

Breaking the silence around infertility: a scoping review of interventions addressing infertility-related gendered stigmatisation in low- and middle-income countries

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Abstract: *Infertility is a reproductive health concern that deserves attention, as reconfirmed by the 2018 report of the Guttmacher-Lancet Commission on Sexual and Reproductive Health and Rights (SRHR). However, governments and SRHR organisations tend to neglect infertility. We conducted a scoping review of existing interventions aiming to decrease the stigmatisation of infertility in low- and middle-income countries (LMICs). The review consisted of a combination of research methods: academic database (Embase, Sociological abstracts, google scholar; resulting in 15 articles), Google and social media searches, and primary data collection (18 key informant interviews and 3 focus group discussions). The results distinguish between infertility stigma interventions targeted at intrapersonal, interpersonal and structural levels of stigma. The review shows that published studies on interventions tackling infertility stigmatisation in LMICs are rare. Nevertheless, we found several interventions at intra- and interpersonal levels aiming to support women and men to cope with and mitigate infertility stigmatisation (e.g. counselling, telephone hotlines, and support groups). A limited number of interventions addressed stigmatisation at a structural level (e.g. empowering infertile women to become financially independent). The review suggests that infertility destigmatisation interventions need to be implemented across all levels. Interventions geared to individuals experiencing infertility should include women and men and also be offered beyond the clinical setting; and interventions should also aim to combat stigmatising attitudes of family or community members. At the structural level, interventions could aim to empower women, reshape masculinities and improve access to and quality of comprehensive fertility care. Interventions should be undertaken by policymakers, professionals, activists, and others working on infertility in LMICs, and accompanied with evaluation research to assess their effectiveness. DOI: 10.1080/26410397.2022.2134629*

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Introduction

Infertility in low- and middle-income countries (LMICs) is widespread and has serious emotional and social consequences for people.^{1–4} WHO defines clinical infertility as “the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (p.1).⁵ Taking different measurement approaches into account, an estimated 48.5 million to 186 million

couples are affected by primary or secondary infertility.^{2,6,7} Primary infertility is defined as the inability to become pregnant or initiate a pregnancy. Secondary infertility is the inability to conceive despite previously doing so,⁸ and is more common than primary infertility, partly resulting from a high prevalence of reproductive tract infections.^{2,6} In most societies, it is culturally expected to become a parent. Many studies in LMICs have

given insights into the social and psychological repercussions for people facing fertility problems and/or being involuntarily childless and the negative impacts on people's health and well-being.^{1,3,4,9–12a} Those who fail to meet the social expectation to have children experience various forms of stigmatisation, leading to grief, stress, marital instability, verbal abuse, intimate partner violence, isolation, and exclusion.^{4,12–19}

While a range of other sensitive sexual and reproductive health and rights (SRHR) topics – such as abortion, adolescent SRHR, or comprehensive sexuality education – are being tackled by governments and SRHR organisations, infertility remains neglected.^{2,6,20} This neglect is exacerbated by the lack of accurate prevalence data on infertility, contributing to its invisibility and undermining arguments to take action, including the provision of comprehensive fertility care and prevention and destigmatisation of infertility.^{2,6,20} In addition, hardly anything is known about existing efforts to tackle infertility stigmatisation in LMICs.^{2,21,22}

Inhorn and Patrizio⁶ have argued that the availability of assisted reproductive technologies (ARTs) is an important way of destigmatising infertility in LMICs, as it increases knowledge about male and female infertility, encourages men to become more involved in infertility management and counselling, and positively changes gender relations. However, high costs of ARTs will remain “the biggest barrier to increasing access” to ARTs in LMICs (p.29).² In addition, many couples seek treatment so late that even ARTs become ineffective. Therefore, other interventions are needed that reduce infertility stigma and the negative effects such stigma has for the lives of people facing fertility problems.

In this article, we address the question “What is currently being done to tackle infertility stigmatisation?” with a focus on male-female couples in LMICs. We offer a scoping review of existing interventions that are intended to decrease the stigmatisation of infertility. Before presenting the methods and results of this scoping review, we

first conceptualise and define stigma, discuss gendered experiences of infertility-related stigma, and introduce an interdisciplinary multiple-level approach to challenge stigma.²³ We end the article with a discussion of the findings and recommendations for policymakers, non-governmental organisations (NGOs), practitioners, support groups, activists, researchers, and others working on infertility in LMICs to further develop, implement and study initiatives in this area.

Theoretical background

Conceptualising stigma

Social theory explaining stigma shows that underlying social inequalities (such as those of gender) underpin stigma.^{24,25} In line with Link and Phelan,²⁵ we conceptualise and define stigma using five inter-related components of stigmatisation processes. First, certain groups are socially distinguished and labelled based on issues of social importance in a certain historical and social setting (e.g. those who can or cannot / do not have children). Second, negative judgements or attributes are allocated to these groups, making these groups “undesirable”, “irresponsible” or even “immoral” and a “threat” to the fabric of society. Third, such labelling and stereotyping create a hierarchy of worth, in terms of a distinction between “them and us”. The fourth component is that the stigmatised groups, such as “women or men who are infertile”, can be inserted into a status hierarchy of inequality, legitimising sanctions and stigmatisation. These four components of stigma are underpinned by a fifth, the power derived from existing social inequalities, such as those based on gender or class. Stigma is usually more harshly enacted on those in already marginalised groups.²⁴ Stigmatisation polices the moral and social order and can therefore be interpreted as the exertion of power to sustain social norms and existing inequalities.²⁵ Stigmatisation has several forms: intrapersonal or internalised stigma; anticipated stigma; interpersonal or enacted stigma (verbally or physically enacted) and structural stigma (e.g. legally or within health facilities).

Gendered experiences of infertility stigma

In many LMICs, women are more often blamed for a couple's inability to have a child than men, even if male infertility causes the problem.²⁶ Gender inequalities and notions of masculinity help explain women's greater burdens of infertility

^aIn this article, we use the term people facing fertility problems or infertility; this includes people being involuntarily childless as a result of fertility problems. Although not the primary focus of this review, some studies also include childlessness due to other reasons (e.g., losing their child during or immediately after the pregnancy).

stigma, men's specific experiences of stigma, and their more limited engagement with fertility care.^{12–19} Obligations of motherhood are deeply enshrined in patriarchal norms: women must have children to be considered “proper” adult women and achieve status and are seen as “gender non-performers” when they do not conform.²⁷ Men often still have other ways to obtain status, in particular through the accumulation of wealth. Infertile and childless women are often ostracised and feel isolated, or self-isolate out of shame,¹² and this is exacerbated when infertility is assumed to have resulted from STIs or unsafe abortion.²² Men may leave their wives to remarry (sometimes pressured by their families), and women may face intimate partner violence or maltreatment by in-laws.^{3,12} Infertility stigmatisation is therefore reproducing matrilineal or patriarchal power structures that seek to suppress and control women's bodies.²² Women's positions and experiences of infertility-related stigma in LMICs, however, may vary according to, among other things, their levels of education, social class, the dominant kinship system in their society (matrilineal or patrilineal), and personal circumstances.^{6,15,18,28,29}

At the same time, in various cultural contexts, the inability for men to become a father is a fundamental challenge to dominant notions of masculinity.³⁰ As a result, infertile men also face stigmatisation, often in the form of internalised stigma.^{14,16,31,32} Men may feel emasculated, and more so because male infertility is often – wrongly – equated with sexual impotence.^{11,28,32} To protect their husband's masculine reputation, some women claim that the fertility problem lies with them. Dominant notions of masculinities and the resulting non-acceptance and stigma might discourage men from engaging in infertility examinations or treatment.³² Social science research on masculinities in LMICs, however, also reveals possibilities for stigma mitigation interventions and support for men to better cope with infertility. It demonstrates men's agency to rethink and refashion masculine values in their communities during different phases of life to accommodate health-related issues such as HIV (e.g. see Russell³³) or infertility.^{28,34}

Tackling stigma

Cook et al²³ provide an interdisciplinary multiple-level approach to tackle stigma in public health that can potentially address the stigmatisation processes discussed above. Inspired by the

ecological model,³⁵ the authors distinguish three levels at which interventions are possible. At the intrapersonal level, interventions such as counselling and education can be directed at individuals to either enhance coping strategies of stigmatised people or change attitudes and behaviours of non-stigmatised individuals. In addition, interventions at this level may aim to strengthen stigmatised individuals' sense of “belonging” or “value” as a strategy to reduce internalised or anticipated stigma. At the interpersonal level, interventions can, for example, encourage collective support among stigmatised groups or “meaningful, high-quality contact” (p.104).²³ between stigmatised and non-stigmatised persons to combat prejudices and increase understanding. At the structural level, interventions should intend “to change social conditions that give rise to stigma”, thus tackling social inequalities driving stigma (p.105).²³ Structural interventions can include gender transformative projects to empower women or refashion masculinities, or the introduction of laws and policies that address and protect people who experience stigma, provide them with better access to relevant health care or improve existing legislation. Interventions at this level may also comprise educational interventions (e.g. changing curricula contents of medical schools) and mass media involvement to influence stigmatising public opinions at larger scales. This can include influential persons expressing themselves in public in a positive way about people who experience stigma or coming out themselves to open up the conversation and address negative stereotypes.

Interventions might aim at a variety of outcomes at different levels and can affect and strengthen one another. For example, an educational intervention might encourage stigmatised people to become activists, advocating for changes in legislation or health provision. Many of the intervention studies reviewed by Cook et al²³ dealt with stigmas related to HIV/AIDs, mental health, obesity, ethnic minorities and LGBTQI people. None of the studies addressed infertility-related stigma.

Methods

This scoping review builds upon a study commissioned by Share-Net International (SNI), the International Knowledge Platform on Sexual and Reproductive Health and Rights, in preparation

for the Co-Creation Conference “Breaking the Silence on Infertility”, held in Amsterdam in 2019.^{22b} The study aimed to identify existing interventions related to infertility (and if available, their effectiveness), as well as gaps in infertility policies, programmes and interventions. It included a review of interventions in three priority areas: (1) the prevention of infertility; (2) access to quality (in)infertility care, and (3) destigmatisation of infertility and childlessness.^{22c} To capture an overview of the different types of existing interventions, a combination of research methods was used: academic database searches, Google and social media searches, and primary data collection (key informant interviews and focus groups; described below). In this article, we build on the third priority area (destigmatisation).

Academic database search

For the academic database search in 2019 for the initial report,²² we developed separate search strings for each subtheme,^d together with experts of the library of the University of Amsterdam. All search strings covered the topics of infertility, intervention, and various ways to refer to LMICs, according to World Bank definitions. Two academic databases (Embase and Sociological Abstracts) were chosen as the most relevant medical and social science databases. Additionally, a Google Scholar search was conducted. The searches of the two academic databases and Google Scholar were repeated in 2021. Articles were excluded if they were published before 1999 or if they did not target infertility interventions. All other articles were examined in more depth to check that they covered or focused on the specific priority area of destigmatisation. In addition to the systematic search, we also included articles identified from cited references in the articles and personal knowledge of relevant articles.

Google and social media

In 2019, and again in 2021, online search engines (Google) and social media platforms including

Facebook, YouTube,^e Instagram^f and the Android Play Store were also searched, to broaden the research strategy and optimise infertility-related findings. Search terms such as, but not limited to, “infertility stigma”, “infertility awareness”, “involvement men infertility stigma”, “workshops infertility”, “initiatives”, “infertility judgement”, “destigmatisation”, and “normalisation”, were used. Under the umbrella term “interventions” we also included activities that had not necessarily been set-up by a formal organisation, but initiated by individuals to share their experiences and break the silence about infertility. These searches yielded information from NGOs, newspapers, blogs, podcasts, social media accounts, and additional academic sources. It should be noted that as the academic search yielded limited articles on destigmatising interventions in LMICs, we also included interventions in high- and middle-income countries (HMICs) in the Google and social media searches, as these might still inform or inspire stakeholders in LMICs.

Primary data collection

Primary data were collected for the initial report through key informant interviews (KIIs) with experts in the field of infertility all over the world and focus group discussions (FGDs) with members of Share-Net International Communities of Practice (CoPs) on Infertility between March and May 2019.

^eYouTube can be easily searched with keywords. An example of a YouTube video (by Merck Foundation): <https://www.youtube.com/watch?v=uEla4dAIEZw>.

^fInstagram is basically a visual platform where users can post a photo and, if they want, add a textual description. The app lets users search with key terms, allowing them to find users who use a name that resembles the key term, or with hashtags, allowing them to find posts that were paired with the corresponding hashtag. Despite occasional images featuring only text, a great portion of the content we found was visual or a combination of visual and textual. Thus, the option to add a description to an image and comment on it together with other users also allows it to be a more textual platform where individuals can share their experiences, advice, opinions, and critiques. Posts were created by all sorts of users, from individuals who are struggling with themes of infertility themselves to accounts that were created by clinics who offered general information on infertility, in the hopes to inform individuals and find new clients. An example of an account we thus found is: <https://www.instagram.com/infertilityillustrated/>.

^b<https://share-netinternational.org/co-creation-conference/>.

^c<https://share-net.nl/wp-content/uploads/2021/12/SNI-Narrative-Review-Breaking-the-Silence-on-Infertility.pdf>.

^dSee for the search strings: <https://share-net.nl/wp-content/uploads/2022/02/SNI-Annexes-Narrative-Review-breaking-the-silence-on-Infertility.pdf>.

The Research Ethics Committee of the Royal Tropical Institute in Amsterdam exempted the initial study proposal (S-109A) from full ethical review based on the consideration that key informants and FGD participants in the primary data collection methods would be involved in their professional capacity only.

In-depth interviews were held in English or French with key informants, all recognised experts in the field of infertility and SRHR.⁸ They represented academia, global institutions, NGOs, medical practitioners/providers, and infertility societies, from different regions in the world. The interviews focussed on all three themes of the initial study.²² Interviews were conducted by telephone, Zoom, Skype or in-person, most of which were audio-recorded with interviewees' permission. FGDs with the Share-Net International Communities of Practice (CoPs) on Infertility in respectively Jordan, Bangladesh and Burundi, were held in English or French through Skype or Zoom and focussed on existing interventions to address infertility in their respective countries.²² For the current study, we only used the data regarding the questions in the KIIs and FGDs on their experiences with and knowledge of interventions to destigmatise infertility and childlessness. Examples of interview questions were: Do you know of existing interventions in your country/the Global South that address infertility? Who are in the lead? What are lessons learned? Any publications/documentation/relevant websites?. Follow-up questions were tailored to the specific contexts. The KIIs and FGDs were thematically summarised (not fully transcribed) and subsequently analysed manually by the second author (HK) in consultation with the first author (TG). Where relevant they have been combined with findings of the scoping review.³⁶

Results

The academic database searches, Google and social media searches, and primary data collection resulted in 15 peer-reviewed academic articles, 28 other sources through Google and

social media searches, 18 interviews with key informants (ranging from 30 to 120 minutes, with an average of 75 minutes), and 3 FGDs with Share-Net International CoPs on Infertility.

All the methods (academic database search, Google and social media searches, key informant interviews and focus group discussions) revealed that interventions aiming to break the silence about infertility and address its stigmatisation in LMICs are rare. Only a few participants in the KIIs and the FGDs in Jordan, Bangladesh, and Burundi were able to refer to an intervention. The few examples mentioned by these participants were also found through other searches. Overall, the limited number of interventions in LMICs aiming to tackle stigma were at all three levels (intrapersonal, interpersonal and structural levels) or combinations of these. No interpersonal interventions were found to stimulate contact between stigmatised and non-stigmatised persons to combat prejudices or increase understanding among non-stigmatised persons. Few interventions had been evaluated to assess their effectiveness and impact, although a positive exception was for intrapersonal level interventions involving counselling, group therapy and support programmes.

Below we distinguish three categories of interventions: (1) interventions aiming to support women and men to cope with and mitigate stigmatisation (at intrapersonal and/or interpersonal level); (2) interventions to reach broader audiences for destigmatisation (at structural level); and (3) interventions targeting infertility-related stigma at all levels.

Supporting women and men to cope with and mitigate stigmatisation

Counselling, group therapy and support interventions

Four recent studies describe or evaluate counselling, group therapy or support interventions in LMICs for coping with intrapersonal (internal) and interpersonal stigma.^{37–40} These interventions are (mainly) implemented within medical settings, often in combination with medical treatments.^{38–40}

Researchers from the University of Liverpool have developed an extended Fertility Life Counselling Aid (FELICIA) to manage the psychological trauma and stigma experienced by women and men dealing with infertility in African countries.³⁷ FELICIA uses techniques based on cognitive

⁸See Kroes et al⁴¹ for the list of key informants. <https://share-net.nl/breaking-the-silence-around-infertility-a-narrative-review/>.

behavioural therapy (CBT). It offers “the opportunity to explore, discover, and clarify ways of living more satisfyingly and resourcefully when fertility impairments have been diagnosed, offering a pathway to reducing the stress levels of the inflicted even when the cause of infertility is unknown” (p.80).³⁷ The method provides a three-step approach: (1) learning to identify unhealthy ways of thinking; (2) learning to replace unhealthy thinking with healthy thinking; and (3) practising healthy thinking and behaviour. FELICIA makes use of stories based on real life events. Core principles are: (1) infertility is a condition that has social, psychological and economic implications and therefore needs holistic care; (2) counselling should be patient-centred, meaning only issues relevant for the participants should be discussed; (3) community-orientation: counselling can be provided by health and community workers (and does not need trained psychologists) and can engage family members and the community as well; (4) cultural sensitivity: acknowledging the cultural meaning of having children, but also “introducing a different way of thinking about their own status” (p.85)³⁷; and (5) empowerment: participants take ownership of their thoughts, challenging their negative ideas and replacing them with positive thinking. FELICIA provides training and materials for trainers, and is a low-cost option for resource-poor settings. Pilot testing and a subsequent full trial are planned to be carried out in Nigeria³⁷ but have not yet started.

Three other studies evaluated the effectiveness of interventions (see Table 1 for an overview of the study details). Naab et al⁴⁰ evaluate a psycho-educational intervention among women with fertility problems in Ghana called “Oh Happy Day Classes” (OHDC). This culturally adapted OHDC intervention aims to reduce symptoms of infertility-related depression and consists of 12 sessions, during which participants can share psychosocial issues they are struggling with and get emotional support from facilitators and group members. In addition, they receive information about medical aspects of infertility, so-called psycho-education (about the relationship between infertility and depression) and CBT to shift negative perceptions and build coping behaviours. This randomly controlled intervention study showed a decrease in depression and infertility-related stress levels resulting from OHDC.⁴⁰

Another counselling intervention explicitly focusing on internalised stigma has been

implemented and evaluated in Iran.³⁹ This intervention consisted of three sessions of 60–90 min, which were scheduled around medical visits to an infertility clinic for intra-uterine insemination (IUI). The first session includes explanations of stigma, women’s experiences of stigma, sources of stigma, talking about fears and concerns, and relaxation techniques. The second session focuses on the main sources of stigma and different coping strategies for these situations: becoming more assertive in social interactions and preventing others from abusing them. It also emphasises relaxation techniques to regulate the expression of negative emotions. The third session focused on medical aspects of the treatment. Moudi et al³⁹ evaluated the intervention using a quasi-experimental design, which showed an improvement on all measured aspects of stigma at post-test (self-devaluation, social withdrawal, family stigma and public stigma) compared to a comparison group that received care as usual. However, stigma reduction experienced at family level was lowest, which probably reflects the intense familial and social pressure to have children in the country. The authors argue that the interventions of talking and social advice, combined with the psycho-education about the medical aspects of infertility, helped to decrease internalised stigma. Yet, they add, infertility stigma should also be addressed at community level to really change values and attitudes.³⁹

Another randomised controlled trial in Iran addressed the effects of group counselling on stress and gender-role attitudes among infertile women.³⁸ This intervention was conducted in hospitals and consisted of five sessions offered only to women who were diagnosed with “female infertility”. These sessions included information about physical, psychological and sexual aspects of infertility, sharing experiences, learning relaxation techniques, and improving communication with their husbands and others. In one session participants discussed “general, sexual and marital roles of women” and “its development in recent years” (p.172).³⁸ Their experiences in social and marital relationships with not having children were also addressed (the term stigma was not explicitly mentioned in the article). The control group received care. Study results showed that group counselling was effective in decreasing stress levels one month after the intervention in all measured domains (social, sexual and

Table 1. Details of studies evaluating the effectiveness of counselling interventions

Authors (year)	Design	Comparison	N (intervention, comparison group)	Analyses	Domains of significant differences between intervention and control-groups
Ehsan et al. (2019)	RCT - pre-post-test (1 month after intervention)	intervention vs care as usual	40, 40	Repeated measures analysis of variance	Infertility stress: <i>Social concern</i> ($F = 32.79, p < .001$), <i>sexual concern</i> ($F = 39.51, p < .001$), <i>relationship concern</i> ($F = 28.17, p < .001$), <i>rejection of childless lifestyle</i> ($F = 125.32, p < .001$), <i>need for parenthood</i> ($F = 57.60, p < .001$), <i>total stress score</i> ($F = 149.47, p < .001$) Gender role attitude: <i>marital roles in sexual and reproductive health</i> ($F = 32.90, p < .001$), <i>marital public roles</i> ($F = 10.19, p < .001$)
Moudi et al. (2019)	Quasi-experimental – weekly allocation – pre-post-test	intervention vs care as usual	68, 67	t-test at pre- and post-test	No significant scores at pre-test Post-test: Infertility stigma scores <i>self</i> ($p < .001$), <i>social</i> ($p < .001$), <i>public</i> ($p < .001$), <i>family</i> ($p < .001$), total ($p < .001$)
Naab et al. (2021)	RCT – pre-test, midway test (6 weeks after start intervention), post-test and follow-up test (3 months post intervention)	Intervention vs psychoeducational attention (contacting them weekly to check on them)	11, 7	EB-GLMM	Depressive symptoms ($\beta = -7.70, p = < .001$), infertility-related stress ($\beta = -8.29, p < .001$), severity of depression ($\beta = .74, p < .04$)

relationship concerns; rejection of childless lifestyle; need for parenthood and gender role attitude).³⁸

Telephone hotlines and mHealth

Studies highlight promising ways to engage men and women with accurate information about infertility through family planning telephone hotlines.⁴¹ In India⁴² and Congo⁴³, the large majority of calls to family planning hotlines

were coming from men, and one of the topics often asked about was infertility. In Myanmar, a reproductive health hotline was established to provide reproductive health information; infertility was the most asked-about topic, and the majority of callers were women.⁴⁴

Online contact is also becoming an important way to get support and information. An example is the Russian initiative “mHealth programme” for persons undergoing ARTs, launched in 2013.

This intervention gives opportunities for interaction with both peers and experts through social networks, online and offline seminars with reproductive health specialists in clinics, and text messages to participants' mobile phones.^h No evaluations were found regarding its effectiveness.

Peer support groups

Peer support groups can be important for individuals to deal with infertility. Participating in a group can bring comfort, information, and relieve feelings of distress and stigmatisation.⁴² Some peer support groups in the global North, which started in the 1970s and 1980s (e.g. RESOLVE in the USA, Fertility Network UK, and Freya in the Netherlands), have become large and highly professionalised institutions.^{i,j,k} More recently in the USA several organisations like “Fertility For Colored Girls”, “Fertility in Colour”, “The Broken Brown Eggs”, and “Fruitful U with Ashly” have been created to reach women of colour and couples struggling with infertility.^{l,m}

We identified several types of peer support groups in LMICs, mostly created during the last decade and still rather small. These include, for example, Joyce Fertility Support Centre in Uganda, the Infertility Awareness Association of South Africa (IFAASA), Footsteps to Fertility in Kenya,⁴³ the Association of Childless Couples of Ghana (ACCOG),⁴⁴ the Safe Haven Foundation in The Gambia,^m the Pejuang Tangguh (Strong Warriors) Permata Hati in Indonesia,⁴⁵ and BeiBei haven in Nigeria.ⁿ Some support groups are connected to clinics, others are peer-to-peer only (e.g. PCOS & Fertility Support Kenya, the Waiting Womb Trust, and the Fertility Support Group Africa).^o Some

^h<https://www.healthynewbornnetwork.org/blog/russian-ngo-launches-mhealth-infertility-support-program/>.

ⁱ<https://resolve.org/>.

^j<https://fertilitynetworkuk.org/>.

^k<https://www.freya.nl/>.

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

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

ⁿ<https://www.facebook.com/foundationSAFEHAVEN>.

^o<https://www.beibehaven.org/home1>.

^phttps://trickleout.net/index.php/directory-pilot/Uganda_/joyce-fertility-support-centre https://www.voanews.com/a/africa_kenyan-women-struggle-overcome-infertility-stigma/

exist only or mainly online, others have face-to-face meetings only. A small-scale project in Indonesia showed that fertility patients did not prioritise running a formal organisation, as they had already invested much of their time in fertility treatment.⁴⁵

Reaching broader audiences for destigmatisation

Several types of awareness and media activity aimed at wider audiences to destigmatise infertility exist at all levels. Examples of these activities are infertility awareness weeks and days (mainly in the Global North),^p television and radio programmes, and working with role models and social influencers. Professionals and peer support groups play an important role in organising these events, which can provide information and support to people, but also draw wider attention to the issue in the public domain, and put infertility on the policy agenda, so complementing lobbying with policy makers and governments to improve access to affordable fertility treatment.⁴²

Occasionally, fertility weeks have been organised in LMICs. For example, the first National Infertility Awareness Week in South Africa (NIAW SA) took place in 2020, organised by IFAASA in association with the House of Fertility (an advice and support service for people considering surrogacy). In 2018 in The Gambia, the Dimbayaa Project marked the International Infertility Awareness Week by showing a film on the role Kanyaleng groups play in supporting childless women.^{q,r} Little is known about the impact of such infertility weeks or days. However, a Google Trends analysis (covering the years 2010–2018) showed an increase in internet search volume for the term “infertility”, associated with the USA NIAW.⁴⁶

In many countries, TV programmes, documentaries, films, and soap operas discuss infertility and show how people react to it and attempt to resolve it.^{47–50} For example, the highly watched “The UFO Fertility Show” in China, draws attention

6205419.html <https://waitingwombstrust.org/?home>; <https://www.vanguardngr.com/2021/05/how-fertility-support-group-africa-is-giving-back-to-women-this-monthofgood/>; <https://www.facebook.com/groups/fsgafrica/>.

^pFor example <https://infertilityawareness.org/>.

^q<https://dimbayaafertilityafrica.com/ivf/international-infertility-awareness-week/>.

^r<https://www.yourfertility.org.au/fertility-week-2020>.

to infertility, its high prevalence in the country, and ways to prevent and handle it.⁵ Although some studies in the global North have examined how infertility is portrayed in television shows and how this affects the audience (e.g. Weihe Edge⁵⁰), no studies in LMICs are available.

Celebrities, role models and influencers sharing their personal infertility stories through mass media also aim to create awareness, decrease the stigma of infertility and might “push couples to seek appropriate care” (p.s307).⁵¹ Examples of prominent female celebrities and influencers who have shared personal infertility stories are the former First Lady of Namibia Monica Geingos,^t First Lady of the United States Michelle Obama,^u and infertility blogger Vanessa Haye.^v Religious leaders also have great influence and in a workshop with fertility patients in Kenya, some participants highlighted the importance of engaging religious leaders in raising awareness for infertility (treatment) and destigmatisation (provided religious leaders are not against ARTs).⁴³

Various male celebrities, mainly in the global North, have spoken out about their struggles with infertility to open the discussion, create awareness and decrease stigma, including, for example, Mark Zuckerberg^w and American television host Jimmy Fallon.^x The male initiator of the Association of Childless Couples of Ghana

(ACCOG)^y referred to the stigma-decreasing effect for himself and his wife, following their television appearances.^{55,56} Such influencers might also encourage people to seek infertility treatment. Nevertheless, no research has assessed the effects of role models or influential people for decreasing infertility-related stigma.

Using art to break the silence around infertility was also identified in our review, but only in the global North. Art projects and exhibitions could however offer ideas for those working in the Global South²²: theatre, dance, music, visual art, film and literature are used to improve awareness of infertility, understand the emotional struggles of people having fertility issues, and to improve public conversation about infertility.^{z, aa, ab} No studies reported on the actual effects of art interventions regarding awareness raising and destigmatising infertility.

Targeting infertility-related stigma at all levels

Two projects were found that targeted all stigmatisation levels. The first is the More Than a Mother (MTM) Project, which has been implemented across multiple countries. The MTM Project,^{ac} initiated by the Merck Foundation (a non-profit organisation founded in 2015 by the pharmaceutical company Merck) aims to reduce infertility stigmatisation in LMICs among women and men through empowering infertile and childless women socially and economically, raising awareness about male infertility, and through infertility prevention and management, integrating it into (SRHR) healthcare infrastructure. It also aims to educate and train embryologists and fertility specialists, improve access to regulated, effective and safe fertility care, and encourage formulation of national level ART policies.⁵⁷ Up to 2021 the project had reached out to 37 countries, mainly

⁵<https://edition.cnn.com/2018/05/07/health/china-infertility-intl/index.html/> (accessed on 14/08/2019).

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

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

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

^whttps://www.huffpost.com/entry/male-celebrities-help-destigmatize-male-infertility_b_594bee3ae4b07cdb1933c06d?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xlLnVna9Vx-xDmZjyBQY13GzpzRnr4uEJhkPba3GeumOyTIFOXXeYe6saQOBMMynqvs-54l80nMgl-y-O-EykEOcTVjxf6ina5kb455zR_XqX9Wc4mKZe1100VQXOHDI06o5BqNcb7NDiV7HA9vpAzvVPsQsqZDJJcmTWt/ (accessed on 06/08/2019).

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

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

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

^{aa}<https://www.fertilityfest.com/> (accessed on 15/08/2019).

^{ab}<https://www.facebook.com/artofinfertility/> (accessed on 14/08/2019).

^{ac}<https://merck-foundation.com/our-programs/Merck-Foundation-More-Than-a-Mother> (accessed on 12/04/2021).

in Africa and Asia, working in dialogue with governments, policy makers, parliaments, healthcare providers and the media, and also often specifically liaising with the countries' first ladies, ensuring broad media attention.

The MTM Project has developed a wide range of resources and activities, including brochures, posters, songs, videos with testimonies of women sharing their personal infertility stories, artwork, children's books, fashion shows, publications and news updates. Core messages are that both women and men can face fertility problems, that they should both be involved in tackling the problem, and that women should be respected when they cannot become mothers. To underline the importance of male involvement in infertility, the Merck Foundation recently also initiated the More Than a Father Project.^{ad}

To achieve its goals, the MTM Project has initiated several structural interventions. For example, the programme "Empowering Berna" financially supports women who cannot get pregnant to set up their own small business, with the aim of enabling them to become financially independent and acquire esteem in their family and community.^{ae} Another structural intervention is the facilitation of training of professionals, aimed at fertility specialists and embryologists,^{af} but also training journalists to help them better understand infertility issues in their own communities and to address these sensitive topics in an ethical manner. The FGD participants in Burundi were aware of the training of fertility specialists and embryologists in their country. They questioned, however, where these trained fertility specialists would work, as Burundi did not have a fertility clinic at that moment.

While information about the MTM Project is widely available on the web and in the 2021 annual report,⁵³ to our knowledge an actual evaluation of the effectiveness of all these interventions has not yet been performed.

The second project found to be tackling infertility stigma at multiple levels is the Dimbayaa Fertility Project in The Gambia, run by a collective of

fertility practitioners from The Gambia and the Netherlands.^{ag} This project was also mentioned in one of the KIIs. The project approaches infertility care in all its aspects, and also attempts to enhance infertility awareness at societal level. The Dimbayaa works with traditional groups called Kanyaleng, which bring together women struggling with infertility or repeated child mortality. Kanyaleng membership is considered to offer great coping support to women, because it unites women, enables them to create strong support networks and potentially to improve their long-term status, both social and economic.⁵⁴ There has not been an evaluation of the project's impact.

Discussion and conclusion

To our knowledge, this scoping review is the first inventory of interventions addressing infertility-related stigmatisation in LMICs. We found a limited number of interventions addressing infertility stigma in a systematic way. These interventions aimed to: (1) support women and men to cope with and mitigate stigmatisation (at intrapersonal and/or interpersonal level); (2) reach broader audiences for destigmatisation (at structural level); and (3) target infertility-related stigma at all levels. It should be noted that none of the interpersonal interventions explicitly focussed on providing contact between stigmatised and non-stigmatised persons to combat prejudices and increase understanding. Interventions at the intrapersonal and interpersonal levels for people facing fertility problems consisted of counselling and education, mainly provided by practitioners (psychologists, counsellors and medical staff), patient organisations and activist individuals. Interventions addressing the structural level were mostly undertaken by patient support groups and activist individuals facing fertility problems themselves. These groups and individuals are making ample use of social media and the internet to spread information, exchange views and experiences, and aim to empower those experiencing infertility. They aim to counteract the idea that women and men facing fertility problems are worthless and do not deserve to be treated respectfully and to change infertility into a topic that people (dare to) speak about, instead of hiding or neglecting. In addition, we

^{ad}<https://merck-foundation.com/news-articles/Merck-Foundation-together-with-Chad-First-Lady-release-a-children-story-as-part-of-More-Than-a-Father>.

^{ae}<https://www.youtube.com/watch?v=KRv2mSaa18o>.

^{af}<https://www.youtube.com/watch?v=uEla4dAiEzw>.

^{ag}<https://dimbayaafertilityafrica.com/>.

found several activities, ranging from TV programmes, films, books, theatre and artwork, to the “coming out” of celebrities and first ladies, all drawing attention to the topic of infertility and ARTs, aiming to decrease stigma. Structural interventions advocating that (destigmatising) infertility deserves attention and investments by policy-makers and the public health system – for example, by providing better infertility care or promoting the training of health care practitioners – using mass media to influence stigmatising opinions, were limited, apart from the Merck Foundation’s MTM and MTF project (aiming at 35 countries in Asia and Africa).

Before further discussing the results, it is important to mention the limitations of the study. First, using only two academic databases and English language sources might have limited the number of publications and interventions identified. Second, we conducted three FGDs in three different countries and interviewed 18 key informants. Given the broad geographical area of the review (LMICs), more FGDs and interviews might have revealed more destigmatising interventions.

Notwithstanding these limitations, we are inclined to argue that the limited number of interventions to destigmatise infertility in LMICs also reflects the sheer reality of limited attention for infertility in LMICs, and infertility destigmatisation in particular.^{20,43,55} While the topic of infertility means a lot to the people involved and may have huge consequences on various life domains, as we discussed in the first part of this article, in many LMICs it is not considered a public health problem that needs priority attention in the public health sector. It is often said that these countries – and their donors – are more concerned with decreasing population growth than with infertility.²⁰ In addition, limited budgets for public health and the plentitude of other more life-threatening diseases in these countries are suggested as other reasons for governments not to invest in infertility. However, from a reproductive rights perspective, as we have argued elsewhere,⁴³ this argumentation is not convincing. Other authors have pointed to the lack of actual knowledge and awareness among national policy makers, NGOs and donors with regard to the size and seriousness of infertility problems in their countries, which strengthens the idea that

infertility is not a priority reproductive health concern.^{22,60,61,62} In addition, given the fact that infertility is a highly stigmatised topic in many LMICs, people involved might be anxious about making a public case of it.⁵¹ And finally, when thinking of “doing something” about infertility, many people, including policy makers and NGO staff, tend to think of doing medical treatments, which – particularly ARTs – are found to be extremely expensive and become an insurmountable obstacle. As a result, attention for prevention of infertility and/or destigmatising infertility tends to disappear. This latter point was, therefore, also the prime reason for the inventory of interventions conducted in this article: to make a call for other options to address infertility beyond offering biomedical treatments.

Nevertheless, the review found an overall increase in the development and provision of interventions in LMICs in recent years (including the initiation of support groups), pointing to a growing interest in this field. While these are positive developments, some findings indicate areas for caution and further work.

First, in only a few cases was the effectiveness of the interventions assessed, and in some of these cases with only small sample sizes and no long-term follow-up studies. The most extensive cross-country multilevel intervention (the MTM Project), which has an impressive scope and visibility of activities, seems thus far not to have published any effectiveness studies to assess the project’s impact. This is worrisome, as interventions can also have unintended or no effects. Therefore, the implementation of interventions should be followed with evaluation studies using suitable research designs.⁶³

Second, access to interventions is also limited in several ways. For example, the few articles which assessed the effectiveness of counselling interventions (all showing positive effects) were mainly about counselling interventions organised by professional counsellors and provided in the context of fertility clinics. Thus, people who do not have access to these clinics (and for most people in LMICs infertility treatment is too expensive), do not have access to this counselling. Likewise, several patient support groups in our review are connected to clinics, and so their activities also do not reach people who cannot afford treatment. Also, activist individuals and support

groups often share information and experiences through the internet or social media, and so this support does not reach people who have no or limited access to these media.

Third, men are rarely addressed in these counselling and educational activities. Although telephone hotlines were used by men and are a relatively low-cost way to engage them in reproductive and infertility care (and positively influence gender relations and destigmatisation), counselling interventions are still mainly focussed on women and geared to help them better cope with internalised, anticipated and/or enacted stigma or to become more assertive in social interactions.³⁸

Fourth, the intrapersonal and interpersonal interventions are not directly seeking to address structural causes of stigmatisation (gender structures and the cultural value or mandate of having children, in particular for women), nor do they change the understanding, attitudes and behaviour of people who stigmatise. In one of the intervention studies in Iran, the decrease in stigma was lowest at the family level. There is thus a need for more interpersonal and structural level interventions to tackle infertility-related stigma at family and community levels.

Lastly, we encountered somewhat contradictory messages within the Merck Foundation's MTM and MTF projects. A unique feature of their structural approach is their intention to empower and support women to become financially independent and acquire a place and esteem in their family and community, other than based on motherhood. However, while the project emphasises that women should be valued if they cannot achieve motherhood, part of the video and other materials also have a somewhat contradictory, but "happy end" scenario, in which the woman gets pregnant through medical treatment (in some cases made available by Merck), which in a way speaks against the project's core message.^{ah}

Interventions tackling infertility-related stigma need to be implemented across intrapersonal,

interpersonal and structural levels. All interventions should be accompanied by evaluations and research, as this is the only way to establish if and how they make a difference for the people who experience infertility. Based on our review, we suggest that activities geared to individuals who experience infertility themselves should include women and men and also be offered beyond clinical settings (such as in community and church groups, and NGOs in the field of SRHR). The counselling and education formats presented in this review might be good starting points to build on. At the structural level, interventions should aim to empower women, for example, to become more financially independent (following the MTM example), and to reshape masculinities. Similarly, at a structural level, improving access to and quality of comprehensive fertility care, including the training of practitioners involved in fertility care and legislation for ARTs, are crucial, both to meet the urgent needs of people with fertility problems, and as a way to decrease stigmatising public opinions at larger scales.²³ It is timely and critical for governments and SRHR organisations to move forward from neglecting infertility stigma and include it in their policies and interventions.

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Résumé

L'infertilité est un problème de santé reproductive qui mérite l'attention, ainsi que l'a reconfirmé le rapport 2018 de la Commission Guttmacher-Lancet sur la santé et les droits sexuels et reproductifs (SDSR). Néanmoins, les gouvernements et les organisations de SDSR négligent en général l'infertilité. Nous avons mené une étude de portée des interventions existantes visant à diminuer la stigmatisation de l'infertilité dans les pays à revenu faible ou intermédiaire. L'examen consistait en une association de méthodes de recherche: bases de données universitaires (Embase, Sociological Abstracts, Google Scholar ayant produit 15 articles), recherches sur Google et les médias sociaux, et recueil de données primaires (18 entretiens avec des informateurs clés et trois discussions de groupe). Les résultats font la distinction entre les interventions en matière de stigmatisation autour de l'infertilité visant les niveaux intrapersonnels, interpersonnels ou structurels de la stigmatisation. L'examen montre que les études publiées sur les interventions s'attaquant à la stigmatisation due à l'infertilité dans les pays à revenu faible ou intermédiaire sont rares. Néanmoins, nous avons trouvé plusieurs interventions aux niveaux intrapersonnel et interpersonnel dont le but était d'aider les femmes et les hommes à faire face à la stigmatisation autour de l'infertilité et à l'atténuer (par exemple le conseil, les permanences téléphoniques et les groupes de soutien). Un nombre limité d'interventions s'attaquaient à la stigmatisation au niveau structurel (par exemple en donnant les moyens aux femmes infécondes de devenir financièrement indépendantes). L'examen suggère que des interventions de déstigmatisation de l'infertilité doivent être mises en œuvre à tous les niveaux. Les interventions destinées aux individus connaissant l'infertilité devraient inclure les femmes et les hommes, et également être proposées au-delà de l'environnement clinique; et les interventions devraient aussi viser à combattre les

Resumen

La infertilidad es una preocupación de salud reproductiva que merece atención, como reconfirmó el informe de 2018 de la Comisión Guttmacher-Lancet sobre Salud y Derechos Sexuales y Reproductivos (SDSR). Sin embargo, los gobiernos y organizaciones de SDSR tienden a hacer caso omiso de la infertilidad. Realizamos una revisión del alcance de intervenciones existentes que pretendían disminuir la estigmatización de la infertilidad en países de bajos y medianos ingresos (PBMI). La revisión consistió en una combinación de métodos de investigación: base de datos académicos (Embase, resúmenes de Sociological, Google Scholar; con un total de 15 artículos), búsquedas en Google y en las redes sociales y recolección de datos primarios (18 entrevistas con informantes clave y 3 discusiones en grupos focales). Los resultados distinguen entre intervenciones sobre el estigma de la infertilidad dirigidas a los niveles intrapersonal, interpersonal y estructural del estigma. La revisión muestra que los estudios publicados sobre las intervenciones que abordan la estigmatización de la infertilidad en PBMI son raros. No obstante, encontramos varias intervenciones en los niveles intra- e interpersonal que buscaban apoyar a mujeres y hombres para superar y mitigar la estigmatización de la infertilidad (ej., consejería, líneas de atención telefónica y grupos de apoyo). Un número limitado de intervenciones abordaron la estigmatización a nivel estructural (ej., empoderando a mujeres infértiles para tener independencia financiera). La revisión indica que las intervenciones de desestigmatización de la infertilidad deben implementarse en todos los niveles. Las intervenciones dirigidas a personas que sufren infertilidad deben incluir a mujeres y hombres, y deben ofrecerse más allá del ámbito clínico; además, las intervenciones deben procurar combatir actitudes estigmatizantes de los miembros de la familia o de la comunidad. A nivel estructural, las intervenciones podrían procurar empoderar a las mujeres,

attitudes stigmatisantes de la famille ou des membres de la communauté. Au niveau structurel, les interventions pourraient s'employer à autonomiser les femmes, refaçonner les masculinités et élargir l'accès à des soins globaux en matière de fécondité tout en améliorant la qualité. Les interventions devraient être entreprises par les décideurs, les professionnels, les militants et d'autres personnes travaillant sur l'infertilité dans les pays à revenu faible ou intermédiaire, et accompagnées d'une recherche d'évaluation pour en mesurer l'efficacité.

redefinir las masculinidades y mejorar la accesibilidad y la calidad de la atención integral a la fertilidad. Las intervenciones deben ser emprendidas por formuladores de políticas, profesionales, activistas y otras personas que trabajan en infertilidad en PBMI, y deben ser acompañadas de investigación de evaluación para evaluar su eficacia.