

# RESEARCH AND FEMALE GENITAL MUTILATION PREVENTION: EVIDENCE FROM AFRICA

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## Abstract

*Research must benefit society, including improving the health and well-being of women and girls and contributing to achieving Sustainable Development Goal target 5.3, which focuses on eliminating all harmful practices, including female genital mutilation. Research that aims to transform gender norms, particularly those related to the sensitive and deeply-entrenched cultural practice of FGM, requires careful consideration of epistemology or the theory of knowledge that will underpin the study question and define the researcher's relationship with the research. The aim of a research study will influence the selected paradigm, methodology and research design. These choices will direct the analysis and interpretation of the results and how the findings will be disseminated and applied to maintain or change policy and practice. This chapter will discuss what research evidence we have concerning interventions that have demonstrated a change in knowledge, attitudes, and behaviour resulting in FGM prevention in communities, across nations, and regionally in Africa. A public health prevention framework will be applied to understanding how these interventions have influenced the practice of FGM at primary, secondary and tertiary levels to prevent FGM and care for affected women and girls. The characteristics of FGM research, including the methodologies applied, will be outlined to reveal the theoretical underpinning of current research and the funding, institutions and countries involved. Current knowledge gaps and research questions*

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*will be identified, and the needs of researchers to build research capacity to generate the evidence required for policy and practice will be explored. The role of research as an instrument for change and ethical questions will be examined alongside the possible pathways for FGM prevention, including current research partnerships and knowledge exchange activities, translation efforts and insights into research in progress.*

## 1 Introduction

Research aims to improve society by advancing knowledge through developing scientific theories, concepts and ideas. However, it is no longer enough to generate and disseminate this knowledge in scholarly journals. Researchers must also engage with stakeholders to select meaningful and relevant questions for study and contribute to applying this knowledge in the world. This includes work to ensure research evidence is used to benefit individuals and their communities and deliver real impact, including preventing female genital mutilation (FGM).

The Sustainable Development Goals (SDGs) contain a set of 17 measures to foster sustainable development across many areas, including target 5.3, which focuses on eliminating all harmful practices, including FGM. Research plays an essential role in delivering evidence on the contribution of interventions, including laws and policies to preventing FGM and how these can be best implemented. Research can evaluate how these interventions change attitudes and norms and track progress or trends over time to demonstrate a reduction in the prevalence of FGM. Research focusing on achieving the SDG5 targets related to gender equality, including eliminating FGM, varies according to the region.<sup>1</sup> A bibliometric analysis of FGM literature between 1930 and 2015 indicates that this is a growing area of research, with more than half of the 1 032 retrieved articles published between 2006 and 2015.<sup>2</sup> Well-resourced research to monitor progress on SDG target 5.3 should be a priority alongside funding to scale up evidence-based interventions.

1 AL Salvia and others 'Assessing research trends related to Sustainable Development Goals: Local and global issues' (2019) 208 *Journal of Cleaner Production* 841-849.

2 WM Sweileh 'Bibliometric analysis of literature on female genital mutilation: 1930-2015' (2016) 13 *Reproductive Health* 130.

There are challenges in undertaking research on FGM due to its sensitive nature. Researchers must carefully consider the risks and consequences associated with such research. This may affect research participants, affected communities and researchers themselves. It may be challenging if the researchers are undertaking work to identify routes to prevention in contexts where there is active support for FGM, or they are documenting FGM prevalence in contexts where it is illegal. The clandestine practice of FGM in many settings means that participants may be hard to reach and data difficult to elicit. There is the potential for research on FGM to cause harm, especially in situations where affected women and girls are interviewed. They may experience distress or anxiety about reawakening painful memories or disclosing sensitive information. Participants may be concerned about the researcher's credibility, power differentials or being stigmatised. Despite this, the experiences of vulnerable populations participating in research on sensitive topics have been largely positive.<sup>3</sup> The research process itself may also contribute to the elimination of FGM by identifying the issue and engaging people in conversations about FGM that may raise awareness, improve knowledge and result in the contemplation of behavioural change.

Achieving SDG 5.3 is a complex task that will require the transformation of embedded gendered social norms. Research activity that is part of this process will involve drawing upon multiple theories, methodologies, and tools to answer a range of research questions that requires the participation of women and girls and affected communities to achieve change.

### 1.1 Epistemological underpinnings of FGM research

Research that addresses a complex issue such as FGM prevention, where there is no single way forward, has led to researchers embracing multiple views on what constitutes knowledge. How knowledge is discovered and analysed in a systematic way is dictated by a subscribed theory or epistemology about how knowledge should be gathered. These epistemological understandings include objectivism, constructivism

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3 S Alexander, R Pillay & B Smith 'A systematic review of the experiences of vulnerable people participating in research on sensitive topics' (2018) 88 *International Journal of Nursing Studies* 85.

and subjectivism.<sup>4</sup> FGM research aligned with objectivism focuses on using credible, objective tools to collect data and make measurements. Knowledge is generated through controlled observation and experimentation to confirm explanations. This draws on positivism or post-positivist theory associated with experimental or survey research. Examples of these quantitative studies include those based on a secondary analysis of the data on FGM that are derived from standard questions in the Demographic Health Survey (DHS) and Multiple Indicator Cluster Survey (MICS).<sup>5</sup> The DHS and MICS are nationally-representative household surveys in over 90 countries that provide programme data for a range of monitoring and impact evaluation indicators in population, health and nutrition.<sup>6</sup> These studies provide insight into trends in the prevalence of FGM,<sup>7</sup> enable researchers to analyse the associated demographic and health factors<sup>8</sup> and future project trends in practice.<sup>9</sup> Such research helps identify a baseline before and after to measure change over time and assess the current context to plan interventions, including the health system response to FGM.

Other FGM qualitative research is underpinned by a constructivist epistemology that posits knowledge depends on interpretation and focuses on the details of phenomena. Interpretative research that draws on constructivism seeks to understand 'how members of a social group, through their participation in social processes, enact their particular realities and endow them with meaning, and to show how these meanings, beliefs and intentions of the members help to constitute their

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4 M Crotty *The foundations of social research: Meaning and perspective in the research process* (2020) 5.

5 N Kandala and others 'Secular trends in the prevalence of female genital mutilation/cutting among girls: A systematic analysis' (2018) 3 *BMJ Global Health* 1-7.

6 USAID 'DHS Overview Washington DC: US Agency for International Development or the US Government' 2022, <https://www.dhsprogram.com/Methodology/Survey-Types/DHS.cfm> (accessed 26 May 2022); UNICEF 'Multiple indicator cluster surveys (MICS)'; <https://mics.unicef.org/> (accessed 26 May 2022).

7 Kandala and others (n 5) 1-7.

8 BO Ahinkorah and others 'Socio-economic and demographic determinants of female genital mutilation in sub-Saharan Africa: Analysis of data from demographic and health surveys' (2020) 17 *Reproductive Health* 162.

9 K Weny and others 'Towards the elimination of FGM by 2030: A statistical assessment' (2020) 15 *PLOS ONE* 1.

actions.<sup>10</sup> One example of such research is by Doucet and others who undertook ethnographic work in villages in Conakry to explore how FGM is embedded in social and family dynamics.<sup>11</sup> Other constructivist research employs a critical paradigm acknowledging that knowledge is not neutral, is socially constructed and constantly influenced by power relations within society. This research seeks to generate theory from action or practice to help people address change in the interest of social justice. One example is a study with young men involved in FGM prevention in Somaliland that explores how they negotiate violence against women and gender norms.<sup>12</sup> Other studies have applied participatory approaches involving people from FGM-affected communities. These studies are underpinned by the notion that research should serve social goals such as emancipation, particularly of marginalised and vulnerable groups such as those with FGM.<sup>13</sup>

FGM research has also embraced subjectivism, which espouses that all knowledge is a matter of perspective. Auto-ethnography is one methodology associated with the post-modern theory that may involve intensely personal studies that challenge the victim mentality. While no such studies can be located in Africa, one example from the United Kingdom is arts-based research with Somali community members engaged in expressing their stories of changing social norms, captured in podcasts to use as education resources.<sup>14</sup>

While some research may be aligned with one epistemology, there is growing support for research that embraces all forms of knowledge. In these studies, knowledge is regarded as constantly renegotiated and debated in terms of its usefulness in different situations. Subjective

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- 10 WJ Orlikowski & JJ Baroudi 'Studying information technology in organisations: Research approaches and assumptions' (1991) 2 *Information Systems Research* 1.
  - 11 M Doucet and others 'Beyond the sociocultural rhetoric: Female genital mutilation, cultural values and the symbolic capital (honor) of women and their family in Conakry, Guinea – A focused ethnography among “positive deviants”' (2022) 26 *Sexuality and Culture* 1858.
  - 12 M Văkiparta *Young men against female genital mutilation/cutting in Somaliland: Discursively negotiating violence, gender norms and gender order* (2019) 107-125.
  - 13 K Greiner, A Singhal & S Hurlburt 'With an antenna we can stop the practice of female genital cutting: A participatory assessment of Ashreat Al Amal, an entertainment-education radio soap opera in Sudan' (2007) 15 *Investigación and Desarrollo* 226.
  - 14 S Penny & P Kingwill 'Seeds of the future/Somali programme: A shared autoethnography on using creative arts therapies to work with Somali voices in female genital mutilation refusal in the UK' (2018) 15 *New Writing* 55.

interpretations and objective phenomena are considered helpful in providing knowledge through qualitative and quantitative research. This research focuses on solving problems or dealing with unique issues. Mixed-methods research is applied to accommodate this pragmatic worldview to answer one or more research questions from different perspectives. This methodology enables exploratory and confirmatory questions to be answered simultaneously, which allows theory to be verified and generated within one study. One example of mixed-methods research is the evaluation of the Tostan's Village Empowerment Programme in Mali. Data was collected using qualitative interviews, observational checklists and surveys that shed light on the empowerment process and how the programme changed attitudes and practices to various issues, including FGM.<sup>15</sup>

No research activity is theory or value-free. The epistemological orientation will determine the paradigm or theoretical perspective that is taken and the methodology employed. This will determine the position of the researcher and their work along a continuum. At one end is realism, where the researcher is distant and knowledge objectively discovered and generalised. At the other end of the continuum is relativism, where the researcher and participants are deeply embedded in the research process. While findings might be transferrable to different contexts, these are constantly changing. These positions and researchers' backgrounds mean that research is culturally and ethically loaded. While those undertaking experimental or survey research appear distant, their gender, ethnicity, culture, and socio-economic background will determine how the research is undertaken and influence the findings, their publication and uptake.

## 2 What research evidence do we have to prevent FGM?

The publication of research findings in peer-reviewed journals or reports is a critical step towards considering research findings as evidence and, therefore, useful to inform policy and practice. The peer review process ensures the rigour of research methods, the quality of the findings and

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15 K Monkman, R Miles & P Easton 'The transformatory potential of a village empowerment program: The Tostan replication in Mali' (2007) 30 *Women's Studies International Forum* 451.

the credibility of their implications. However, not all published evidence is considered equal depending on the research discipline. In medicine, hierarchies of evidence dictate the relative strength of the evidence.<sup>16</sup> The Oxford Centre for Evidence-Based Medicine Levels of Evidence<sup>17</sup> begins with expert opinion, moving to individual studies or primary research, to systematic reviews of randomised controlled trial studies (RCTs). Quantitative systematic reviews constitute a meta-analysis of pooled statistical data from individual studies that have been filtered and reappraised to ensure included studies are of high quality. The Cochrane library and the Campbell Collection are repositories of this top-level systematic review evidence that focuses on the effectiveness of interventions. Another useful source of systematic reviews on child well-being in low and middle-income countries is the Mega-Map.<sup>18</sup>

However, in emerging research fields or areas where RCTs are difficult to conduct, including in FGM, individual studies are a useful indication of evidence or promising prevention policy or programmes. Different study types may be required to answer different questions. Table 1 outlines different clinical questions and the suggested experimental individual study types that may be required to answer these questions. The issue with adopting this approach to understanding research and its role in preventing FGM is that it would be restricted to post-positivist studies underpinned by objectivism. This would result in the continued dominance of a bio-medical approach to prevention and the classification of FGM as a 'disease-like state' that would discount other views of what constitutes evidence that may provide helpful insights into understanding and preventing FGM.

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- 16 A DiCenso, L Bayley & RB Haynes 'Accessing pre-appraised evidence: Fine-tuning the 5S model into a 6S model' (2009) 151 *Annals of Internal Medicine* 99-101.
  - 17 J Howick *The 2011 Oxford levels of evidence* (2011); <https://www.cebm.ox.ac.uk/files/levels-of-evidence/cebm-levels-of-evidence-2-1.pdf> (accessed 4 February 2023).
  - 18 UNICEF 'Mega-map on child well-being interventions in LMIC's New York' UNICEF Innocenti Centre 2022, <https://www.unicef-irc.org/megamap/> (accessed 2 June 2022).



**Table 1:** *Question types and study types*

Type of question	Description of research	Best study type
Prevalence/ risk	Seeks to determine the occurrence of a condition and the likelihood of exposure	Local and current random sample surveys
Aetiology/ Causation	Seeks to determine if a harmful factor is related to the development of an illness	Cohort study or case-controlled study Case report for a rare illness
Prognosis	Seeks to determine the likely course of a disease or condition	Longitudinal survey
Diagnosis/ Screening	Tests the validity of diagnostic or mass screening tests	Cross-sectional survey
Therapy/ Intervention	Tests the efficacy of drugs, surgical procedures, therapy, or service delivery	RCT
Prevention	Seeks to determine how to reduce the chance of disease by identifying and reducing risk factors, and to achieve early diagnosis by screening	RCT, cohort study or case-controlled study

A comprehensive understanding of prevention requires including evidence from science-based disciplines such as medicine alongside the humanities, arts and social sciences. This knowledge can be used to describe interventions and make observations about outcomes (observational studies) but also examine issues, contextual factors, artefacts or phenomena that may or may not contribute to the prevention of FGM. This research enables the exploration of power dynamics and ethical dilemmas and the embracement of various research questions, theoretical perspectives, methodologies and study designs, including qualitative research synthesis. Qualitative systematic reviews are not concerned with measuring effectiveness. These meta-syntheses explore phenomena such as health-care experiences, the meaning of health or well-being, as well as environmental, organisational, and individual factors that affect the implementation of a healthcare service, educational initiative, policy, law or clinical intervention.

A valuable way to understand how research can contribute to preventing FGM is using a public health approach that embraces the



knowledge of multiple disciplines. Prevention is categorised according to four stages: primordial, primary, secondary and tertiary prevention levels.<sup>19</sup> Primordial prevention focuses on reducing risk factors for health issues at the population level by improving social and environmental conditions. Improving the education and employment opportunities of girls and women from FGM-practising communities may be one approach at this level. Primary prevention consists of individual and population efforts to prevent FGM from occurring through laws or community education, for example. Secondary prevention emphasises early detection and could include antenatal screening for women affected by FGM and safeguarding activities. Tertiary level prevention focuses on the care and support for those affected by FGM.

## 2.1 The evidence for the primordial prevention of FGM

While no longitudinal intervention studies identify the social determinants that contribute to preventing FGM at the population levels, we have systematic reviews of observational studies that show associations with factors that place women and girls at risk or protect them from FGM. These factors are valuable considerations when planning large prevention programmes.

Studies of DHS and MISCS data provide insight into the relationship between FGM and socio-economic factors. Ahinkorah and others<sup>20</sup> undertook a study of pooled DHS data collected between 2010 and 2018 in 12 countries in sub-Saharan Africa (Côte d'Ivoire and The Gambia excluded). A binary logistic regression analysis on the influence of socio-demographic characteristics on FGM found that FGM among women and their daughters decreases according to wealth status, education and urban residence. A study by Batyra and others<sup>21</sup> provides a greater understanding of the situation within countries. Batyra and others examined relative changes in prevalence rates in 23 African countries from DHS and MSICs data collected between 2002 and 2016 and related socio-demographic characteristics in two cohorts of women born

19 L Kisling & J Das *Prevention strategies* (2022), <https://www.ncbi.nlm.nih.gov/books/NBK537222/> (accessed 4 February 2023).

20 Ahinkorah and others (n 8) 162.

21 E Batyra and others 'The socio-economic dynamics of trends in female genital mutilation/cutting across Africa' (2020) 5 *BMJ Global Health* 1-9.

between 1965 and 1969 and 1990 and 1994. While there was a decline in FGM prevalence, except for The Gambia, considerable variation exists across countries over time. There is also cross-national variation in the magnitude of educational and urban-rural differences in FGM prevalence. For women born in the youngest cohort (1990-1994) those with no education have a much higher prevalence in Guinea-Bissau, Côte d'Ivoire, Eritrea, Sierra Leone and Kenya (differentials of >15 percentage points as compared with those who have any education). However, the opposite is the case in Sudan, where those with education have a higher prevalence. There is little difference between women with education and those without in Benin, Somalia, Togo and Ghana, where educational differentials have reduced over time and FGM prevalence is low. In most countries, women residing in urban areas had lower FGM prevalence than rural women. However, the difference is small or negligible in many cases. This study found that countries with the highest prevalence of FGM for women born 1965 to 1969 also had a much smaller relative change in prevalence than women born over the next 30 years.

Research has explored other social determinants worthy of consideration in planning prevention programmes at the population level. These include gender norms and values that may predict the practice and, therefore, present opportunities for strategies in prevention programmes. A qualitative systematic review of reviews by Yount and others<sup>22</sup> notes an association between FGM, later child marriage and forced first sexual encounter. Research conducted in Egypt, Mali, Côte d'Ivoire and Kenya reported a positive association between FGM and intimate partner violence (IPV).<sup>23</sup> Programmes designed to prevent FGM may also need to consider IPV, child marriage and rape.

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22 KM Yount, KH Krause & SS Miedema 'Preventing gender-based violence victimisation in adolescent girls in lower-income countries: Systematic review of reviews' (2017) 192 *Social Science and Medicine* 1.

23 HM Salihu and others 'The association between female genital mutilation and intimate partner violence' (2012) 119 *BJOG An International Journal of Obstetrics and Gynaecology* 1597-1605; K Peltzer & S Pengpid 'Female genital mutilation and intimate partner violence in the Ivory Coast' (2014) 14 *BMC Women's Health* 13; A Refaat and others 'Female genital mutilation and domestic violence among Egyptian women' (2001) 27 *Journal of Sex and Marital Therapy* 593-598; Y Sano and others 'Physical intimate partner violence justification and female genital mutilation in Kenya: Evidence from the Demographic and Health Survey (2021) 30 *Journal of Aggression, Maltreatment and Trauma* 781-791.

Social-cultural determinants can also influence FGM and provide insights for prevention. A systematic review by Berg and Dennison<sup>24</sup> identified factors that were perceived to interrupt the continuation of FGM, including laws prohibiting FGM, information on adverse health outcomes, the belief that FGM is not a religious requirement, and community opposition to the practice. The picture is complex. Those involved in making decisions regarding FGM were found to differ according to region depending on the power and status they hold.<sup>25</sup> One ethnographic study examines decisions around FGM concerning gender, culture, ethnicity and place, including the ongoing effects of colonialism in Kenya.<sup>26</sup>

Maternal attitudes toward the practice of FGM and community-level characteristics were examined in research based on the DHS from Burkina Faso, Côte d'Ivoire, Guinea and Mali.<sup>27</sup> While considerable variation was found within each country, mothers' attitudes towards FGM were significantly associated with a lower threat of a daughter being cut in all four countries. Community opposition was also negatively associated with FGM, except in Guinea, with relatively low community support levels for the practice. The study also examined 'community extra-familial opportunity structures' defined as the proportion of married women in the community who had their first co-residential union under 18 years of age, the proportion of adult women not in a polygamous union at the time of the survey (unmarried or in a monogamous marriage) and the proportion of women who had completed primary school or above. These factors were found to lower a woman's reliance on marriage and kinship networks and were significantly and negatively associated with daughters' FGM in Burkina Faso and Côte d'Ivoire. The presence of high levels of community support was not necessarily related to the low

24 RC Berg & E Denison 'A tradition in transition: Factors perpetuating and hindering the continuance of female genital mutilation/cutting (FGM/C) summarised in a systematic review' (2013) 34 *Health Care for Women International* 837.

25 A Alradie-Mohamed, R Kabir & SMY Arafat 'Decision-making process in female genital mutilation: A systematic review' (2020) 17 *International Journal of Environmental Research and Public Health* 3362.

26 EP Graamans and others 'Lessons learned from implementing alternative rites in the fight against female genital mutilation/cutting' (2019) 32 *Pan-African Medical Journal* 1.

27 SR Hayford and others 'Community influences on female genital mutilation/cutting: A comparison of four Francophone West African countries' (2020) 51 *Studies in Family Planning* 3.

prevalence of FGM. Research has indicated the importance of involving men as allies in prevention.<sup>28</sup>

A meta-analysis by Berg and others<sup>29</sup> provides insight into the effectiveness of a village-level programme in Mali, Burkina Faso and Senegal that is concerned with addressing social determinants of health such as education in hygiene, problem solving, women's health and human rights.<sup>30</sup> The Empowerment through Education (TOSTAN programme) is not focused on FGM. Instead, it is included, as are many other issues under the broader goal of community development. Descriptive analysis showed how this programme fared on indicators related to FGM. Statistically significant findings ( $p < 0.05$ ) post-intervention was only found in the studies from Senegal and Burkina Faso. Statistically significant findings were noted for women and men in both studies concerning improved recall for at least two consequences of FGM post-intervention.

This research clearly shows that any prevention programmes at the primordial level will need to address multiple social determinants of FGM based on a detailed understanding of the setting. However, these studies were conducted in relatively stable environments, not humanitarian contexts, where community attitudes towards FGM and their practice may change to cope with crises such as displacement due to conflict or epidemics. For example, a report noted that in a camp setting in Mali, a displaced minority group who did not traditionally practise FGM experienced social pressure from their host communities to take up FGM, among whom the practice was prevalent.<sup>31</sup> This observation indicates the need for population-level programmes to focus on multiple groups. One study reported that isolation measures put in place due to

28 E Brown and others 'Female genital mutilation in Kenya: Are young men allies in social change programmes?' (2016) 24 *Reproductive Health Matters* 118-125.

29 RC Berg & E Denison 'Effectiveness of interventions designed to prevent female genital mutilation/cutting: A systematic review' (2012) 43 *Studies in Family Planning* 135.

30 P Easton, R Miles & K Monkman 'Final report on the evaluation of the TOSTAN/IEP village empowerment program pilot project in the Republic of Mali Florida State University' (2002); N Diop and others 'The TOSTAN program: Evaluation of a community-based education program in Senegal' FRONTIERS Final Report Washington, DC Population Council (2004); D Ouoba and others 'Experience from a community-based education program in Burkina Faso: The Tostan program' FRONTIERS Final Report Washington, DC Population Council (2004).

31 M Ryan and others 'The impact of emergency situations on female genital mutilation 28 Too Many' Briefing Paper (2014).

the Ebola epidemic in Sierra Leone affected the ability of communities to come together to conduct FGM.<sup>32</sup> However, public health measures to reduce infectious disease rates may also interrupt prevention measures and increase the incidence of FGM. Modelling commissioned by the United Nations Children's Fund (UNICEF) based on data from 31 countries estimated that due to the COVID-19 pandemic, there would be a 30 per cent reduction in progress towards ending FGM by 2030, resulting in two million cases of FGM that would otherwise have been prevented.<sup>33</sup>

## 2.2 Primary prevention and FGM research

Primary prevention focuses on individual, community or population-level actions taken to prevent FGM from occurring. There are several systematic reviews of primary prevention programmes,<sup>34</sup> a scoping review<sup>35</sup> and a rapid review.<sup>36</sup> United Nations (UN) bodies have also conducted various reviews.<sup>37</sup> These reviews and individual studies provide

32 K Kostelny and others 'Worse than the war: An ethnographic study of the impact of the Ebola crisis on life, sex, teenage pregnancy, and a community-driven intervention in rural Sierra Leone' Save the Children (2016).

33 UNFPA 'Impact of the COVID-19 pandemic on family planning and ending gender-based violence, female genital mutilation and child marriage' Interim Technical Note (2020).

34 RC Berg & E Denison 'Interventions to reduce the prevalence of female genital mutilation/cutting in African countries' (2012) 8 *Campbell Systematic Reviews* 1; RC Berg & E Denison 'Effectiveness of interventions designed to prevent female genital mutilation/cutting: A systematic review' (2012) 43 *Studies in Family Planning* 135-146; RC Berg & E Denison 'A realist synthesis of controlled studies to determine the effectiveness of interventions to prevent genital cutting of girls' (2013) 33 *Paediatrics and International Child Health* 322; S Waigwa and others 'Effectiveness of health education as an intervention designed to prevent female genital mutilation/cutting (FGM/C): A systematic review' (2018) 15 *Reproductive Health* 62; C Njue and others 'Preventing female genital mutilation in high income countries: A systematic review of the evidence' (2019) 16 *Reproductive Health* 113; TM Abidogun and others 'Female genital mutilation and cutting in the Arab League and diaspora: A systematic review of preventive interventions' (2022) 27 *Tropical Medicine and International Health* 468.

35 H Baillot and others 'Addressing female genital mutilation in Europe: A scoping review of approaches to participation, prevention, protection, and provision of services' (2018) 17 *International Journal for Equity in Health* 21.

36 D Matanda and others 'Effectiveness of interventions designed to prevent or respond to female genital mutilation: A review of evidence Nairobi' UNFPA, UNICEF, WHO & Population Council Kenya (2021).

37 SS Piazza 'The dynamics of social change: Towards the abandonment of female genital mutilation/cutting in five African countries' United Nations Children's Fund Innocenti Research Centre (2010); WHO 'Female genital mutilation

insight into multidimensional community activities, school education, health worker training, laws, safeguarding and child protection efforts, and media communication and advocacy campaigns. Primary prevention initiatives are also often based on a theory of change. A review of reports of community-based FGM programme evaluations in West Africa published between 2000 and 2013 described various health promotion models underpinning interventions, including behaviour change, client-centred/empowerment, social change and health education.<sup>38</sup>

### **2.2.1      *Research on community-level prevention interventions***

There are no randomised control trials of community-level interventions to provide a clear view of the effect of activities on the practice of FGM. However, Berg and others undertook a meta-analysis of the effectiveness of interventions in controlled before-and-after studies outlining programmes in community settings in African countries. Three studies included community activities in a refugee camp in Kenya, villages in Ethiopia<sup>39</sup> and villages, local government and at the state level in Nigeria.<sup>40</sup> This featured education, advocacy via media and drama and measured FGM knowledge, beliefs, attitudes and intentions. The descriptive analysis found statistically significant positive findings concerning participant's FGM/C beliefs post-intervention. In Kenya and Ethiopia most participants changed their views to agree that FGM/C compromised women's human rights. Participants' knowledge of the harmful consequences of FGM significantly improved in the Ethiopian study, and changes were found in participants' intention not to perform FGM on their daughters. In the Nigerian study, significant results were noted from women participants who reported having encouraged someone not to perform FGM/C on their daughter since

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programmes to date: What works and what doesn't' World Health Organisation (2011).

- 38 R Ekundayo & S Robinson 'An evaluation of community-based interventions used on the prevention of female genital mutilation in West African countries' (2019) 15 *European Scientific Journal*.
- 39 J Chege and others 'Testing the effectiveness of integrating community-based approaches for encouraging abandonment of female genital cutting into CARE's reproductive health programmes in Ethiopia and Kenya' FRONTIERS Final Report Population Council (2004) 12-32.
- 40 'Evaluation report of female circumcision eradication project in Nigeria' Annual meeting of the American Public Health Association (1996).



the programme had commenced and had changed their intention to perform FGM on their daughter. Significant findings were identified concerning the number of men who believed that FGM had no benefits since the programme commenced. More men thought that community members were more likely to favour discontinuation.

Systematic reviews have been conducted to provide insight into the mechanisms that contribute to the successful implementation of community-level FGM prevention interventions. Berg and Dennison's realist review suggests that disseminating information about FGM is critical to changing knowledge, attitudes and behaviours.<sup>41</sup> Some community-level FGM education initiatives were examined in Waigwa and others'<sup>42</sup> qualitative synthesis. Factors influencing programme outcomes were noted, including religious affiliations of either the participants or the facilitators of health education interventions in a refugee camp in Kenya and villages in Ethiopia.<sup>43</sup> It was recommended that facilitators and participants be of the same religion, but mixed results were noted with regard to including religious leaders, especially when they believed FGM was a religious requirement. Mounir and others<sup>44</sup> indicated that facilitators in their quasi-experimental study of an education programme for female students living in hostels in an Egyptian university dressed in a similar style of clothing to participants in an attempt to encourage shared identity and break down barriers. The outcomes of education sessions were found to be affected by attendance<sup>45</sup> and building rapport with communities prior to interventions was key. An FGM health education programme in rural villages in Nigeria noted the importance of including all members of the community including traditional practitioners, health professionals, community and religious

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41 Berg & Denison (n 34) 322-333.

42 Waigwa and others (n 34) 62.

43 Chege and others (n 39) 12-32.

44 GM Mounir, NH Mahdy & IM Fatohy 'Impact of health education programme about reproductive health on knowledge and attitude of female Alexandria University students' (2003) 78 *Journal of the Egyptian Public Health Association* 433.

45 S Babalola and others 'Impact of a communication programme on female genital cutting in Eastern Nigeria' (2006) 11 *Tropical Medicine and International Health* 1594-1603; N Diop & I Askew 'The effectiveness of a community-based education programme on abandoning female genital mutilation/cutting in Senegal (2009) 40 *Studies in Family Planning* 307.



leaders (male and female) as they are also responsible for change.<sup>46</sup> Another review appraised studies focusing on using religious and cultural leaders has described their critical role in supporting the abandonment of FGM,<sup>47</sup> but this varies according to the setting.<sup>48</sup>

Matanda and others'<sup>49</sup> rapid evidence assessment of the available literature on FGM interventions published from 2008 to 2020 provides a synthesis of community-level primary prevention activities categorised by community engagement, health education, media/social marketing/communication, public statement/declarations, rescue centres, use of religious/cultural leaders, conversion of traditional practitioners and alternative rituals.<sup>50</sup> While some pre- and post-intervention studies in this review show promising results, they are still focused on knowledge and attitude change.<sup>51</sup> Findings confirm the importance of contextual factors and positive framing.<sup>52</sup>

Alternative and non-harmful rites of passage have been trialled to replace the ceremonies in many countries with another event that does not include FGM or remove FGM from the original ceremonial activities. Ceremonies in Kenya and Tanzania have been described that involve the families, community members and leaders in the development of training activities for young girls that are held in seclusion, followed by a public

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46 EO Asekun-Olarinmoye & OA Amusan 'The impact of health education on attitudes towards female genital mutilation (FGM) in a rural Nigerian community' (2008) 13 *The European Journal of Contraception and Reproductive Health Care* 289.

47 Matanda and others (n 36) 49-50.

48 G Mehari and others 'Exploring changes in female genital mutilation/cutting: Shifting norms and practices among communities in Fafan and West Arsi zones, Ethiopia. Evidence to end FGM/C: research to help girls and women thrive' Population Council (2020).

49 Matanda and others (n 36).

50 REB Johansen and others 'What works and what does not: A discussion of popular approaches for the abandonment of female genital mutilation' (2013) 2013 *Obstetrics and Gynecology International*.

51 O Ekwueme, H Ezegwui & U Ezeoke 'Dispelling the myths and beliefs toward female genital cutting of woman assessing general outpatient services at a tertiary health institution in Enugu State, Nigeria' (2010) 7 *East African Journal of Public Health* 66-69; M Galukande and others 'Eradicating female genital mutilation and cutting in Tanzania: An observational study' (2015) 15 *BMC Public Health* 1147; DM Abdulah, A Dawson & BM Sedo 'The impact of health education on attitudes of parents and religious leaders towards female genital mutilation' (2020) 46 *BMJ Sexual and Reproductive Health* 51.

52 A Winterbottom, J Koomen & G Burford 'Female genital cutting: Cultural rights and rites of defiance in Northern Tanzania' (2009) 52 *African Studies Review* 47.

celebration and awarding of certificates.<sup>53</sup> While these can be valuable efforts to change attitudes towards FGM, the risk of exclusion, perceived loss of cultural identity and negative stereotyping may limit the success of such programmes.<sup>54</sup> Programmes focused on interventions encouraging traditional practitioners to abandon FGM have not provided conclusive insights for prevention.<sup>55</sup>

## 2.2.2 *Research on school-based prevention interventions*

Some research has explored the outcomes of interventions designed to prevent FGM in school settings. A cross-sectional study in the Somali and the Harari regional states of Eastern Ethiopia found that among the 480 male and female school students surveyed, school-based awareness campaigns and TV-based media communications were the main sources of information that influenced a high proportion of young people.<sup>56</sup> A mixed-methods observational study in Kenya examining a multifaceted educational campaign involving school clubs disseminating information about FGM was found to influence children's attitudes.<sup>57</sup> Mahgoub and others<sup>58</sup> undertook an observational study of school-based education sessions on FGM in Sudan. A pre-post intervention survey found significant changes in knowledge of FGM and attitudes towards the practice. A pre-post design was reported in a paper by Moustafa and Muhammad<sup>59</sup> described an increase in FGM knowledge among female school students following an educational programme on reproductive health in Egypt.

53 Johansen and others (n 50); D Matanda, AK Meroka-Mutua S & Kimani 'Lessons from a five-year research programme on FGM/C and their relevance for policy and programmes in Kenya' (2020).

54 Graamans and others (n 26) 1.

55 Matanda and others (n 36) 51; Johansen and others (n 50).

56 AD Abathun, J Sundby & AA Gele 'Pupil's perspectives on female genital cutting abandonment in Harari and Somali regions of Ethiopia' (2018) 18 *BMC Women's Health* 167.

57 Galukande and others (n 51) 1147.

58 E Mahgoub and others 'Effects of school-based health education on attitudes of female students towards female genital mutilation in Sudan' (2019) 25 *East Mediterranean Health Journal* 406-412.

59 N Moustafa & Y Muhammad 'Impact of educational programme on reproductive health knowledge of female preparatory school students in Alexandria Governorate' (2018) 48 *Journal of High Institute of Public Health* 24-29.

### 2.2.3 *Research on the law and FGM prevention*

Studies have examined the effect of the law on FGM knowledge, attitudes and behaviours in various African nations. Muthumbi and others<sup>60</sup> reviewed the current status of legislation and policies in 27 African countries. This literature review identified programme evaluations in Burkina Faso and Eritrea that suggest that strict enforcement may have some effect on preventing FGM. In addition, the authors suggest that awareness of FGM laws among criminal justice personnel can positively reinforce laws. National FGM legislation was enacted in Burkina Faso in 1996. While reports of prosecutions are noted in the literature in 2010, the socialisation of the law alongside national advocacy efforts and politics may have affected the prevalence of FGM over the ten years. However, there has been little reduction in FGM prevalence in Burkina Faso. There was a slight rise in FGM from 71.6 per cent in 1999 to 75.8 per cent in 2010.<sup>61</sup> FGM legislation was introduced in Eritrea in 2007, but prevalence has been falling since 1995 when the prevalence was 94.55 per cent, dropping to 83 per cent in 2010.<sup>62</sup>

Research has not been able to determine whether the introduction of laws in Egypt has had any impact. New FGM legislation was introduced in Egypt in 2008 through amendments to the Child Act (1996) and the Penal Code. In September 2016 Law 58 was further strengthened, and penalties were increased.<sup>63</sup> A study comparing a 2006 sample of 500 women with another sample of women in 2011 in the same location noted a decline in prevalence among the mothers who had indicated that at least one of their daughters had been circumcised (71.6 per cent versus 77.8 per cent,  $P=0.04$ ).<sup>64</sup> However, this change cannot be attributed to

60 J Muthumbi and others 'Female genital mutilation: A literature review of the current status of legislation and policies in 27 African countries and Yemen' (2015) 19 *African Journal of Reproductive Health* 32-40.

61 World Bank 'Female genital mutilation prevalence (%) – Burkina Faso' 2022, <https://data.worldbank.org/indicator/SH.STA.FGMS.ZS?locations=BF> (accessed 3 November 2022).

62 World Bank 'Female genital mutilation prevalence (%) – Eritrea' 2022, <https://data.worldbank.org/indicator/SH.STA.FGMS.ZS?locations=ER> (accessed 3 November 2022).

63 World Bank *Compendium of international and national legal frameworks on female genital mutilation* (2021).

64 IMA Hassanin & OM Shaaban 'Impact of the complete ban on female genital cutting on the attitude of educated women from Upper Egypt toward the practice' (2013) 120 *International Journal of Gynecology and Obstetrics* 275-278.

the effect of the law alone, as female education and wealth had improved over this time. National prevalence has also fallen from 97 per cent in 1996 to 87 per cent in 2014.<sup>65</sup> Quasi-experimental and cross-sectional studies from Senegal, Mauritania and Mali have shown little effect of the law on FGM practice.<sup>66</sup>

Other scholars have explored the inadequacies of current FGM legislation that could affect prevention efforts. Yusuf and Fessha<sup>67</sup> discuss the limitations in the Tanzanian Penal Code. These include the lack of a specific definition of acts that constitute FGM; the inadequate scope of criminal liability; issues concerning punishment; and the failure to criminalise FGM performed on women above the age of 18 years. The authors also note contextual issues impacting the ability of laws to be enacted, such as community views that support FGM. The political will of key decision makers in shaping laws is analysed in a working paper examining FGM legislation in the Red Sea state in Sudan. al-Nagar and others<sup>68</sup> outline how conservative tribal groups such as the Beja tribe and its subgroups Hadendawa and Beni Amer played a key role in preventing the criminalisation of FGM in the Child Act of 2007. Although the Act was revised in 2011 to address FGM, it does so only weakly and does not prohibit the most severe types of FGM.

There are divergent views on the role of legislation and its effect on prevention. Some argue that legal prohibition of the practice has a deterrent effect. In contrast, others argue legislation can be coercive and disrupt local efforts to end FGM. Perceptions of the law and its influence on FGM practice were explored in a mixed-methods study in Senegal.<sup>69</sup> In-depth interviews with community people in three villages were

65 World Bank 'Female genital mutilation prevalence (%) – Egypt', <https://data.worldbank.org/indicator/SH.STA.FGMS.ZS?locations=EG> (accessed 3 November 2022).

66 G Camilotti 'Interventions to stop female genital cutting and the evolution of the custom: Evidence on age at cutting in Senegal (2016) 25 *Journal of African Economies* 133; V Cetorelli and others 'Female genital mutilation/cutting in Mali and Mauritania: Understanding trends and evaluating policies' (2020) 51 *Studies in Family Planning* 51.

67 C Yusuf & Y Fessha 'Female genital mutilation as a human rights issue: Examining the effectiveness of the law against female genital mutilation in Tanzania' (2013) 13 *African Human Rights Law Journal* 356.

68 S al-Nagar, L Tønnessen & S Bamkar 'Weak law forbidding female genital mutilation in Red Sea State, Sudan' Working Paper (2017).

69 B Shell-Duncan and others 'Legislating change? Responses to criminalising female genital cutting in Senegal' (2013) 47 *Law and Society Review* 803.

analysed and informed an ethnographically-grounded survey to examine readiness to change. The study found that participants' decisions to practise were influenced by their consideration of the threat of criminal sanctions against the effects of defying local norms. The study also found that law enforcement was not necessary to instil fear of persecution. In contexts where the practice is contested, a legal norm may predispose readiness to change and provide a platform for those who do not wish to practise enacting this. While some participants reported that the law had resulted in their decision to reluctantly not practise, others stated that they were defiantly practising covertly. A similar finding has been noted in qualitative interviews with community members in Ghana, where participants reported that legislation had driven the practice underground.<sup>70</sup>

Many researchers have examined contested issues concerned with FGM, traditional cultural practices, secular laws, women's rights, and Islamic ethico-legal standpoints. Sallah's doctoral thesis explores how the criminalisation of FGM in Ghana and the Western values underpinning this legislation are at odds with the social norms supporting the practice.<sup>71</sup> As a result, Sallah argues that the law has a limited effect. In 2009 in Mali, a new family code was proposed by the government. These changes included banning FGM; setting 18 years as the minimum age for marriage; changing inheritance rules for women that enabled them to remain in their homes after their husbands died; and changing the regulations for adoption and recognising children born out of marriage. However, the reform was not signed into law due to vehement opposition. The High Islamic Council of Mali repeatedly stated that this proposed law was a 'vision from another culture, another milieu' to describe the reform.<sup>72</sup> In Mali, a Muslim-majority country where the national FGM prevalence has declined, banning FGM was not regarded as consistent with Islamic law or Shari'a. However, internationally, there is no clear consensus among Muslim scholars regarding the need

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70 M Aberese Ako & P Akweongo 'The limited effectiveness of legislation against female genital mutilation and the role of community beliefs in Upper East Region, Ghana' (2009) 17 *Reproductive Health Matters* 47-54.

71 AA Sallah 'International imposition vs domestic assimilation: The criminalisation of female genital cutting in Ghana' LLM thesis, University of Windsor, 2021.

72 M Diamoutani 'Position du HICM relative à l'adoption par l'Assemblée Nationale du code des personnes et de la famille. Bamako: Ligue Malienne des Imams et Erudits pour la Solidarité Islamique (2009).

to perform FGM, as there is no direct mention of this in the Qu'ran. Blaz analysed a historical case from Egypt and found that while the Court argued that there were no legitimising reasons to force FGM on women, they also held that circumcision was neither a duty (*fard*) nor an obligation (*wâjib*) under Islamic law.<sup>73</sup> Researchers have suggested a middle ground between secular law, human rights, zero tolerance and an Islamic ethico-legal standpoint as a harm-reduction strategy.<sup>74</sup> This constitutes medicalisation but has been opposed in many countries as it has been argued that this has undermined abandonment efforts.<sup>75</sup> If prevention is the goal, then secular law appears to play a role, but it may not require vigorous enforcement to be effective. Alongside advocacy, political will and bottom-up participatory community-development activities are required.

#### 2.2.4 Research on advocacy and communication

Matanda and others<sup>76</sup> bring together studies that have examined outcomes related to media and communication interventions on the practice of FGM. A quasi-experimental study investigating the Saleema social marketing strategy effectively changed norms in Sudan.<sup>77</sup> This examined self-reported exposure to the awareness campaign, social dialogue, public declarations and role models and pro-FGM social norms using a household survey across a nationally-represented sample across 18 states in Sudan. An RCT study in Sudan examined the effect of film dramas where family members debate whether they should continue or abandon FGM on attitudes toward FGM.<sup>78</sup> The results show that emphasising local consensus in terms of both values and marriageability

73 K Bälz 'Human rights, the rule of law, and the construction of tradition. The Egyptian Supreme Administrative Court and female circumcision (Appeal 5257/43, 28 December 1997)' (1998) 34 *Egypte/Monde arabe* 141.

74 R Duivenbode & AI Padela 'The problem of female genital cutting: Bridging secular and Islamic bioethical perspectives' (2019) 62 *Perspectives in Biology and Medicine* 273.

75 S Kimani and others 'Female genital mutilation/cutting: Emerging factors sustaining medicalisation related changes in selected Kenyan communities' (2020) 15 *PLOS ONE*.

76 Matanda and others (n 36) 44-47.

77 WD Evans and others 'The Saleema Initiative in Sudan to abandon female genital mutilation: Outcomes and dose response effects' (2019) 14 *PLOS ONE*.

78 S Vogt and others 'Changing cultural attitudes towards female genital cutting' (2016) 538 *Nature* 506-509.

can change attitudes to favour the abandonment of cutting. Other observational studies show that communication interventions, including theatre and TV-based media in Nigeria and Ethiopia, can help to increase knowledge, stimulate conversations about the practice and change attitudes.<sup>79</sup>

## 2.3 Secondary prevention and FGM research

Secondary prevention aims to reduce the impact of FGM on the lives of girls and women who have already experienced the practice. Sensitive, multifaceted, collaborative approaches appear to be required.

### 2.3.1 *Research on protection and safeguarding measures*

Safeguarding measures are based on policies and laws aimed at protecting children or women at risk of FGM. Women at risk may be preparing to marry a partner whose family fully supports FGM while a child whose mother and sibling may be cut, is likely to be at risk. Matanda and others<sup>80</sup> identify several studies that evaluate the use of rescue centres or safe houses to provide protection and refuge for girls at risk of FGM during the cutting period in Africa. Limited resources and a lack of buy-in from the community affect the ability of these centres to keep girls safe in Tanzania and Kenya. Van Bavel's<sup>81</sup> ethnographic study documents the conflict the shelters cause between girls and their families in Kenya.

### 2.3.2 *Research on interventions to support women with FGM*

Deinfibulation (antenatal or intrapartum) is recommended for preventing and treating obstetric complications in women with type III FGM by the World Health Organisation (WHO).<sup>82</sup> A systematic

79 I Ugwu & A Ashaver 'TFD and community education on female genital mutilation in Iggede Land of Benue State: Ugengen community experience' (2014) 8 *A Journal of Theatre and Media Studies* 74.

80 Matanda and others (n 36) 58-59.

81 H van Bavel 'At the intersection of place, gender, and ethnicity: Changes in female circumcision among Kenyan Maasai' (2020) 27 *Gender, Place and Culture* 1071.

82 WHO *Care of women and girls living with female genital mutilation. A clinical handbook* (2020).



review by Bello and others<sup>83</sup> could not locate any studies demonstrating evidence of the impact of counselling before deinfibulation on patient satisfaction, marital satisfaction, and rate of requests for reinfibulation among women living with type III FGM.

A systematic review and meta-analysis found that providing information to improve body image and care-seeking behaviour of women and girls living with FGM can be a helpful approach to preventing FGM continuations.<sup>84</sup> Women and girls who received the educational intervention were more willing to discuss FGM, and women demonstrated a change in their attitudes toward not recommending FGM for their daughters and were less likely to plan to cut their daughters than those who did not receive the intervention.

### 2.3.3 *Research on supporting health professionals to provide secondary FGM prevention*

Several studies have examined health professionals' experiences providing care for women and girls with FGM.<sup>85</sup> Socio-cultural challenges have been noted by professionals related to medicalisation that pressure them to provide FGM.<sup>86</sup> Some health professionals remain supportive as they regard their involvement as a harm reduction strategy despite knowledge of adverse effects and a low understanding of legal status.<sup>87</sup> Midwives in Sudan reported providing re-infibulation as a valuable service for women

83 S Bello and others 'Counselling for deinfibulation among women with type III female genital mutilation: A systematic review' (2017) 136 *International Journal of Gynecology and Obstetrics* 47-50.

84 E Esu and others 'Antepartum or intrapartum deinfibulation for childbirth in women with type III female genital mutilation: A systematic review and meta-analysis' (2017) 136 *International Journal of Gynecology and Obstetrics* 21-29.

85 M Reig-Alcaraz, J Siles-González & C Solano-Ruiz 'A mixed-method synthesis of knowledge, experiences and attitudes of health professionals to female genital mutilation' (2016) 72 *Journal of Advanced Nursing* 245-260.

86 E Isman and others 'Midwives' experiences in providing care and counselling to women with female genital mutilation (FGM) related problems (2013) 2013 *Obstetrics and Gynecology International* 3-6.

87 AAA Ali 'Knowledge and attitudes of female genital mutilation among midwives in Eastern Sudan' (2012) 9 *Reproductive Health* 2-3.

that supplied them with an income.<sup>88</sup> Providers in Guinea were found to largely oppose FGM and its medicalisation.<sup>89</sup>

Few studies are available on interventions to support providers in FGM abandon medicalisation. There are considerable gaps in the capacity of the health workforce and system limitations,<sup>90</sup> and there have been efforts to improve provider education.<sup>91</sup> A systematic review of interventions to improve healthcare provider skills<sup>92</sup> identified only one study. This controlled before-and-after study examined a training intervention in Mali that was found to improve 108 health professionals' knowledge, attitudes and practice on FGM.<sup>93</sup>

## 2.4 Evidence-based tertiary prevention for FGM

Tertiary prevention aims to assist women and girls in managing long-term, often-complex health problems and injuries associated with FGM to improve their ability to function and their quality of life. These are medically-indicated procedures and are carried out with consent. The WHO has developed research-informed clinical guidelines<sup>94</sup> and training to support health professionals to communicate effectively with women and girls (WHO 2022) effectively. Many countries have responded with their clinical practice guidelines with recommended approaches to management, such as Kenya and Ethiopia.<sup>95</sup>

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88 V Berggren and others 'An explorative study of Sudanese midwives' motives, perceptions and experiences of re-infibulation after birth' (2004) 20 *Midwifery* 299.

89 MD Balde and others 'Attitudes of health care providers regarding female genital mutilation and its medicalisation in Guinea' (2021) 16 *PLOS ONE* 6-13.

90 S Kimani & C Okondo 'A diagnostic assessment of the health system's response to female genital mutilation/cutting management and prevention in Kenya' Population Council (2020).

91 S Kimani and others 'Female genital mutilation/cutting: Innovative training approach for nurse-midwives in high prevalent settings' (2018) 2018 *Obstetrics and Gynecology International* 3-9.

92 Berg & Denison (n 34) 135-146.

93 N Diop and others 'Study of the effectiveness of training Malian social and health agents in female genital cutting issues and in educating their clients' Bamako: Division of Family and Community Health' Population Council, Association for the Support and Development of Population Activities, Republic of Mali (1998).

94 WHO (n 82) 1-445.

95 'Management of complications, pregnancy, childbirth and the postpartum period in the presence of FGM/C' A Reference Manual for Health Service Providers' Ministry of Health Kenya; W Gudu, S Kumbi & M Abdulahi 'Guidelines for the

Systematic reviews on tertiary prevention interventions for women with FGM can be categorised according to those focused-on counselling and those related to surgical procedures. A qualitative evidence synthesis of psychological and counselling interventions for FGM<sup>96</sup> identified two African studies from The Gambia and Somaliland. However, no information concerning preferences or direct psychological outcomes from the interventions were reported. Women in these studies described personal coping mechanisms to deal with FGM-related trauma. They were often reluctant to seek help due to shame and poor health professional knowledge and attitudes. Midwives in Somaliland described friction between practising their culture and caring for women.

The types of surgical interventions available to manage FGM, women's motivation for seeking them, and their satisfaction with these procedures are examined in a qualitative systematic review by Berg and others<sup>97</sup> that included studies from eight African nations. Three types of surgical intervention were described: defibulation or separation of fused labia; excision of a cyst with or without some form of reconstruction; and clitoral or clitoral-labial reconstruction. Women sought surgery to remove cysts and reduce associated swelling, improve birth and sexual pleasure and the appearance of their genitalia, and recover their identity. Most women were satisfied with their surgery.

Three systematic reviews have examined the evidence for clitoral reconstructive surgery after FGM.<sup>98</sup> These note limitations with current studies and weak evidence for the procedure's effectiveness. Researchers have summarised that clitoral reconstructive surgery after FGM cannot be medically indicated on physical or anatomical grounds. There may be

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management and prevention of female genital mutilation in Ethiopia' *Ministry of Health Ethiopia* (2016).

96 H Smith & K Stein 'Psychological and counselling interventions for female genital mutilation' (2017) 136 *International Journal of Gynecology and Obstetrics* 60-64.

97 RC Berg and others 'Reasons for and experiences with surgical interventions for female genital mutilation/cutting (FGM/C): A systematic review' (2017) 14 *Journal of Sexual Medicine* 977.

98 J Abdulkadir, MI Rodriguez & L Say 'A systematic review of the evidence on clitoral reconstruction after female genital mutilation/cutting' (2015) 129 *International Journal of Gynecology and Obstetrics* 93-97; RC Berg and others 'The effectiveness of defibulation and reconstructive surgery following female genital mutilation/cutting: A systematic review' (2017) 14 *Journal of Sexual Medicine*; e246; V Auricchio and others 'Clitoral reconstructive surgery after female genital mutilation: A systematic review' (2021) 29 *Sexual and Reproductive Healthcare*. 2-4.

exceptions in situations where women continue to experience pain or sexual dysfunction when they have not responded to other treatments.<sup>99</sup> Clinicians should be aware of the need for women to understand the risks versus the possible benefits of such a procedure and ensure that they make an informed decision. However, informed consent may be difficult if women are experiencing pressure from the media or their partner to undertake surgery to restore their vulva in the hope that they will achieve physical and sexual fulfilment. Clinicians must ensure that women are appropriately informed of the risks of such surgery, educated on genital anatomy and any myths dispelled. The ethical implications of clitoral reconstructive surgery after FGM have not been fully considered, including the medico-legal implications.<sup>100</sup>

### 3 Limitations of FGM prevention research and knowledge

This review of the research on the prevention of FGM in Africa on four levels summarises what is currently known, as well as the gaps in the research. This review also reveals the characteristics of FGM research, including the types of studies and the discipline areas involved. The evidence for prevention is diverse, embraces multiple paradigms and provides views across different cultural and socio-economic contexts at the individual, community and population levels.

There are considerable challenges with using the findings from these studies in policy and practice. No longitudinal studies or RCTs of interventions provide insight into the effectiveness of interventions to prevent FGM. While RCTs will give the most reliable evidence of the efficacy of interventions, ethical issues concerning the appropriateness of assigning women to intervention and control groups will also affect women's willingness to undergo randomisation. As a result, conducting RCT trials will be challenging. There is only one published study protocol outlining African research to establish the effectiveness of the

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99 M Sharif and others 'Clitoral reconstruction after female genital mutilation/cutting: A review of surgical techniques and ethical debate' (2020) 17 *Journal of Sexual Medicine* 531-542.

100 As above.

implementation of an initiative targeting antenatal care providers to provide FGM and care services in Guinea, Kenya and Somalia.<sup>101</sup>

This means that the evidence is primarily based on quasi-experimental pre-test-post-test designs. Most of these studies do not include control groups. Such designs have weak internal validity and cannot establish a reliable cause-and-effect relationship between a treatment and an outcome. Issues affecting the reliability of the result can include selection bias, where those in the intervention group and those in the control are so different they are not comparable. The composition of the sample and the size may not be representative of the population and, therefore, results are not generalisable. In addition, individuals in a study may experience some event outside of the study that affects the measurements before and after exposure, so the change may not be attributable to the intervention. The measures taken in most of these before and after studies only assess increased knowledge and intention to change but not actual behavioural change. No follow-up studies of these interventions identify whether individuals abandoned FGM. As a result, we rely on the findings of DHS and MISCs studies that provide an understanding of changes in prevalence over time at the population level, not at the individual level. While these prevalence studies cannot map change to interventions, including legislation, they are also limited by the fact they are cross-sectional surveys based on self-report data or discursive explorations.

Much of the evidence cited in this review of current knowledge of prevention is based on evaluations conducted by various agencies concerned with assessing the merit of a project or a programme and producing information for decision making and reporting. These pragmatic studies are descriptive or quasi-experimental and focus on short-term outcomes and understanding the contextual factors that help to support their implementation. Many are in report format, not published in peer-reviewed journals, and have weak methodology sections. Matanda and others<sup>102</sup> note that many evaluation studies are of moderate to low quality. This review has also identified a diverse range of qualitative studies that explore factors that affect the implementation of

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101 W Ahmed and others 'A hybrid, effectiveness-implementation research study protocol targeting antenatal care providers to provide female genital mutilation prevention and care services in Guinea, Kenya and Somalia' (2021) 1 *BMC Health Services Research* 109.

102 Matanda and others (n 36) 27.

interventions or those that should be considered in the development of prevention programmes. These studies explore individuals' FGM-related knowledge, what they understand, emotional drivers and the meaning ascribed to attitudes, beliefs and behaviours. Qualitative studies also research shared meanings, norms, and codes in relation to FGM and how these are shaped by culture. While these insights can be enlightening, they provide rich descriptions of FGM in unique contexts that are not generalisable and help to understand the acceptability and feasibility of interventions.

Numerous authors have raised issues concerning the methodological limitations of FGM research.<sup>103</sup> These methodological limitations highlight the complex nature of research in this field and the need for research that is designed with translation in mind from the beginning and underpinned by a theory of change.<sup>104</sup> Therefore, a systematic approach to planning, executing, and disseminating high-quality FGM prevention research is needed to coordinate efforts and effectively use resources to deliver a comprehensive picture of what works, how and why. This will enable evidence derived from different approaches to be connected to provide the best insights for change. Askew<sup>105</sup> outlines the need for quality research designs and using valid and feasible indicators to map behavioural change process, outcomes and impact. This will enable programme monitoring and evaluation objectives to be linked to research so that progress towards SDG 5.3 can be assessed.<sup>106</sup> FGM

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103 I Askew 'Methodological issues in measuring the impact of interventions against female genital cutting' (2005) 7 *Culture, Health and Sexuality* 463; J Abdulkadir, MI Rodriguez & L Say 'Research gaps in the care of women with female genital mutilation: An analysis' (2015) 122 *BJOG: An International Journal of Obstetrics and Gynaecology* 294-303; T Esho, J Karumbi & C Njue 'Rapid evidence assessment: Quality of studies assessing interventions to support FGM/C abandonment' (2017); L Droy and others 'Alternative rites of passage in FGM/C abandonment campaigns in Africa: A research opportunity' *LIAS Working Paper Series* (2018).

104 K Brown, D Beecham & H Barrett 'The applicability of behaviour change in intervention programmes targeted at ending female genital mutilation in the EU: Integrating social cognitive and community level approaches' (2013) 2013 *Obstetrics and Gynecology International* 1-11; JM Strachan 'A commentary: using a theory-based approach to guide a global programme of FGM/C research: What have we learned about creating actionable research findings? Evaluation and programme planning' (2021).

105 Askew (n 103) 463-477.

106 D Matanda & E Lwanga-Walgwe 'A research agenda to strengthen evidence generation and utilisation to accelerate the elimination of female genital

prevention studies should examine effectiveness, acceptability, and feasibility and be underpinned by rigorous theory and models. Theory provides a way of structuring the prevention intervention and the research analysis. This can ensure that assumptions and hypotheses are empirically testable or logically connected. The theory of change approach is one such causal model that can explain the complexity of FGM-related change by revealing the conceptual framework that describes the causal relationships between prevention activities and the immediate, short term and long-term outcomes.<sup>107</sup> Coherent research questions are also required that strengthen the evidence and address knowledge gaps.

The Population Council has called for ‘high-quality evidence as the basis of our responses’ to FGM,<sup>108</sup> and various researchers have described research gaps.<sup>109</sup> Mpinga and others<sup>110</sup> identified a dearth of research on the socioeconomic impact of FGM. Abdulcadir and Say identified several gaps in the clinical evidence, including the obstetric outcomes of women with FGM, the impact of surgical interventions (defibulation and clitoral reconstruction) and the effect of skills and training of healthcare professionals involved in the prevention and management of FGM.<sup>111</sup> Evidence on how the law works to promote the abandonment of FGM has been found to be lacking.<sup>112</sup> Alternative rites of passage have been highlighted as an important area that has so far received inadequate attention.<sup>113</sup>

A Research Agenda to Strengthen Evidence Generation and Utilisation to Accelerate the Elimination of FGM was published by the Population Council in Kenya.<sup>114</sup> This document reports the top-

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mutilation, Kenya’ UNFPA, UNICEF, WHO & Population Council (2022).

107 I Vogel ‘Review of the use of “Theory of Change” in international development’ *Review Report: UK Department of International Development* (2012).

108 B Shell-Duncan and others ‘Using research to understand and accelerate abandonment of FGM/C presentation at end-of-project dissemination meeting, Nairobi’ Population Council (2020).

109 Matanda & Lwanga-Walgwe (n 106) 66-72.

110 EK Mpinga and others ‘Female genital mutilation: A systematic review of research on its economic and social impacts across four decades’ (2016) 9 *Global Health Action* 1-12.

111 Abdulcadir and others (n 103) 294-303.

112 Matanda & Lwanga-Walgwe (n 106) 32-37.

113 Droy (n 103) 1.

114 D Matanda & E Lwanga-Walgwe ‘A research agenda to strengthen evidence generation and utilisation to accelerate the elimination of female genital mutilation’ (2022).



ten ranked research questions discussed in a plenary session where experts reached a consensus. None of these questions relates to the criminalisation of FGM despite there being two lawyers and a child protection officer from UNICEF on the list of experts who participated in the consensus-building workshops. It is possible that research focusing on efforts to strengthen laws and enforce legislation is not considered a helpful focus. However, the role of legislation can be considered in some of these questions, particularly one, nine and ten, as they relate to medio-legal and child protection issues.

**Table 2:** *Top ten prioritised research questions*

1	How can healthcare providers and the health system be effectively utilised in the prevention of FGM and the provision of services to women and girls affected by FGM?
2	How can FGM intervention activities be more effectively integrated into educational, social and economic development programmes (e.g., programmes dealing with SRHR and gender-based violence (GBV), formal and informal education avenues for girls and boys as well as women empowerment programmes?
3	What are the valid measures of change in social and gender norms and practices that should be used in the evaluation of FGM interventions?
4	What intervention approaches are effective in preventing FGM across countries that border each other?
5	How can interventions integrate girl-centred approaches in bringing social change?
6	How can other health-related areas, including mental health, social work, sexology, and psychology, be incorporated to support response and prevention of FGM?
7	How do we strengthen partnerships and collaboration with governments, UN agencies, humanitarian partners, CSOs, and private partners in emergency settings to enhance prevention and support services as part of (prevention, protection, and recovery measures) routine package of care?
8	How can men and/or boys be effectively engaged as allies of gender equality and ending FGM?
9	What lessons on the effectiveness of interventions can interventions that seek to end FGM gain from other related fields such as GBV, SRHR and child marriage?
10	What context-specific factors (mechanisms) motivate communities or individuals to stop practising FGM?

## **4 Best practice high-quality FGM research**

FGM research should not only strive to be of the highest quality but be conducted according to ethical principles, embrace diversity, and engage stakeholders throughout all aspects of the research process. Research support is needed to ensure that studies can provide a comprehensive picture of the merit of complex FGM prevention initiatives. This will require input from multiple disciplines, such as medicine, law, demography, epidemiology, health services, community development and the arts. Researchers will also need to consider important issues of power, trust, cultural competence, respectful and legitimate research practice and recognition of individual and communities' health assets in a decolonising research process.

### **4.1 Ethical research practice**

Any researcher conducting research with human participants must ensure that their research is conducted in a way that provides honesty and sincerity and demonstrates the utmost respect for the dignity of participants. Informed consent is necessary so that participants knowingly and voluntarily consent to participate in research. Participants must have the right to withdraw at any study point without fear of penalty. Researchers have an ethical obligation to maximise possible benefits, minimise potential harm to the respondents, and ensure their anonymity and confidentiality. A statement declaration outlining ethical approval is required in primary research studies reported in papers in peer-reviewed journals. This is not always the case in evaluation reports. For example, several reports outlining the research undertaken in the community do not outline ethical procedures.<sup>115</sup> Ethical frameworks for FGM research must be decolonised so that those affected by FGM are represented on human research ethics panels so that the expertise and world views of community people inform decisions about the research at all stages. Ethical qualities of care should be applied (attentiveness, responsibility, competence, responsiveness, plurality, communication,

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115 Diop and others (n 30) 4-7.

trust and respect) emphasising that research is relational and requires care.<sup>116</sup>

Any assessment of the quality of FGM prevention research must examine that these ethical principles are adhered to by checking that there is a statement describing human ethics research committee approval and demonstrating adherence in the procedures. This strengthens the foundations of research and accurate guideline development and promotes community trust. While quality assessment has been undertaken in many reviews of FGM research, an ethical check has not been included.<sup>117</sup>

## 4.2 Intersectionality and FGM research

Research conducted in contexts where FGM is practised must be cognisant of intersectionality, providing a framework for considering how aspects of an individual's social and political identities interact to create discrimination and privilege. Little is written on how FGM intersects with gender, sex, ethnicity, class, sexuality, religion and disability and how prevention efforts should respond to interconnecting and overlapping social identities. Intersectionality must be considered to ensure FGM interventions are effective and appropriate for various population segments.<sup>118</sup> An intersectional lens was applied to social network analysis undertaken in two regions in a low FGM/C prevalence, ethnically mixed region in Central Senegal, and a high FGM prevalence, ethnically homogeneous region in South Senegal.<sup>119</sup> This study identified differences in intersecting lines of power and influence over FGM decision making. The study recommended that prevention efforts should engage older women and men, especially fathers of young girls and their brothers. It also identified the need to reduce structural barriers to abandonment, such as negative responses to the law, gendered vulnerability to prosecution, reduced community cohesion and social

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116 J Tronto *Caring democracy: Markets, equality and justice* (2013) 34-35.

117 Esho and others (n 103) 2-7.

118 RM Mestre i Mestre 'Exploring intersectionality: Female genital mutilation/cutting in the Istanbul Convention' in J Niemi, L Peroni & V Stoyanova (eds) *International law and violence against women* (2020) 157-172.

119 A Moreau & B Shell-Duncan 'Tracing change in female genital mutilation/cutting through social networks: An intersectional analysis of the influence of gender, generation, status, and structural inequality' Population Council (2020).

support, and factors preventing healthcare seeking. While studies of the intersectional factors that promote FGM abandonment or work to maintain it are essential in unique contexts, the findings of this lens need to be applied in practice and interventions evaluated to establish their usefulness.

### 4.3 Stakeholder engagement in research

Stakeholder engagement is central to all FGM research to ensure meaningful prevention strategies can be found and buy-in for implementation. Participatory methods have been applied across several studies and insights have been identified to guide future efforts. One study in Kenya used participatory ethnographic evaluation research to understand young men's perceptions of FGM, demand for FGM among future spouses, and perceptions of efforts to end FGM.<sup>120</sup> These men saw themselves as part of the solution. Greiner and others used drawing and photography exercises to examine how listeners of a radio soap opera entertainment-education initiative in Sudan understood the adverse effects of FGM. This research raised awareness and dialogue on the topic.<sup>121</sup> The Tostan project is an example of how community members can be involved in deciding the focus of a project on FGM as well as the evaluation of the programme.<sup>122</sup> While these studies engaged communities in generating the research data, there do not appear to be studies that engage stakeholders in the data analysis.

What is clear is that if research is to be part of a change in communities, then researchers will need to be part of those communities and initiatives directed by them. While we have seen that top-down legal strategies have little benefit, in contrast, bottom-up initiatives such as the Tostan project have value, including at scale.<sup>123</sup> While non-Africans may play a role in supporting FGM research endeavours on the continent, African

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120 Brown and others (n 28) 118-125.

121 Greiner and others (n 13) 226-259.

122 Monkman and others (n 15) 451-464.

123 B Cislighi and others 'Changing social norms: The importance of "organised diffusion" for scaling up community health promotion and women empowerment interventions' (2019) 20 *Prevention Science* 936-946; I Katz and others 'Cost and impact of scaling up female genital mutilation prevention and care programmes: Estimated resource requirements and impact on incidence and prevalence' (2021) 16 *PLOS ONE* 1-11.

researchers and communities must be empowered to develop their own research agenda and plans for intervention research. This involves a genuine decolonisation of knowledge production that must rest on indigenous knowledge and self-determination.

#### 4.4 Building the capacity of researchers to prevent FGM

Supporting the capacity building of researchers from all research disciplines to undertake research and develop their careers is a key part of all efforts to produce quality evidence to prevent FGM. The African Coordinating Centre for abandonment of FGM at the University of Nairobi and the Population Council have been actively training researchers in national organisations and individuals to undertake research. Partnerships are vital to delivering impactful research, including south-south, north-south, or transnational collaborations.<sup>124</sup> Several international efforts have brought researchers together to share their work and network. The Universities of Geneva, Brussels, and Montreal (Le G3 de la Francophonie) organised three international experts' meetings to promote dialogue debate and build research relationships (2017-2019).<sup>125</sup> The Transnational Observatory of Research Applied to New Strategies for Preventing FGM, located in The Gambia and Spain at the Universitat Autònoma de Barcelona, also runs regular conferences for researchers.<sup>126</sup> Another group is the Community of Practice on Female Genital Mutilation (CoP FGM), an international, bilingual (French/English) network for professionals and activists.<sup>127</sup> An initiative

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124 AK Marcusan 'Transnational observatory of applied research and knowledge transfer in cascade to key agents for the management and prevention of FGM/C' (2020) 42 *Journal of Obstetrics and Gynaecology Canada* e19.

125 J Abdulcadir and others 'Female genital mutilation/cutting: Sharing data and experiences to accelerate eradication and improve care' (2017) 14 *Reproductive Health* 96.

126 ENDFGM. Wassu Gambia Kafo and our member Wassu-UAB Foundation organised the V International Forum on Female Genital Mutilation (FGM) in The Gambia on 7 and 8 February, commemorating the International Day of Zero Tolerance for FGM. Brussels: ENDFGM European Network, 2022, <https://www.endfgm.eu/news-en-events/news/wassu-foundation-international-forum-on-gender-based-violence-and-harmful-traditional-practices-in-the-gambia-and-west-africa/> (accessed 17 June 2022).

127 G Belgium 'Community of practice on female genital mutilation (CoP FGM)' Brussels GAMS Belgium 2022, <https://copfgm.org/> (accessed 17 June 2022).

led the key stakeholders from the African Centre for the Abandonment of FGM at the University of Nairobi and researchers at the University of Technology Sydney (UTS) brought together 37 researchers from sub-Saharan Africa and the middle eastern North African region to discuss research priorities and capacity-building needs. In response, a series of 14 workshops have been run for early career researchers, including PhD students and lecturers at institutions across the regions.<sup>128</sup>

#### **4.5 Embracing complexity and scale**

Achieving Sustainable Development Goal target 5.3 will require research to deliver high-quality evidence of the value of complex interventions to eliminate FGM. A systematic approach is needed to co-ordinate research efforts and use resources efficiently to provide a comprehensive picture of what works, how and why. Complex intervention research can incorporate questions about the effectiveness, appropriateness and feasibility of interventions and glean insights into the mechanisms that support successful implementation. This knowledge is critical to real world decision making that can inform how interventions can be scaled up in one context or transferred to others and what resources need to be dedicated.<sup>129</sup> A framework commissioned by the National Institute of Health Research and the Medical Research Council in the UK can be used to support FGM researcher's work with stakeholders to identify research questions for complex interventions and to design and conduct research with diverse perspectives and appropriate methods.<sup>130</sup> This framework considers complex intervention research as a series of phases: development or identification of an intervention; assessment of the feasibility of the intervention and evaluation design; evaluation of the intervention; and impactful implementation. At each phase, six questions are asked to complete the assessment before moving to the next stage:

- How does the intervention interact with its context?
- What is the underpinning programme theory?
- How can diverse stakeholder perspectives be included in the research?

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128 A Dawson and others 'Addressing female genital mutilation in Africa and the Middle East: Ways forward for research' The University of Technology Sydney (2021).

129 Katz (n 123).

130 Berg and others (n 98).

- What are the key uncertainties?
- How can the intervention be refined?
- What are the comparative resources and outcome consequences of the intervention?

## 5 Conclusion

Research is essential to prevent FGM. Research provides intervention and descriptive studies to understand the distribution and determinants of FGM, why it is practised and associated risk factors in specified populations at community, provincial, national, regional and global levels. This knowledge is central to developing and tailoring tools, programmes, laws and policies to better care for affected women and girls and change behaviour to end FGM. Reviews of research on FGM prevention demonstrate the need for complex interventions where multiple approaches are employed to assess social norms and structural change within and alongside communities. Such interventions should be delivered and evaluated at individual and societal levels. We have found promising insights from research that show the need to incorporate prevention at the primordial,<sup>131</sup> primary,<sup>132</sup> secondary and tertiary levels.<sup>133</sup> This research provides qualitative and quantitative insights and embraces multiple paradigms and theories of change. While considerable limitations have been identified in the research to date, we note the need for ethical, participatory and inclusive multi-disciplinary approaches that incorporate capacity building for researchers and partnerships

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131 Abidogun and others (n 34) 468-478.

132 Kostelny and others (n 32) 1-59.

133 Berg and others (n 98).



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