 21 women interviewed mentioned that a diagnosis of infertility led to a turmoil of emotions such as sense of shock, denial, disappointment, self-doubt, failure, isolation, anger, blame, frustration, and such profound sadness that some referred to as depression(90).

#### 5.4.2 Health System and Infertility

The structure of the health system is outlined in the background. This chapter will look at issues around quality and accessibility of infertility care and health services in RSA. In general RSA faces gaps between implementation of policies and service delivery (54).

#### **Quality and Accessibility of Health Care Services**

Infertility can be the (unintended) result of low-quality health care services and practices. Unsafe abortions, unhygienic obstetric practices, poor management of pelvic infections can all lead to infections that block the fallopian tubes (29)(30)(31). These causes are not mentioned in the available literature of RSA. The magnitude to which these causes contribute to infertility in RSA therefore remains unclear. RSA legalized abortion in 1996 (91). In 2008 amendments were made that allowed trained and registered nurses to provide abortion. Since then, deaths and complications from unsafe abortions have reduced. According to Favier et al there is geographic disparity in accessibility of abortion services between provinces and urban and rural areas. Illegal abortions still happen(92). It is unclear to what extent complications of unsafe abortions lead to infertility in RSA(17)(28)(93).

#### **Affordability**

ART services in RSA always require out-of-pocket payments. The costs differ largely between private and public sector and are unaffordable for the majority of South Africans dealing with infertility (23)(87).

The national tertiary ART units depend on public funding and cannot offer these services for free. The costs are usually dependent on a couples' income level and depend on their insurance. Low-Cost IVF care is offered in most national tertiary ART units (73)(74) and just recently, also in the private sector.

Dr. Basu expresses his worries about the inaccessibility of infertility care for most of the population in an editorial published in the South African Medical Journal. Individuals can access these services only by making high out-of-pocket expenditures (travel, accommodation etc.)(87).

#### **Availability**

RSA offers world class ART services in the private sector. There are few infertility specialists and infertility care is not widely taught at the medical faculties. In general, most specialists work in the private sector and in urban areas.

Dr. Basu claims that there is a lack of skilled providers, lack of diagnostics, high costs and services are geographically not equally distributed. Couples entering primary health facilities are not met with the right attitude and there is a delay in referring. Most couples invest significant time and money and make high direct and indirect costs(87).

It was impossible to find research on waiting lists for ART treatment in RSA. Dr. Matsaseng mentioned in his interview that the current waiting time for couples accessing ART treatment in the public Tygerberg Hospital in Cape Town is about 8 tot 9 months. This is very long for couples in need of ART treatment.

#### **Accessibility**

The primary entry point for most infertile couples seeking care is the public primary health care system (94). Clients of these clinics mentioned in interviews that it takes years before they reach the infertility clinics in tertiary hospitals. Dyer et al found the average time to be 4.8 years for women who live in the catchment area of the hospital. Others also mentioned delays in referrals (87). Commonly, women presenting at public health services were turned away due to lack of resources for investigations or infertility treatment (94). Because African respondents often believed that their infertility was caused by

problems with their ancestors, they first visited traditional healers to fight off evil spirits (57)(94). Men and women also use traditional herbal remedies as a first step in overcoming infertility(95)(96).

The Southern African Society of Reproductive Medicine and Gynecological Endoscopy (SASREG) says there are 18 centers of excellence offering infertility services(97). Another international platform, IVF-worldwide (Figure 6), mapped 47 facilities that offer IVF(98). They are all located in urban areas. These sources do not distinguish between private or public facilities. RSA has 4 public tertiary hospitals which offer ART services (87)(74). Travel distances are long for couples that don't reside in these urban areas. Currently, infertility care is poorly accessible due to the long travels and time investment needed for checkups and treatments.



Figure 6: Distribution of IVF Centers in SSA (98)

#### **Accommodating**

I was not able to find information on how couples experience the fertility services that they seek. Dyer 2002 et al looked at reproductive health knowledge of women seeking infertility services at the infertility clinic in Cape Town. None of the respondents could give a basic summary of events leading to conception. The cause of infertility was unknown to 50%. This, whilst the mean duration of fertility upon presentation was 4.8 years. Examination and diagnosis were valued more than "miracles" in treatment outcomes(94).

#### 5.4.3 Social Cohesion and Social Capital

#### **The Private Health Sector**

RSA has a vast network of private fertility clinics. They offer most of the ART in the country and fulfill a regional need. More and more of these clinics are now also offering LCIVF cycles and promote it on their websites. This to better cater to the financial constraints of most of the population. RSA also attracts international travelers from within and outside of Africa for infertility treatments for what is called "IVF/Egg safaris" (99).

#### The Health Insurance Companies

According to the Council for Medical Schemes (CMS) RSA had 78 medical schemes in 2019. The total number of medical scheme beneficiaries was 8.95 million. As previously described, the fact that infertility is listed in the PMB list should mean that insurance companies cover the costs of infertility treatment.

Until now diagnostic workup was covered and not treatment (100). Recently, the country's largest health insurance, called Discovery Health Medical Scheme promised to cover limited cycles of ART under strict conditions. They are the largest scheme in RSA with 31% of total number of beneficiaries (101).

#### <u>Infertility Awareness Society of South Africa (IFAASA)</u>

IFAASA was established in 2013 (102). It is a non-profit organization aiming at supporting South Africans living with reproductive health issues, through education, research and advocacy, and educating the public and industry about reproductive health diseases. They act on behalf of the community of persons affected by infertility as advocates, and lobby for fair support and equal access to public and private sector treatment.

It has engaged in a 7-year battle with the medical health insurance companies for financing of quality infertility care in the PMB. After 5 years of discussions and by partnering with SASREG, IFAASA were successful in their plight. Their legal team feels confident it can overturn the exclusion and have started a public fundraising for this.

They also participate in the organization of a yearly conference that brings together individuals dealing with infertility, fertility specialists, psychologist and other professionals and collaborate and coordinate with other partners (102).

#### **SASREG**

This society represents a vast group of health staff working on infertility, including gynecologists, embryologist, theater staff, nurses, psychologist, and social workers. "The society serves to protect the interests of the patients undergoing fertility treatment" (103).

They promote high quality care for all in need of treatment, represent members and defend their interests to the government and other health care bodies. They aim to provide and improve medical education (conferences, guidelines, workshops) and promote research in the field. They negotiate preferential prices with pharmaceutical companies and serve as distributor of information between health care workers. They set up an accreditation system and many protocols for infertility clinics which are openly published and accessible on their website. The website also provides links to fertility clinics that received the accreditation (103).

#### **Traditional Healers**

Respondents in most of the studies have mentioned that they visit traditional healers early in the process when not conceiving. This is common for black African, Hindu and Muslim respondents (11)(57)(64). These traditional healers are not recognized as formal stakeholders by the previously listed stakeholders. Yet they are for many persons affected by infertility the first step in their quest to deal with infertility.

#### **Religious Leaders**

Just like traditional healers, religious leaders are not frequently mentioned as an important group. However, as Baloyi and Sewpaul describe they often interact with persons dealing with infertility and could have a major role in breaking stigma, improving the position of women, organizing support, and referring to the right care. They can also influence perceptions and can strengthen the position of women(11)(57).

#### **Research Groups and Universities**

RSA counts 26 public universities and 10 medical schools(104). The research group linked to the Groote Schuur Hospital in Cape Town has produced a vast body of articles concerning infertility, its consequences and treatment. The public tertiary hospitals providing ART were also the first to start implementing LC-IVF services which was later followed by the private clinics.

#### **Public Figures**

I have not been able to find famous or well-known South Africans speaking out about the topic of infertility as we have seen in other African countries (Namibia and Burundi with the first ladies speaking about it). They can be especially important in the creation of awareness.

#### **International Donors or NGO's**

I have not been able to find an international donor or NGO that has projects, programs, or a lobby for infertility in RSA. Until now there has not been a lobby by human rights activists or lawyers when it comes to people dealing with infertility in RSA.

#### **African Network and Registry for ART (ANARA)**

ANARA is a platform that enhances collaboration between ART centers within and between African countries. It collects and disseminates scientific data on availability and practice of ART in Africa. Their aim is to strengthen the ART network to reduce the burden of infertility (105).

#### 6 Discussion

This thesis analyzes and explores existing knowledge about the extent of the infertility problem in RSA, its determinants, and its consequences for creating a better understanding of this problem. It also reviews ways in which infertility is addressed now and aims at suggesting recommendations for improving preventive and supportive policies for people dealing with infertility in RSA.

#### Magnitude of the Problem

Infertility is a very big problem. The exact prevalence of infertility in RSA is not well researched nor documented in population-based studies. The current estimate of 15-20% of couples facing difficulties in conceiving, is repeatedly quoted in reports, research and government communication, but there is no good reference to this figure.

Therefore, the exact magnitude of the problem is unknown and probably underestimated. The prevalence of male factor infertility is even less researched with one study examining semen profiles without clear reasoning or mention of the implications of the results on infertility. Most of the studies done are performed in urban areas with small patient groups that cannot be extrapolated to RSA.

The DHS holds an entire chapter on fertility but not one question is dedicated to infertility or difficulties conceiving. Currently well represented data on TTP and infertility is limited in many countries (106). Polis et al, suggested a research framework to estimate infertility based on data from the DHS. Their estimates of infertility using this method were similar to data from small scale research in equivalent populations in Nigeria(106). The NDOH writes in their integrated SRHR policy that they have well established data collection systems, for example for maternal deaths. So far there is no data on infertility published from there.

#### **Causes and Determinants**

The causes of infertility in RSA are understudied. Several studies from LMIC and RSA show that the most prominent cause of infertility is secondary infertility (83)(30)(31) which is preventable to a large extent. Female factors are mostly related to blocked tubes which for a majority are a result of preventable causes such as PID, STIs, HIV/AIDS and to some degree also to infections after unsafe abortions, endometriosis, previous pelvic surgery or previous tubal ligation (23). It is not known what the exact magnitude is of preventable causes in RSA.

Causes of infertility in men are not well studied in RSA, and this is a worldwide problem. Dr. Matsaseng mentioned mostly chronic conditions such as HIV, hypertension and diabetes, conditions that could be treated well and thus prevent infertility.

Lifestyle factors influencing infertility are also very common in women, although these factors have not directly been studied in relation to infertility. The importance of addressing these factors is underscored by the global burden of disease report that looked at what 10 factors drive most death and disability in RSA (Figure 4). The national policy and guideline do mention these factors and state that collaboration with other programs should be made. However, there is no specification of the strategy or goals regarding this.

Some groups in RSA are more vulnerable and at higher risk for becoming infertile. Firstly, these are the large number of PLHIV in RSA. Secondly, individuals with STIs since the prevalence is high. The integrated

policy of the DOH mentions the importance of prevention and the need for collaboration with other health care departments. A strategy on how this should be achieved is currently lacking.

Thirdly, Infertility in RSA is strongly linked to socio-economic-position in society and also leads to large disparities within the society. There is circumstantial evidence that shows that women seeking infertility services had lower levels of education and were less likely to be employed. It is hypothesized that these women have higher risk behaviors, due to lack of empowerment, inability to negotiate safe sex, lower knowledge on reproductive health and its implications (64).

All in all, the determinants are many amongst which STIs, HIV, lifestyle, gender imbalance, low SES and inaccessible fertility services are most prominent in RSA. The societal and cultural value of having children is very high and issues of infertility are surrounded by a lot of secrecy and stigma. Individuals dealing with infertility face a multitude of different problems.

#### Consequences

The consequences of infertility are well studied in RSA. This review has shown that respondents dealing with infertility suffer tremendously at many levels. The high pressure to conceive in combination with stigma and silence surrounding it, isolates people, making them more vulnerable and excluded from society.

Stigma is mentioned as a big problem by most respondents in different qualitative studies (36)(62)(65). Stigma negatively impacts on people's lives and is also a barrier in accessing services which worsens their situation. This is also mentioned in the policy and guidelines of the government as well as editorials by Basu. Women carry the highest burden as they are often blamed for infertility. It reinforces gender imbalances in relationships if men automatically blame their wives.

For women living with HIV the burden is even higher. When women have childbearing desires, they have higher risks of becoming infertile then others in the population. In addition, they have concerns about safe conception to prevent spreading the virus to their partners or unborn child (86). And they must deal with stigma around HIV and now also their infertility.

The inability of the health system to cater to the needs of the individuals dealing with infertility has negative consequences on individuals' mental health and lives. In the absence of infertility services individuals seek other sexual partners to see if they can conceive which leads to more exposure to STIs and HIV. This in return increases the chances of secondary infertility

In absence of psychosocial support individuals often resort to substance abuse. This further reduces their fertility and leads to gender-based violence and further dependence on their partners also for financial support and in accessing services (36)(65).

Infertility negatively impacts one's socio-economic-position due to the high financial burden for couples accessing infertility services in combination with travel and time investments. This again has negative impact on their mental health.

All in all, infertility both for women and men, has a tremendous impact on individuals' mental health, health status, economic status and their position in society as well as their relationships with family, friends and partners. There is probably no other health problem that has such a detrimental effect on peoples' lives and living conditions.

## **Access to Prevention and Care**

This study showed that the general health system in RSA itself is an important intermediary determinant to infertility. The system is overburdened, understaffed and there is competition for resources. It goes beyond the scope of this study to analyze the health systems strengths and weaknesses, but various studies highlighted problems with limited numbers of skilled health care workers, limited service-delivery points, that are not always well distributed geographically, high levels of co-payments in both public and private sector, stigma and misinformation amongst health care workers that delay referrals and many others (87).

The specialized high quality infertility private services are not accessible for most of the population and the ones who can are dealing with long waiting lists and high costs(107). There are only 4 public infertility clinics. This highlights the large inequities for people accessing infertility services in RSA.

Although infertility is not linked to sex, ethnicity, or geographic location, one could argue that in RSA these factors are important for access to infertility services. The large inequities in income follow racial lines with poor black South Africans living in rural areas and shanty towns. They have less access to services due to their location, their inability to finance out of pocket spending for travel, diagnostics, and treatments.

#### **National Response**

The government acknowledges the problem of infertility and has developed an integrated policy for SRHR and safe conception and infertility treatment guidelines (23). As far as we know, RSA is the only country in SSA that has such extensive integrated human rights-based guideline. The guidelines and policy are aligned with regional and international frameworks and international recommendations (23).

The integrated SRHR policy specifically mentions vulnerable groups that have difficulties accessing the services and states they deserve special care and interventions. They mention costs, geographic location, Socio-Economic-Position and to some degree gender but all in the general context of all SRHS. Individuals dealing with infertility are not mentioned as a special group.

The guideline also clearly outlines a medical approach for PLHIV and mention them as a vulnerable group. It mentions safe conception strategies as well as treatment options when infertility occurs. But the guideline does not mention what type of special interventions are needed to overcome these structural barriers.

The good part of the policy and guideline is that it aims for integration of infertility services within SRHR, especially since prevention of STI/HIV, teenage pregnancies and complications of labor are very important determinants of infertility in RSA. This policy and guideline also speak about the importance of providing psychosocial support to people dealing with infertility and thereby acknowledges the tremendous burden these people face. Unfortunately, the guidelines or policy do not specify how this support is to be organized and if it is offered free of charge. There is little known about the dissemination and implementation of this policy and guidelines. The policy lacks an implementation strategy on how to reach health care workers and stakeholders.

The results of not covering expenditures for infertility treatment and work up is that an already vulnerable groups become even more marginalized for not being able to access the services. This is against the aim of the government's policy. Multiple authors support the argument that the government should cover the costs for treatment of infertility and highlight the importance of future economic

growth by investing and creating a reproductive and economically active generation to grow and improve GDP in the future. They calculated that provision of limited ART could deliver a net positive outcome to the government (56)(108). Currently the country is facing the effects of the covid-19 pandemic with overburdened health care systems which make this shift in budget allocation even more challenging.

#### **Public Awareness**

The integrated policy mentions the importance of engaging civil society groups and others in holding the government accountable to their own commitments to improve the health of individuals with infertility and uphold human rights. It is very important that stakeholders actually engage with one another, but there is no wider platform to do so. The only NGO that lobbies for individuals dealing with infertility is IFAASA.

#### Limitations

This study is a desk review of available literature and documents. Most of the literature used is from RSA itself. One limitation is that the data usually are from small scale, singular studies and therefore lack reconfirmation of findings by other studies and authors. The subject of infertility is a neglected public health issue which is reflected in the amount of evidence. The determinants of infertility in RSA are understudied. Most data stem from qualitative research. Quantification of the magnitude of these issues is lacking. There is a knowledge gap about what programs and policies have proven successful in the context of infertility in SSA. The design of this desk review did not allow for conducting key informant interviews with different stakeholders, that could have provided information about how the policy and guideline are implemented.

# 7 Conclusion and Recommendations

#### 7.1 Conclusions

- 1. Infertility in RSA is a big problem, although the exact magnitude is unknown. There is old research and quite some circumstantial evidence that supports this point.
- 2. The WHO framework worked well in studying the many determinants to the problem of infertility. In RSA specific structural determinants were identified that are important for addressing infertility. These include issues around the cultural value of children, the position of women, gender and inequities within the Socio-Economic-Position of individuals in society. These factors influence intermediary determinants for infertility in RSA such as exposure to toxins and environmental hazards in workplace, life style factors as in obesity, tobacco-and alcohol abuse, untreated diseases such as diabetes, STIs and HIV as well as psychological factors due to high stigma and burden for individuals dealing with infertility.
- 3. The health system is overburdened and understaffed and does not cater well for people dealing with infertility. There are many barriers for individuals trying to access services. The most important is high out of pocket payments, which make services inaccessible for most. Other barriers include geographic distribution, limited services, long waiting lists, stigma and delays in accessing services due to seeking of care with traditional leaders.
- 4. The framework helped in showing that infertility has many negative consequences for the socio-economic-position of individuals in society. People deal with stigma from their family and society and have problems within their relationship. Women must deal with gender-based violence and blame. This has severe consequences on their health and mental health status. Furthermore, people make catastrophic expenditures to access infertility services and expose themselves to factors that increase their risk of infertility.
- 5. The government of RSA has done an outstanding job in creating the integrated SRHR policy and treatment guidelines on infertility. They should be seen as an example for other LMIC countries and especially within the region. This policy is a demonstration of South Africa's political will to deal with infertility as a disease. The implementation of it is still lagging.
- 6. The international trend whereby infertility does not receive enough attention in international fora, development partners' agendas and NGO's working in the field of SRHR is also seen in RSA. There is only one local NGO that focusses on infertility awareness and support which is a locally led organization.
- 7. The costs of current ART treatments are high in RSA. There are promising low cost treatment options for couples with infertility underway also in RSA. Prevention of infertility remains the key intervention that could result in reduction of the burden of infertility.
- 8. The causes of infertility are multifactorial and warrant a public health-based approach that focuses on integration of infertility services in SRHR services.
- 9. The framework developed by WHO has proven to be very applicable and suitable for the structural analysis of the social determinants for infertility and this study is the first to have used it for infertility analysis in LMIC.

### 7.2 Recommendations

#### **Better Data Monitoring and More Research**

- The NDOH should seek collaboration with the National Health Statistics department and universities for quantifying the magnitude of infertility problems of both men and women, its causes, and consequences.
- There is need for a better monitoring and evaluation system and this should be added to the DHS.
- The NDOH should integrate infertility indicators in the systematic data collection programs that are currently in place.

# **Better Implementation of the Policy and Guideline**

- NDOH should develop strategies for the implementation and dissemination of the integrated SRHR policy and safe conception and infertility guidelines. A coordinated approach is needed to ensure that service providers are trained, skilled and aware of the guidelines and referral paths and to reduce stigma within the health care system.
- Prevention should receive much more attention within the implementation strategy.
- Proper psychological support should be available for individuals dealing with infertility. NDOH should seek collaboration with the mental health department (part of primary health care) and with the South African federation of mental health.
- The NDOH should identify marginalized groups who are vulnerable to the causes and consequences of infertility and develop specific strategies for reaching them. These should include education about prevention (lifestyle, STIs, HIV), and address accessibility of services for these groups.

#### **Strengthening of Service Delivery**

- Better collaboration with NDOHs programs dealing with HIV, STI, non-communicable diseases, safe termination of pregnancy and healthy lifestyles (smoking, obesity, alcohol abuse and toxins in the workplace. These should create awareness of the problem of infertility and promote integration of services.
- Improve access to services by collaborating with all 8 university hospitals that should offer infertility services in their public clinics. Universities can train more health workers on aspects of infertility and provide research opportunities.
- Develop interventions for reducing inequity in health care and improve the accessibility of services for people dealing with infertility.
   The NDOH should continue efforts to strengthen the health care system across the board.

#### **Increasing Awareness**

 Develop interventions for improving infertility awareness and education through different channels ranging from television, radio shows, social media campaigns and comprehensive sexual education in schools. Include traditional healers, religious leaders, and famous South

- Africans in these interventions. The awareness campaigns should also tackle issues of stigma and gender.
- Seek collaboration with international donors, NGOs and stakeholders in the HIV field that have experience in lobbying and dealing with human rights issues. The aim is integration of infertility in existing programs and provision of free services.

### **Specific Interventions for Dealing with the Consequences**

- The government should acknowledge the marginalized position of women regarding infertility and the wider context and address it with targeted policies.
- The government and NDOH should move towards covering expenses for infertility treatment within the NHI. There is a need for more equity and thus a need for more resources and an adequate funding strategy. This should include first line fertility treatments provided in the 2<sup>nd</sup> line health system. Tertiary care of ART should contain a limited number of LCIVF cycles based on an analysis of minimum costs of these services. Due to high burden of disease it might not be feasible to cover this for all the inhabitants. NDOH should strive to cover treatment costs based on income levels and socio-economic status.
- Specific campaigns and interventions should be developed for reducing stigma and exclusion of people dealing with infertility. Reduction of Gender-based violence should be an important message in these campaigns. Messages are needed at national level, but also need to reach communities.

### **Strengthen Civil Society and Private Sector**

- A stronger response of civil society is needed to hold the government accountable for the implementation of its policies and guidelines. They can play a role in reducing stigma and provision of support to individuals and couples dealing with infertility.
- NDOH should seek collaboration with the private sector to address economic structural factors that hinder access. One could think of spreading the LCIVF options to the private clinics, making it more affordable.
- Fertility treatment services should support the establishment of patient support groups.
- IFAASA or universities could consider creating a multidisciplinary platform where workers on infertility can share knowledge and experience and learn from each other.

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