POLICY BRIEF

Share–Net
International
The Knowledge Platform on
Sexual and Reproductive Health & Rights

Addressing Infertility within Sexual and Reproductive Health: A Commitment to Human Rights and Sustainable Development

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Key Messages

- Infertility is a reproductive health issue that has been neglected within the global sexual and reproductive health and rights agenda.

- Infertility impacts over 180 million individuals worldwide, equally affecting men and women.

- Women and girls often bear the societal burden of infertility and its consequences, including gender-based violence.

- Access to fertility care shows large inequities within and between countries.

- A country-specific national action plan is needed to address the detection, prevention, and management of infertility and related stigma.

- Addressing infertility means addressing human rights and gender inequality, contributing to achieving SDGs.

Although recognized as central to reproductive rights, addressing infertility has been neglected within the global sexual and reproductive health and rights (SRHR) agenda. Growing awareness of the magnitude and consequences of infertility has garnered increased national, regional, and international attention to the detection, prevention, and management of infertility and infertility-related stigma. In this policy brief, we document the magnitude and impact of infertility and its connection to broader human rights principles, a SRHR agenda, and sustainable development goals. We call on policymakers, public health and health care providers, and other stakeholders to develop a national action plan to address infertility and infertility-related stigma. We outline 5 priority areas to engage, educate, address, and advocate for a broader focus on infertility and provide country-specific examples of programs designed to meet these priorities.

MAGNITUDE AND IMPACT OF INFERTILITY

Infertility is a reproductive health issue and refers broadly to the situation that a pregnancy occurs later than desired or not at all (1,2). Efforts to address infertility for all individuals and couples have long been recognized as central to reproductive rights, but have been neglected within the global sexual and reproductive health agenda (1,3). This absence of programmatic focus is far-reaching with infertility estimated to impact at least 180 million individuals worldwide, equally affecting men and women (4). Fertility care encompasses the prevention, diagnosis, and treatment of infertility, yet these services are overlooked as part of essential healthcare. Accordingly, large inequities in access to fertility care persist within and between countries due to significant geographic, demographic, economic, social, health infrastructure, and regulatory barriers, ultimately impacting the attainment of reproductive health and rights for all (5-7).

The implications of infertility extend far beyond a diagnosis. Infertility has been associated with adverse physical and mental health, economic strain, stigma, gender-based violence, and relationship abandonment (5, 8-15). Gender inequities also persist in the absence of coordinated efforts to address infertility. Men and women are equally likely to be infertile, yet women often bear the societal burden and blame of infertility, particularly in settings where a woman's identity and value are closely tied to her ability to bear children (11,14). Finally, fears or myths of the causes of infertility have hindered public health services, including vaccination campaigns, contraceptive uptake, and safe sex practices (16-18).

Moreover, infertility arises from preventable factors, including sequelae of poorly managed or untreated infections and environmental and lifestyle exposures (17). Taken together, progress toward achieving the United Nation's Sustainable Development Goals (SDGs) by 2030 requires a more concerted effort to address infertility detection, prevention, treatment, and its consequences (Figure 1). These goals cannot be attained without an increased focus on infertility as an essential component of family planning and reproductive health services.

A BROADER COMMITMENT TO HUMAN RIGHTS

A broader commitment to infertility can be endorsed through multiple human rights treaties and declarations (6). In keeping with reproductive rights, a person's ability to decide the number, spacing, and timing of their children and the means to do so extends to both preventing unintended pregnancy as well as becoming pregnant. Concerns over population growth combined with limited resources have constrained global family planning programs to predominantly focus on contraceptive access. Although these efforts remain extremely critical for ensuring individuals' reproductive
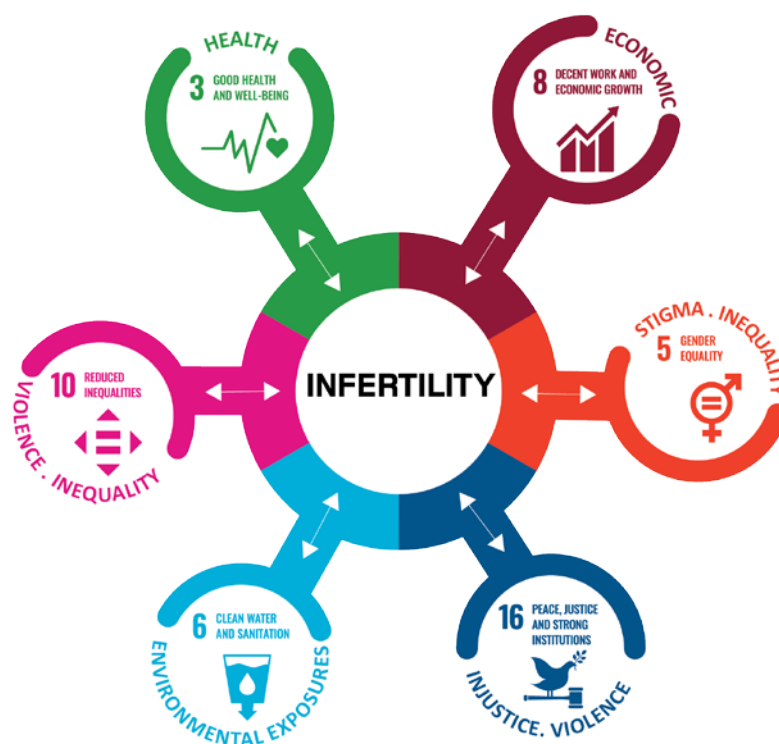

Figure 1: The connection between infertility and SDGs

autonomy, it fails to acknowledge the parallel needs of individuals who want to become pregnant and the overwhelming impact to their lives when they cannot (1). Infertility also encompasses the rights to health, equality and non-discrimination, privacy, form a family, and the benefits of scientific progress (6).

Growing awareness of the magnitude and consequences of infertility alongside further advancements in affordable treatment options (19-21), has increased national and international attention to infertility. Several countries have started to incorporate infertility programs and services into their national health plans, human rights monitoring, and reporting of their progress toward SDGs (6). However, a more coordinated national, regional, and international strategy is needed to address the current and emerging infertility-related health needs and priorities within countries, rather than a lingering focus on priorities outlined decades prior.

STEPS TOWARD ACTION

A significant investment from the global health sector is needed to ensure these rights are realized. In October 2019, Share-Net International, a knowledge platform on sexual and reproductive health and rights, convened its first Co-Creation Conference of researchers, public health officials, policymakers, and advocates to engage in efforts and develop knowledge products on "Breaking the Silence Around Infertility." The products were developed to influence policy and practice at the country level. A narrative review was prepared that identified a number of programmatic, policy, and research gaps to address infertility (17). This narrative review along with a growing body of literature on the need to incorporate infertility within the global SRHR agenda served as the basis for the development of this policy brief.

We urge policymakers and other stakeholders to take steps toward the development of a national action plan for the detection, prevention, and

management of infertility and infertility-related stigma. This will require significant stakeholder engagement, training and education for the general public and providers, and advocacy and implementation to develop or scale-up existing programs and services, and research and public health infrastructure to support these efforts (Table 1). The success of a national action plan on infertility rests on its ability to address gaps in research, programs, and services, generate linkages and collaborations across sectors, and establish political will and attention. Specifically, a national action plan would require sustained investments in five priority areas to address infertility and infertility-related stigma:

Five Priority Areas to Address Infertility

1. Public Awareness on Infertility and Infertility-related Stigma

2. Data Systems to Detect and Monitor Infertility and its Causes and Consequences

3. Prevention Programs to Address Infertility

4. Quality Fertility Care, Treatment, and Psychosocial Support Programs

5. Research and Public Health Infrastructure and Regulation

Table 1 provides an overview of key actions that can be used to engage, educate, and advocate for change around infertility. Components within these priority areas can be tailored to best meet the needs and priorities of different countries. **Table 2** provides examples of country-specific programs and services designed to address infertility or infertility-related stigma across these five key priority areas. However, these approaches will have limited effect without a comprehensive national strategy on infertility and infertility-related stigma. A national strategy provides the framework for coordination, sustainability, and accessibility of these programs and services.

CONCLUSIONS

Infertility and its consequences have been largely neglected in sexual and reproductive and global health agendas, but there is growing recognition of its centrality in ensuring sustainable development and human rights (3,6,17). Access to infertility services and reduction of related stigma has the potential to reduce gender inequities by creating greater awareness of infertility for both men and women, options for individuals to overcome this condition, and opportunities to empower women (22).

Policymakers can use priority areas outlined in this

"Reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health."

1994 International Conference on Population and Development in Cairo

policy brief to establish country-specific goals and timelines that best meet their policy and program needs. In utilizing and addressing these recommendations, policymakers and other stakeholders can identify current gaps in programs and services, areas for cross-sector collaboration, and ways to leverage funding and resources to ensure sustainability of investments. Many of these efforts build on existing programs or can be integrated within cross-sector efforts (e.g., including questions and education on infertility in primary care settings or addressing infertility-related stigma and myths in comprehensive sexual education). As such, we can ensure that appropriate, ethical, feasible, and locally relevant approaches can be developed to best meet the sexual and reproductive health needs of individuals globally.

Summary

In order to address these emerging priorities, countries can prepare by focusing on:

- Increasing awareness of infertility across multiple sectors and the establishment of political will to address this topic.

- Expanding data on the extent, causes, and consequences of infertility and barriers to access and receipt of quality fertility care and infertility screening and treatment.

- Identifying affordable options for infertility treatment, establishing regulatory frameworks for its provision, and ensuring these services are equitably accessible.

- Expanding the health care workforce equipped to provide diagnostic and affordable [basic] fertility care services and treatment.

- Providing psychosocial and peer support for individuals experiencing infertility.

- Expanding programs that can prevent infertility, including programs to address sexually transmitted infections, unsafe abortion, postpartum infections, obesity, smoking, and environmental toxicants.

- Enhancing comprehensive sexual education to include information on fertility awareness, signs and symptoms of reproductive health concerns, and infertility more broadly.

- Investing in research and public health infrastructure to monitor infertility, its risk factors, related stigma, as well as quality fertility care, treatment, and support.

- Enhance regulatory systems to incorporate infertility policies and regulations within their health systems and reproductive health care.

- Addressing infertility-related stigma and factors that perpetuate this stigma, such as poverty, gender stereotypes, and lack of access to education for girls.

Table 1. Priority Areas for the Development of a National Action Plan to Address Infertility

Priority Areas	Stakeholder Engagement	Education and Training	Advocacy and Implementation
Public Awareness on Infertility and Infertility-related Stigma	• Establish infertility as a priority and create awareness within existing SRHR programs (e.g., HIV/STIs, family planning). • Examine the intersection of infertility with other cross-sector efforts and engage with colleagues in those areas. • Convene an advisory group of stakeholders (researchers, clinicians, policymakers, religious leaders, advocates, and non-biomedical/traditional healers) working on infertility or other related sectors. • Engage donors and funders in efforts to address infertility.	• Provide educational resources on facts and myths about infertility into sexual and reproductive health education programs. • Provide educational resources on causes of infertility and reframe infertility as a reproductive health issue, rather than an issue of masculinity or femininity. • Provide educational resources on age-related infertility. • Provide training for providers to increase awareness on culturally-component and person-centered fertility care and treatment. • Create educational opportunities to challenge predominant norms around fertility and parenthood. • Provide infertility resources in multiple accessible formats and languages.	• Advocate for investments and create awareness on the need for infrastructure to support infertility research and programs, including infertility-related stigma. • Expand family planning and other SRHR services to encompass basic fertility care. • Address predominant norms around fertility and parenthood, particularly as it relates to limited seeking of information and care by men or blame for women. • Include non-biomedical and traditional healers in educational efforts (e.g., peer support groups) to address and de-stigmatize infertility.
Data Systems to Detect and Monitor Infertility	• Identify existing databases or create new data systems to monitor infertility, stigma, causes, and services, including ART and non-ART treatments, and attendant disparities. • Engage with researchers and clinicians in developing and expanding these data and detection systems.	• Develop approaches for providers or researchers to monitor infertility, including identification within health records. • Include standard definitions of infertility within data systems for comparison. • Establish inclusive definitions of infertility (or unfulfilled child wish) for LGBTQ+ and other populations. • Expand education and training on diagnosing infertility for primary care providers.	• Implement data systems to identify the magnitude, causes, stigma, and disparities/barriers related to infertility and fertility care. • Utilize population data, health records, or other reporting systems to inform program and policy development on infertility and infertility-related stigma.

Priority Areas	Stakeholder Engagement	Education and Training	Advocacy and Implementation
Infertility Prevention Programs	• Engage with stakeholders in public health programs that directly address causes of infertility (e.g., HIV/STIs, safe abortion and delivery) or risk factors (e.g., environmental health, smoking cessation, obesity prevention) and identify linkages across sectors. • Engage researchers in understanding causes and risk factors for infertility.	• Integrate topics related to infertility within comprehensive sexual education programs. • Provide educational resources on fertility awareness (e.g., menstrual cycles, fertility windows, lifestyle and environmental chemicals that affect fertility) and identifying irregularities and abnormalities that may necessitate further medical support. • Provide educational resources on normal changes with hormonal contraception use and prevent misconceptions around fertility and contraception. • Educate health care providers on the causes and risk factors for infertility	• Expand existing public health programs and services that directly address causes of infertility (e.g., HIV/STIs, safe abortion and delivery) or risk factors (e.g., environmental health, smoking cessation, obesity prevention). • Incorporate and implement prevention strategies identified by stakeholders. • Advocate for coverage of prevention services and fertility care under a universal health coverage benefits package

Quality Fertility Care, Treatment, and Psychosocial Support Programs	• Convene the advisory group to identify unmet needs in quality fertility care and treatment, including
	
	  o barriers to accessing infertility services
	
	  o approaches for equitable access to care, including psychosocial needs.
	
	  o gaps in service coverage for men
	
	  o emerging needs or issues (e.g., oncofertility)
	
	• Engage traditional or non-Western treatments into infertility management approaches
	
	• Encourage engagement of men in fertility care and treatment
	
	• Research the efficacy, safety, and cost-efficiency of different infertility methods within country contexts
		• Expand local gynaecologic services and train health care workers on fertility care
		
		• Identify local fertility care and services and inform clinicians of these referral resources
		
		• Provide in-country training and education to support specialised fertility specialists (doctors, embryologists, nurses and counsellors)
		
		• Develop training for primary care and other providers on fertility care (examination, diagnosis, treatment) and psychosocial support services
		
		• Ensure training is culturally-competent and person-centered
		
		• Educate the public on effective treatments and avoidance of supposed
			• Provide equipment and supplies to expand local fertility care, psychosocial and peer support services
			
			• Establish locally-relevant treatment protocols, ethical guidelines, and regulatory frameworks that are equitable (e.g., clear language that is not exclusionary)
			
			• Identify (and evaluate) locally relevant approaches to prevent infertility or provide infertility services, including affordable ART or IUI and primary prevention strategies.
			
			• Provide public financing or public sector support for affordable [basic] infertility services and psychosocial support
			
			• Organize new or empower existing advocacy and peer support groups on infertility
			
			• Advocate for the inclusion of fertility care and treatment in national insurance schemes

Priority Areas	Stakeholder Engagement	Education and Training	Advocacy and Implementation
		fertility care practices that could harm health • Provide education, training, and services in local languages	• Provide information on other options for family formation (e.g., adoption) or ways of life that do not include being a parent (e.g., women's education and empowerment) • Ensure access to services is accessible to all
Research and Public Health Infrastructure and Regulation	• Identify research and public health stakeholders that can address priority areas • Coordinate with researchers and public health stakeholders to identify critical issues and topics on infertility	• Incorporate infertility topics into public health training and research	• Scale-up existing infrastructure that can support infertility prevention and management across multiple sectors. • Establish a regulatory body, to develop policies and regulations around the provision fertility services • Ensure systems, policies, and regulations are monitored and quality of services continually improved. • Invest in new research and public health initiatives that can address gaps in knowledge and service • Examine both short and long-term outcomes, including unintended consequences, related to infertility and related programs.

Table 2: Examples of Country Commitments to Address Infertility

Public Awareness and Education	A short film to break the silence on infertility [e.g., Share-Net International] Merck's More Than a mother campaign to destigmatize infertility and improve quality of fertility care [e.g., Global] National public education programs about fertility [e.g., YourFertility, Australia] First Lady of Burundi sensitized people on infertility and infertility stigma - develops song to raise awareness [e.g., Burundi] Engagement of religious leaders & churches in raising awareness of infertility and reduce stigma [e.g., Kenya] National Infertility Awareness Week hosted by Resolve [e.g., United States] Engaging influential people to speak out about infertility [e.g., First Lady Michelle Obama (U.S.), First Lady Monica Geingos (Namibia), Jimmy Fallon) Television programs, such as Fertility UFO Show [e.g., China] Websites on fertility knowledge, such as FertiStat developed by Cardiff University [e.g., Global] Art for awareness raising [e.g., works displayed at Fertility Fest, The Art of Infertility, and Infertility Illustrated] Additional examples of awareness and education described in the Share-Net narrative review on Breaking the Silence Around Infertility include: ● Dispel myths or misconceptions of causes of infertility, such as contraception causing infertility (p.20, 21) ● Hotlines and mHealth programs to increase infertility awareness (p. 34) ● Engage men, primary care providers, online communities, social media, and apps (p. 21) ● Advocacy for specific populations and de-stimatization (p.50)
Detection and Monitoring Systems	Data sources to examine infertility in population-based surveys [e.g., existing data sources found in Table 1 of Smarr et al.] Data sources to examine infertility treatment [e.g., African Network and Registry for ART (ANARA), International Committee Monitoring ART (ICMART)] User-friendly electronic health record system for infertility clinics [e.g., South Africa]
Prevention Programs	Comprehensive sexual education that includes fertility awareness, STI prevention, and identification of reproductive abnormalities [e.g., Canada] Identify country-specific causes of infertility in men and women (e.g., STIs, unsafe abortion, postpartum infections) [WHO] Scale-up existing programs of known causes of infertility within countries (e.g., STI screening, occupational exposures) Prevention programs should include both men and women, such as what is done in other family planning programs [e.g., Global]

Quality Fertility Care and Treatment, Psychosocial Support	Incorporation of basic fertility care within quality family planning services [e.g., CDC/OPA Recommendations: Quality FP Services] Integration of infertility services within SRHR programs [e.g., Profamilia, Columbia] WHO Rapid Assessment Tool for integration of fertility awareness and assisted fertility services [e.g., Global] International Federation of Gynaecology and Obstetrics (FIGO) Fertility Toolbox Guidelines for infertility treatment in lower-income countries [e.g., ESHRE guidelines] Low-cost assisted reproductive technology initiatives [e.g., The Walking Egg, INVOcell, Sub-Saharan Africa, Gabon] International Society for Mild Approaches in Assisted Reproduction (ISMAAR) Mobile IVF-ICSI clinic and laboratory [e.g., Lebanon, United States] Low-cost at-home testing and mobile apps for male infertility [e.g., ExSeed, Trak app, Harvard Medical School, Dadi] Apps to monitor clinical indicators of female infertility, also known as "FemTech" [e.g., BluDiagnostics, Grace Health, Nabta Health, Fengkuangzaoren] Telehealth consultations with fertility specialists [e.g., Australia] Workshops and partnerships to foster training of medical personnel in fertility care [e.g., Merck More than a Mother, Zimbabwe, Sub-Saharan Africa) Provision of equipment and training for this equipment [e.g., Sudan, Nigeria] Psychosocial support and counseling [e.g., ESHRE guidelines for fertility staff] Jembatan Project: Peer Support Groups for Individuals with Fertility Issues [e.g., Indonesia] Social support through churches [e.g., Kenya] or therapy through art [e.g., Drawing Out]
Research and Public Health Infrastructure	Action plans and policies to support infertility services and research [e.g., United States, Moldova, Malawi, Burundi, Europe (9 countries)] Reporting of Sustainable Development Goals for 2030 [e.g., Serbia] or human rights [e.g., Hungary] Public funding mechanisms for fertility care [e.g., Global, Ireland, United States as part of publicly-funded family planning clinics]

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