EVIDENCE BRIEF: BREAKING THE SILENCE AROUND INFERTILITY
DEVELOPED FOR THE 2019 CO-CREATION CONFERENCE OF SHARE-NET INTERNATIONAL

This Evidence Brief[1] summarises the key messages and evidence of the Narrative Review[2] on "Breaking the silence around Infertility", which was conducted by the University of Amsterdam in preparation for the Share-Net International (SNI) 2019 Co-Creation Conference, "Engaging in Knowledge Translation Together".

Key Messages

Breaking the silence on infertility

1. Infertility and involuntary childlessness impact millions of women and men in low and lower middle-income countries with often devastating consequences: sexual and reproductive health problems, stigma and ostracization, psychological distress, marital instability, gender-based violence and economic hardship.

2. Infertility is insufficiently integrated in sexual and reproductive health and rights policies and programs in lower and lower-middle income countries. Linkages need to be made to family planning, comprehensive sexuality education, safe abortion and maternal and reproductive health services, menstrual health, contraceptive counselling, screening and treatment of sexually transmitted infections (STIs), gender-based violence services, gender equality and non-discrimination.

3. Limited quantitative data exist about infertility. Prevalence is hard to measure, and measured in divergent ways, which contributes to the invisibility of the issue. There is a need for more studies.

4. There is hardly any funding for infertility. Various stakeholders – national governments, (I)NGOs and donors - are pointing to each other to 'justify' the neglect of addressing infertility. This vicious cycle of neglect should be broken[3].

Increasing access to quality fertility care

1. In Low and Lower Middle-Income Countries (LLMIC), (affordable) quality infertility care is nearly non-existent. Even diagnosis and low-tech treatment options are not offered systematically at primary health care level and are rarely part of national insurance schemes. There is a strong need for more fertility specialists, guidelines and regulations, counselling and information services, good referral systems, laboratory standardisation, quality assurance and people-centred approaches.

2. Access to fertility care is subjected to devastating inequities whereby mostly the rich can afford expensive diagnosis and treatments (in the private sector). Lower cost variations of Assisted Reproductive Technologies (ARTs), including IVF treatments, exist but are not widely introduced. There is a need for a systematic overview and assessment of the efficacy, safety and cost-efficiency of lower cost ARTs.

3. There are few peer support groups and counselling services, while these can relieve the emotional burden of infertility.

Photo: Nienke Elenbaas

Preventing infertility

1. A significant number of cases of infertility can be prevented e.g. through increased fertility awareness and comprehensive sexuality education, life style advice, screening and treatment of STIs, avoiding unwanted pregnancies and access to safe delivery and safe abortion care. More awareness should be raised on male infertility and how to prevent it.

2. The lack of awareness about the fertile period causes part of the increasing incidence of infertility worldwide. Women should be made aware about their fertile days and optimal timing of sexual intercourse to achieve pregnancy.

De-stigmatising infertility

1. In many contexts it is culturally expected to be a parent. People who are infertile or involuntary childless face stigma and exclusion with far-reaching personal, social and economic consequences.

2. Even though both men and women can face fertility problems, the burden of infertility falls predominantly on women. This can result in violence and discrimination against them, perpetuating persistent and enforcing gender inequality.

3. There are very few interventions in LLMIC that address infertility stigma. Gender transformative approaches need to be applied in all interventions, to change dominant norms on masculinity, femininity, patriarchy and motherhood. These interventions can consist of various activities, including the use of social and mass media and documentaries.

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- An estimated 180 million couples worldwide are affected by infertility[4].
- Large-scale studies have not been done in LLMIC on causes of infertility, but age, factors related to genetics, lifestyle, or environment, and fallopian tube occlusion (which can be consequences of post-partum infections, STIs, or infections after pregnancy loss, including due to unsafe abortion) are considered to be the main causes of infertility in these settings[5] and are largely preventable[6].
- Women in LLMIC sometimes do not use contraceptives out of fear for infertility[7].
- Low-cost IVF, simplified treatment and at-home treatments are examples of lowering the costs of infertility care[8].
- Psycho-social support and counselling can relieve the psychological burden of infertility, support the success of infertility treatment and improve the spousal relationship[9].
- Those who fail to meet the cultural expectation to procreate and become a parent are often stigmatised and experience stress, a loss of identity and grief, and in some cases even ostracism, violence and abuse. Women are often the ones blamed for a failure in getting pregnant. The views of womanhood and motherhood are deeply enshrined in patriarchal norms and women are seen as "gender non-performers"[10], when they are childless.

[1] For more information or questions, please contact Dr. Trudie Gerrits (G.J.E.Gerrits@uva.nl) (Chair) or Hilde Kroes (hilde@hildekroes.nl) (member) of the SNI Community of Practice on Infertility, The Netherlands. https://share-net.nl/communities-of-practice/infertility/

[2] The Narrative Review consisted of a literature review, through the academic databases Embase and Sociological Abstracts and through Google and Google Scholar, social media platforms, as well as app stores. Eventually 86 articles and several unpublished were used. In addition, key informant interviews were conducted with 18 key infertility and SRHR experts. Focus Group Discussions were held with the Communities of Practice on Infertility in Bangladesh, Jordan and Burundi.

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