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REVIEW



How to ensure policies and interventions rely on strong supporting facts to improve women's health: The case of female genital cutting, using Rosling's Factfulness approach

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Abstract

Rosling et al's book Factfulness aims to inspire people to use strong supporting facts in their decision-making, with 10 rules of thumb to fight dramatic instincts. In this paper, the Factfulness framework is applied to female genital cutting (FGC), in order to identify possible biases and promote evidence-based thinking in studies on FGC, clinical guidelines on management of FGC, and interventions aimed at abolishing FGC. The Factfulness framework helps to acknowledge that FGC is not a uniform practice and helps address that variability. This framework also highlights the importance of multidisciplinarity to understand causalities of the FGC issue, which the authors argue is essential. This paper highlights the fact that FGC is a dynamic practice, with changes in the practice that are ongoing, and that those changes are different in different contexts. The "zero tolerance" discourses on FGC fail to acknowledge this. Factfulness encourages us to be more critical of methodologies used in the area of FGC, for example when estimating girls at risk of FGC in migration contexts. Factfulness provides the tools to calculate risks rather than judgments based on fear. This may help limit stigmatization of women with FGC and to allocate resources to health problems of migrant women based on real risks. The framework also calls for more research and production of less biased facts in the field of FGC, in order to improve interventions aimed at abolishing FGC, and clinical guidelines for the treatment of FGC. Factfulness is a useful and structured foundation for reflection over constructs, biases and disputes surrounding FGC, and can help improve the quality of future evidence-based interventions and education that address the actual needs of women with FGC and girls at risk of FGC.

KEYWORDS

evidence-based interventions, factfulness, female genital cutting, female genital mutilation, global reproductive health and rights

Abbreviations: FGC, female genital cutting; WHO, World Health Organization.

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1 | INTRODUCTION

Female genital cutting (FGC), also called female genital mutilation or female circumcision, is defined by the World Health Organization (WHO) as "all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons". The practice has many different local names and ways to describe it, as it is an heterogeneous practice. The WHO has categorized FGC into four major types according to severity of the procedure. Type 1 is the (partial) removal of the clitoral glans or hood, whereas type 2 also includes removal of labia (minora and/or majora). Type 3, or infibulation, is the narrowing of the vaginal opening, sometimes through stitching. Type 4 includes all other types of harmful procedures, including pricking and piercing of the female genitalia. FGC is, however, often presented as one uniform practice, despite its well-known variation when it comes to age, reasons for upholding the practice or level of injury.

Although FGC has initially been studied in its local contexts, the rise in international migration has made the issue a global concern, with various cultural understanding and attitudes towards it. International efforts to prevent FGC practices have been ongoing for three decades, mostly in Africa. Initiatives driving abandonment of the tradition have taken different approaches. The WHO has based their interventions on the negative health consequences of the procedure. However, studies linking FGC to maternal death and obstetric ill-health are weak and have many methodological issues.³ Other interventions have been focusing on human rights frameworks, legal aspects or alternative rites. ⁴ There is little quality evidence, however, that these interventions aimed at abolishing FGC are working, and few evaluations of what is effective. 3 Social norms theory, among other theories, has shown promising results as a starting point for driving change. 5 Social norms theory assumes that FGC is being upheld by social norms and conventions, and that the decision to circumcise is dependent on other people's decisions in the community. ⁵ The majority of countries where FGC is performed have adopted legal frameworks prohibiting the practice.⁶

Interpretation of research results on FGC has been a divisive issue among scientists, activists and scholars over the last decades, featuring several opposing discourses. For different reasons described in this paper, multiple biases occur in discourses about FGC. Varying cultural ideas and values about health, body and sexuality make the issue of FGC complex.

Sociologist Donileen Loseke defines *social problems* as "conditions that we believe are troublesome, prevalent, can be changed, and should be changed". *Claims* are all messages that aim to convince an audience that a certain condition is a social problem. The case of FGC fits all the criteria to be a "social problem" according to Loseke: it is perceived as troublesome, prevalent and a phenomenon that can and should be changed. *Loseke analyzes the different roles of various claim-makers (activists, scientists and media) in making an issue a social problem. Scientists have the highest credibility because of the ideal of an unbiased science, and therefore play a crucial role in convincing audiences of an issue's relevance. However, most

Key message

The factfulness framework is a useful foundation for reflection on constructs, biases and disputes surrounding female genital cutting, and can help improve the quality of evidence-based guidelines, interventions and education that address the actual needs of women with female genital cutting and girls at risk of female genital cutting.

social problems are about moral evaluations, where, as human beings, no scientist can be neutral; a process that Loseke calls social construction of scientific knowledge. The lines between scientists and activists can sometimes be blurred, as one person can take on both roles. Activists have the role of convincing audiences that a certain condition is a social problem in order to initiate social change. To achieve this, they might act upon people's instincts and emotions to convince them that there is a moral problem. They can and should also use scientific results to support their claims, without ignoring the complexity of the problem. Scientists, however, should try as much as possible to remain neutral and immune to these instincts and emotions.

In his book Factfulness, Rosling et al encourage people to think instead of feel, and gives a practical framework of 10 "rules of thumb" (see Table 1) to fight our dramatic instincts in order to use data to see things clearly. 10 Rosling's foundation, Gapminder, aims to "work against devastating ignorance with a fact-based worldview". 11 That, per se, is nothing new, but he argues that facts are not always based on empirical data or logical arguments. The Factfulness framework of Rosling is a suggested tool to separate thinking from feeling, fighting instincts and biases and instead relying on data and facts. 10 This review aims to present a re-evaluation of the literature on FGC inspired by Rosling's critical framework of Factfulness. To the authors' knowledge this framework has not been applied to any other specific topic. The overall goal is to identify possible biases and to inspire interventions, studies and clinical guidelines on FGC to use more evidence-based information, and to reflect on these facts. Factfulness may be a useful guiding framework for this specific area because of the many misconceptions, the lack of strong supporting facts and the high amounts of divergences and disputes FGC has generated among policymakers, non-governmental organizations, professionals and the target groups.

Now that FGC has been defined as a social problem through the lens of Factfulness's dramatic instincts, various arguments and stances will be parsed and reflected upon.

2 | NEGATIVITY INSTINCT

Negative news is usually more striking and dramatic than positive news, leading to a negativity bias.¹⁰ Additionally, better surveillance means more reporting of adverse events, but this does not

TABLE 1 A summary of our recommendations applied to the area of female genital cutting (FGC) based on the Rosling et al *Factfulness'* dramatic instincts and their rule of thumb

Dramatic instinct	Rule of thumb	Applied to FGC
Negativity instinct	Expect bad news	Remember that evidence shows large-scale change in the practice in diaspora
Destiny instinct	Slow change is still change	FGC is a dynamic practice and cultural change takes time
Straight line instinct	Lines might bend	Changes in FGC practices can vary, the tipping point of cultural change is context related
Size instinct	Get things in proportion	Be critical of the methods used for estimations of FGC
Fear instinct	Calculate the risks	Refrain from stigmatizing and allocate resources according to real risks
Gap instinct	Look for the majority	Consequences of FGC are not uniform
Urgency instinct	Take small steps	Do research and gather solid evidence before planning interventions
Blame instinct	Resist pointing your finger	Refute single causality
Single perspective instinct	Get a tool box	Work in a multidisciplinary and multiprofessional team
Generalization instinct	Question your categories	Address variability, emphasize different types of FGC and its consequences.

necessarily mean that things are worse than they used to be, only that we are more aware of it.

Although underreported, studies show changes in prevalence and severity of FGC. There is a growing opposition to and change of attitudes towards FGC after migration among migrants in Sweden. ^{12,13} Additionally, fewer FGC procedures occur in unhygienic circumstances, although the "medicalization" of FGC is a problematic and unethical issue, as extensively discussed elsewhere. ^{14,15} In some settings, such as in Mali and Chad, there is a slight movement towards less severe forms of FGC, replacing tissue removal with symbolic nicking/pricking. ¹⁶ There is also evidence from the Somali region of changes in the type of cutting from "pharaonic" to "sunna" cutting, the perceived milder form of FGC. ^{17,18} Despite regional variation, there is strong evidence for a significant decline in FGC rates among girls aged 0-14 years in Africa over the last 20 years, suggesting success of the various FGC interventions. ¹⁹ As will be discussed in the next paragraph, it is important to notice slow change.

Acknowledging these changes in FGC practice is not equal to accepting FGC or stopping the fight against FGC; rather it is an opportunity to understand which changes are happening, explore what worked in order to achieve this, and to build further on these interventions. The "Zero tolerance" discourses adopted by WHO, frame FGC as a violation of human rights and fail to acknowledge these changes, as all forms of FGC are considered equally bad. Moving away from the Zero tolerance discourse could provide an opportunity to leave the practices stepwise. ¹³

Additionally, there is a lack of evaluation of the implementation of interventions to prevent/abolish FGC, although the very few evaluations performed point towards positive results. ^{3,20} More evaluations by scholars from both medicine and social sciences disciplines

are needed to provide facts about the efficiency of FGC interventions in order to improve them and to fight the negativity instinct.

3 | DESTINY AND STRAIGHT-LINE INSTINCTS

The destiny instinct makes us believe that some things are destined to be one way forever, and will never change. We may feel this way about culture, religion, values or ideals. Factfulness tells us to appreciate slow change, as things that seem static might actually be changing slowly. If we look back at our own societies a few generations ago, we will notice that dramatic changes in cultures have occurred, even if they happened slowly (for example public opinion about gay rights).

There is evidence of significant declines in rates of FGC among children in African countries.¹⁹ There is also evidence of rapid cultural change with migration from an FGC-practicing country to a non-practicing country; for example, Somalians who reevaluate and reject FGC when living in Sweden, even recently arrived migrants.¹² The idea that FGC is inevitable in certain cultures needs to be challenged, as cultures are dynamic.

At the same time, the straight-line instinct makes us notice a trend and assume that it will continue in the same way for the fore-seeable future. We see a straight line on a graph and our minds imagine the continuation of the line following the same curve. However, it is quite rare for trends to follow a linear curve over a long period of time, and it is wrong to assume that they will for certain. Cultural and behavioral changes can often follow an S-shaped curve.²¹ Initially a few people are willing to take the risk to go against the social norm,



and the change is very slow. After a critical point where enough people have made the change, the norm shifts. The behavior of an individual is influenced by the behavior of other people in the society. ^{5,22} In a society where most women are cut, it might be preferable for parents to cut their daughter, to avoid her being excluded from social life or marriage. In this situation, it might be challenging to convince parents not to perform FGC; thus the decreasing rate might be slow at the beginning of a community-based intervention. However, once a tipping point is achieved and it becomes clear that it is possible to be both uncut and included in the community, the change and abandonment of the FGC practice may occur at a faster rate. ⁵

The culture around the practice of FGC can change, and may change with different patterns. It is crucial to realize this in order to plan appropriate guidelines and sustainable long-term interventions with the aim to abolish FGC, rather than assume it will follow a straight line.

4 | SIZE INSTINCT

We tend to see things out of proportion, overestimating the importance of a single event or person that is visible to us, and base the scale of an issue on a standalone number. The discourse in media and preventive interventions towards FGC in Europe relies on assumptions of high estimations of girls at risk of FGC, and illegal hidden practice of the procedure. 23-25 However, empirical data on FGC convictions in Europe show the opposite of this instinct: less than 50 court cases, most from the 1980s and none on Scandinavian soil, and a dozen convictions, despite hundreds of thousands of people from countries where circumcision of girls living in Europe is practiced.²⁶ This instinct is grounded in the estimations of girls at risk that are calculated by looking at the number of female migrants from a certain country and the prevalence of FGC in the home country. 27 Since 2017, the European Institute for Gender Equity has updated its methodology to measure girls at risk, by adding a qualitative component to the measure, accounting for cultural change after migration.²⁸ In doing so, they now provide two estimates, one for low-risk scenarios (assuming total cultural change and no circumcision of second-generation migrants) and one for high-risk scenarios (accounting for no cultural change). 28 Large-scale attitude changes towards FGC are reported in Sweden, Germany, Switzerland and the UK among migrants. ²⁹⁻³¹ In a qualitative study from 2009, Swedish-Eritreans and Swedish-Somalis referred to FGC as a "brutal practice", 32 which suggests the low-risk scenario estimations might be more representative.

5 | FEAR INSTINCT

The things we fear the most are not necessarily the most dangerous things around us. Fear diverts our energy from consideration of real risks to perceived risk, distracting us from assessing real risks based on empirical data. Activists might think that creating fear by exaggerating claims is justified because it is the only way to make people act on the issue. However, Rosling warns about the dangers of this in his book: fear can lead to bad decisions and insensible actions.

A recent review by WHO Europe points out that maternal health complications in migrant women were due mainly to socioeconomic factors, such as low income, low education and limited access to healthcare.³³ In Sweden, women and newborn from the Horn of Africa have a higher risk of dying during pregnancy or childbirth compared with the host population. A maternal and perinatal death audit showed, however, that FGC was not a contributory factor in accounting for these deaths, which were due rather to miscommunication and suboptimal perinatal care.³⁴⁻³⁶ Healthcare providers need to be able to rationally detect risk factors in their patients in order to prevent complications. Fear of FGC might mislead healthcare providers' diagnoses, leading to less effective preventive healthcare.

This fear can also lead to unintended stigmatization and harassment, as shown in a recent report from the UK. Somali women living there found the FGC safeguarding policies stigmatizing and traumatizing.³⁷ Some women reported being repeatedly asked about FGC, even when consulting healthcare for unrelated health problems, meaning they did not receive the healthcare they expected to.³⁷ In Sweden, safeguarding mechanisms aimed at protecting girls from FGC have had harmful consequences as well, for example when minor girls were taken out of school and forced to have genital examinations, based on suspicions of FGC.²³ This raises a practical question for healthcare providers and social services: how can one screen patients (which entails identifying risk factors) without stigmatizing and racial profiling? How can healthcare providers identify and protect women who are at risk of FGC, without FGC becoming a marker for stigmatization?

As mentioned by Loseke, fear is a powerful tool for claim-makers to make people act and change. Activists in every field try to convince people of the importance of their cause compared with other causes, and might even try to exaggerate facts and describe worst-case scenarios. Non-governmental organizations and in certain cases even researchers often have to compete for funding and this pushes them to dramatize the issue they work on. Exaggerated discourses about striking examples and a single-perspective view can lead to ill-informed funding decisions that will not benefit the most people.

6 | GAP INSTINCT

When we compare extremes, the gap instinct makes us believe that there are two groups with a gap in between. In most cases, there is actually a majority somewhere in the middle, as many phenomena follow a Gaussian curve. For example, few people are extremely poor and few people are extremely rich; most people are found somewhere in the middle. The same reasoning could be applied to the health of women who have undergone FGC.

One striking example of the perception of a gap concerns sexual dysfunction. There is a common generalization that all women with

FGC are unable to enjoy sexual relations fully.³⁸ We imagine two categories of women, one with FGC having painful sexual relations, and one without FGC having rich sexual lives, with a gap between the two groups. While a number of women have serious problems, or no problems at all, the majority lie somewhere in the middle. In a systematic review, Obermeyer concludes that "the available evidence does not support the hypotheses that [female] circumcision destroys sexual function or precludes enjoyment of sexual relations". 39 There is therefore no reason to believe that all women with FGC are on the extreme negative side of the sexual function spectrum and, although it is probable that women with FGC have on average worse sexual function, there is high individual variability. A systematic review by Berg in 2011 "provided evidence in support of the argument that FGC is associated with attenuation of a woman's sexual function". 40 However, it is important to note "sexual satisfaction is highly personal, and is difficult to measure with indicators chosen arbitrarily", such as standardized questionnaires. 41 Research shows that orgasm and sexual satisfaction are not significantly correlated and therefore orgasm alone should not be used as an indicator of sexual satisfaction. 41 Additionally, notions of pain, pleasure, beauty and sexuality are culturally defined as well as individually variable, and it is therefore impossible to have one standardized tool with which to measure sexual function.42

7 | URGENCY INSTINCT

The urgency instinct pushes for immediate action rather than small steps and reflection. Rosling argues that people usually make more rational decisions after first taking some time to evaluate the situation.

In 2016, WHO published recommendations on the management of health consequences of female genital mutilation, based on the GRADE methodology, to systematically rate the certainty of evidence in systematic reviews. 43,44 Every single study they based recommendations on, has the lowest quality GRADE score possible. 44 The intentions for this publication might be good, trying to solve a problem by acting as soon as possible, but will the expected outcome be achieved? To quote Hans Rosling: "when you are called to action, sometimes the most useful action you can take is to improve the data". 10 There is very little high-quality evidence on FGC health outcomes.3 The "gold standard" study design to establish causality, randomized control trials or prospective cohorts, are neither appropriate nor ethical to study FGC, as this would involve one group of the study population to undergo FGC as an intervention of the study.²⁰ The only studies available on FGC are cross-sectional, and have considerable issues with sampling. In countries where FGC is not usually practiced, FGC can be studied in migrants, but it might be challenging to find enough cut women to have statistical power while still being representative of the population. In societies where FGC is practiced, the problem is to find a comparison group (women

who are not cut) without any other confounding factors. Ethnicity and migration are often confounding factors and go hand in hand with FGC exposure. Additionally, it is challenging to establish a "dose-response" relation between the severity of complications and how much genital tissue was removed. The women themselves may not know how much tissue was removed if FGC was performed during early childhood. The WHO classification does not fit all types of FGC and requires a trained observer. ⁴⁵ In some cases, it might even be difficult to establish whether FGC has occurred at all, as we can see in court cases where multiple experts debate and disagree on allegations of FGC. ⁴⁶ Low quality of data means the studies have very high uncertainty. FGC is a complex issue and the research should acknowledge this complexity with careful interpretation of results.

8 | BLAME INSTINCT

FGC is often cited as a main reason for the high maternal mortality ratios in African countries, without much solid evidence. Somalia has one of the highest maternal mortality ratios in the world (732 per 100 000 live births) and 98% of Somali women have undergone FGC.⁴⁷ However, if we compare Egypt, Sudan and Mali, three countries with the same incidence of FGC (87%-89%), there are significant differences in maternal mortality ratios (33, 311 and 587 per 100 000 live births, respectively).⁴⁷ Additionally, the Central African Republic has a maternal mortality ratio even higher than Somalia (882 per 100 000 live births) and does not practice FGC. 47 Although FGC might pose a risk to women during pregnancy and childbirth, there would appear to be other contributory factors that are being neglected while our attention is focused on FGC. The findings from a WHO report linking FGC with adverse obstetric outcomes has been heavily criticized, due to findings not being based on adequate evidence (7,8,48).

Another example of the blame instinct is to point fingers at men for upholding FGC, whereas it is typically managed by women. The theory of men controlling women's sexuality through FGC is not well established by facts.^{8,49} According to a UNICEF report, daughters were more likely to remain uncut when fathers were involved in deciding whether their daughters should undergo FGC.⁵⁰

9 | SINGLE PERSPECTIVE INSTINCT

The single perspective instinct makes us look at a problem and draw conclusions from one area of expertise. In the case of FGC, to understand the complexity there is a need for insights from a wide range of scientific areas: medicine (obstetrics and gynecology), sexology, epidemiology, psychology (attitudes and behavior change) and anthropology (culture and mechanisms behind harmful practices). S1 Rosling advises refuting single causality and getting a toolkit of different perspectives.



10 | GENERALIZATION INSTINCT

Humans tend automatically to categorize and generalize, to structure our thoughts and experiences. However, it might be useful to question the categories we are using. We should look for differences within groups: within the group of women who have undergone FGC, there is considerable variability. Depending on the exact type of FGC performed, health outcomes vary greatly. In Western countries, the burden of disease of migrants from high-prevalence FGC countries is higher than the host population, which means attention needs to be redirected to health issues that affect migrant population. ⁵² However, FGC does not seem to represent a contributing factor to the adverse obstetric outcomes. ^{36,53}

There is a lack of understanding and awareness that there are different forms of FGC and that these have different consequences. Some studies investigating health consequences of FGC group all types of FGC together.⁵⁴ Many studies, however, differentiate types of FGC in their methods, using the WHO classification, but still make broad generalizations in their conclusion, stating that FGC causes a certain health outcome, without specifying which type of FGC.⁵⁵⁵⁷

Some of the claims-making strategies identified by Loseke are typifying stories (categorizing) and constructing extreme consequences. This is also what Rosling is warning us about, and he advises us to locate the majority instead of focusing on the unrepresentative extremes. Exaggerated discourses created by activists and/or by media are problematic for several reasons. If this is the only discourse that receives attention, it can lead to "unfactfulness" in decision-making. Let us take the example of the discourse that FGC causes maternal mortality. Policymakers trying to improve women's and children's health could allocate all the resources to eradication of FGC, which will not have the desired effect on maternal mortality. Blaming FGC for adverse obstetric outcomes means we do not look at other causes of morbidity and thus miss opportunities for improving health.⁵⁸ In clinical practice of migrant women from high-prevalence FGC countries, we encourage colleagues to separate facts from values and to treat patients from a holistic perspective rather than from the perspective of their cut genitals.

11 | CONCLUSION

Applying Factfulness dimensions to research and interventions concerning FGC has been useful to discuss the various instincts and biases that abound. This article has cast a new Factfulness lens upon the current state of affairs for FGC in an effort to challenge the many assumptions that affect how we see FGC. The exercise of challenging assumptions around thinking and feeling is useful in this reflection and deconstruction of discourses; however, thinking and feeling cannot be completely separated. Pure science uncontaminated by political, social and governmental factors is an ideal, and recognizing that human biases exist can help us achieve less biased knowledge.

Factfulness is a useful and structured way to approach these biases in the case of FGC with the intention to give the best respectful care and treatment. Factfulness can serve as a foundation for reflection on constructs of discourses, biases and disputes, in order to improve quality of future evidence-based interventions and education that address the actual needs of affected and potentially affected women.

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CONFLICT OF INTEREST

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