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Original Research

Female genital cutting (FGC) type: proposing a multifaceted, interactive method for FGC self-assessment

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Abstract

Background: Self-reporting female genital cutting (FGC) status and types by patients and clinicians is often inconsistent and inaccurate, particularly in community settings where clinically verifiable genital exams are not feasible or culturally appropriate.
Aim: In this study we sought to discern whether integrating multiple dimensions of participant engagement through self-reflection, visual imagery, and iterative discourse informed the determination of FGC status by a panel of health and cultural experts using World Health Organization (WHO) typology.
Methods: Using community-based participatory research, we recruited 50 Somali women from the Minneapolis-St. Paul, MN, metropolitan area through convenience and snowball sampling to participate in semi-structured interviews. Participants were asked to discuss their recollection of their *original* circumcision—including the procedure itself and their assessment of the type of circumcision they experienced. Anatomical drawings of uncircumcised and circumcised vulvas were shown to participants to assist them in identifying their FGC type. A panel of health and cultural experts reviewed and independently assessed participant FGC type. Interrater reliability and degree of concordance between participants and panel were determined.
Outcomes: Outcomes included the following: (1) development of WHO-informed, anatomically accurate visual depictions of vulvas representing FGC typology, (2) development of an iterative, self-reflective process by which participants self-described their own FGC status aided by visual depictions of vulvas, (3) application of WHO FGC typology by a panel of health and cultural experts, and (4) determination of the degree of concordance between participants and panel in the classification of FGC type.
Results: High interrater reliability (kappa = 0.64) and concordance (80%) between panel and participants were achieved.
Clinical Translation: Incorporation of FGC visual imagery combined with women's empowered use of their own self-described FGC status would optimize clinical care, patient education, and informed decision making between patients and their providers when considering medical and/or surgical interventions, particularly among women possessing limited health and anatomic literacy.
Strengths and Limitations: Strengths of this study include the incorporation of anatomically accurate visual representations of FGC types; the iterative, educational process by which participants qualitatively self-described their FGC status; and the high interrater reliability and concordance achieved between panel and participants. Study limitations include the inability to conduct clinical genital exams (due to the community-based methodology used), recall bias, and small sample size ($n = 50$).
Conclusion: We propose a new patient-informed educational method for integrating anatomically accurate visual imagery and iterative self-reflective discourse to investigate sensitive topics and guide clinicians in providing patient-centered, culturally informed care for patients with FGC.

Introduction

Female genital cutting (FGC), otherwise known as female genital mutilation or cutting (FGM/C), is an ancient cultural tradition that affects over 200 million women and girls, with more than 3.6 million girls considered at risk annually.[1,2] As a global practice, FGC is found throughout 30 countries across regions of Sub-Saharan Africa, Asia, the Middle East, and South America, as well as among migrant communities who have resettled in Europe and North America.[1]

FGC encompasses all procedures that involve the partial or total removal of the external female genitalia or other injury to the female genital organs for cultural and/or nontherapeutic purposes.[3] The World Health Organization (WHO) classifies FGC into four categories with corresponding subtypes based on the extent of tissue altered and/or removed.[4] Type 1 a/b encompasses excision of the prepuce/clitoral hood (type 1a) and/or partial or total excision of the external clitoral glans (clitoridectomy; type 1b). Type 2 a/b/c encompasses excision

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of the labia minora (type 2a) and partial or total removal of the external clitoral glans and/or prepuce along with the labia minora (type 2b) and/or the labia minora with the labia majora (excision; type 2c). Type 3 a/b encompasses narrowing of the vaginal introitus with the creation of an external vulvar covering using the apposition of either the labia minora (type 3a) or the labia majora (type 3b) with or without excision of the external clitoral glans (infibulation). Type 4 encompasses all other procedures to the external female genitalia for non-therapeutic purposes, which may include pricking, piercing, incising, scraping, and cauterization.[5]

Available global statistics indicate that about 10%-15% of circumcised women have been infibulated (type 3), with the remaining having undergone type 1, 2, or 4 FGC.[3,6] Somalia (and Somali-dominant regions of its bordering countries Ethiopia, Kenya, and Djibouti) has the highest FGC prevalence rates in the world.[7] While current estimates are unavailable due to ongoing conflict in the region, FGC is almost universally practiced throughout Somalia with 99% of women and girls between 15 and 49 having undergone the procedure,[7,8] wherein type 3 (infibulation) has been predominant.[1,3]

Over 3.5 million people from Somalia have migrated since 1990 due to decades of war, conflict, and climate related disasters.[9] Minnesota, the site of the present study is home to the largest Somali population (CDC, 2021)[10] within the United States; "there may be as many as 35,760 to 150,000 Somalis living in Minnesota, with 80% residing in Minneapolis—likely the highest concentration of Somalis in the United States."[11] Of that number, 53% are female and 59% were born outside of the United States[12] This large number of Somali women living in Minnesota, many of whom have experienced FGC, makes the Minneapolis-St. Paul metropolitan region auspicious for investigating FGC self-assessment.

Prior studies indicate that FGC self-report may estimate general community prevalence of FGC; however, determinations of FGC type specificity are often fraught with inaccuracies and have been found to have low reliability,[13] particularly in regions with lower FGC prevalence.[14] Both women and clinicians have been found to inaccurately report FGC status,[15] with inconsistency between self-reported and clinically verified examination being observed in more than one-fifth of respondents.[16] Moreover, clinical genital examination may not be feasible in large population-based cohorts or community-based studies due to its invasive nature, the stigmatization of patients, and persistent taboos surrounding FGC, along with concerns for privacy and confidentiality. Furthermore, historic legacies of distrust remain persistent barriers to meaningful participation of communities of color in clinical trials.[17,18] These concerns may serve as strong deterrents to robust study recruitment, enrollment, and retention. Additionally, emerging discourse in the scholarly literature has begun to critique the existing WHO terminology, contesting the original typology for its imprecision, ethnocentricity, and stigmatizing tone, which targets non-Western forms of female-only genital cutting with denotations of cultural hegemony that lead to further othering of already marginalized groups.[19–21]

Community-based participatory research (CBPR) has emerged as foundational to building, nurturing, and sustaining trust within "hidden" communities,[22] an approach that engages community members in all phases of research as full partners by recognizing the knowledge, expertise, and resources of the community and bringing those to bear at the research table.[23] Valuing community members as arbiters of expertise and active participants in defining reality facilitates equitable engagement and agency in women who are thereby emboldened to define the embodiment of FGC for themselves.[24] In this article, we describe the iterative process of implementing a multifaceted and interactive approach to optimizing concordance in FGC self-assessment, incorporating qualitative inquiry with an educational component, visual imagery, as well as an expert consensus panel. Through this iterative process, the researchers were able to facilitate the relationship and communication between Somali female participants and interviewers, provide educational materials about the vulva indirectly, and provide triangulation of data to increase validity.[25]

Our research question was to discern whether integrating multiple dimensions of participant engagement, including women's own self-reflection, iterative verbal discourse, and the use of visual imagery helps elucidate how language used by community members to describe their lived experience informs the classification of FGC status by a panel of cultural and health experts applying WHO typology. We hypothesized that using this approach would enhance the confidence that mutually understood terminology is used by researchers and Somali community participants to improve concordance and methodological rigor, particularly among communities with a high prevalence of FGC type 3.

Methods

This project was part of a larger community-engaged study of sexual pain among women who have experienced FGC.[17] Our research study was grounded in a CBPR.[19] Academic partners at the University of Minnesota collaborated with a community partner SoLaHmo that specializes in CBPR approaches within intercultural communities. Both organizations hired and trained three female Somali-English bilingual interviewers to conduct the interviews for the study. In addition, an 11-member Community Advisory Board, composed of Somali health professionals, school administrators, and community leaders, provided additional culturally informed guidance on research methods as part of the CBPR process.[26] Two coinvestigators, who were both physician experts in FGC, and the most experienced bilingual female Somali-born interviewer on our staff were primarily responsible for determining FGC type based on translated and transcribed written transcripts of the face-to-face interviews. The staff physicians are experts in FGC: (1) an obstetrician/gynecologist (first author) with over 2 decades of clinical work—including reproductive, gynecological, and surgical care through pregnancies and complications of FGC as well as extensive CBPR with over 40 FGC-specific peer-reviewed publications concerning FGC-affected populations. (2) A family physician (fourth author) with 2 decades of clinical practice serving a large Somali immigrant population—including women with FGC needing reproductive and gynecological care. The bilingual female Somali-born interviewer conducted the majority of the face-to-face interviews with Somali women ($n = 56$), participated on a select state taskforce on FGC, and facilitated numerous women's health workshops on FGC with African women.

Institutional Review Board approval

On May 20, 2019, the University of Minnesota Human Research Protection Program, Office of the Vice President of Research, approved this study, Institutional Review Board (IRB) ID: STUDY00002117. The IRB determined that "the criteria for approval have been met and that this study involves no greater than minimal risk."

Participants

Study participants were a subset ($n = 50$) of participants drawn from a larger interview study with 75 Somali women. Eligibility criteria for this subset included Somali ethnicity; female; circumcised; childbearing age (18 to 45); either married, divorced, or separated (as a proxy variable for having been sexually active); and being asked and willing to view FGC anatomical illustrations during the interview to clarify their circumcision type.

Sampling and recruitment

Through convenience and snowball sampling methods, bilingual community researchers recruited Somali women who had experienced FGC. Using a convenience sampling approach, we recruited 30 women (60%) face to face from community centers, resettlement agencies, apartment buildings with large Somali populations, community health fairs, interviewers' social networks (eg, neighbor, former coworker, etc), and flyer postings on university campuses. Twenty women (40%) were referred by study participants and contacted by interviewers via telephone. Most participants had no prior knowledge of the interviewers or the research.

Interviewers were three Somali-born women fluent in English and Somali (including the third author). Their ages ranged from early to late 20s and they had college degrees in community health, human resources, and social work. Interviewers completed 12 hours of training on qualitative interviewing skills before conducting semi-structured in-person interviews with participants.

Participants were interviewed at their preferred private location to preserve confidentiality. The majority were interviewed in their homes or a friend's home ($n = 39$, 78%), with the remainder interviewed at the study or participant's office, school, or other community location. All interviews were audio-recorded, lasting 23 to 136 minutes (mean, 53 ± 20 minutes), although the section of the interview focusing on FGC was a shorter portion of the interview. Interviewers kept detailed field notes, including information about the environment (eg, family member interrupted), the conversation, and the general tone of the interview (eg, participant was open, appeared guarded, etc.). Participants received a $75 prepaid debit card for their time.

Interview materials

An interview guide was developed by the third, fifth, and last authors based on previous literature and pilot tested by the third author before data collection. The interview guide covered a range of topics; however, here we discussed their reflections on their circumcision memories—most notably their recollection of the FGC procedure and their self-assessment of their original FGC type.

Anatomical drawings of vulvas based on the WHO classification system[4] were used as visual representations of FGC types 1–3,[5,27] and a verbal description of type 4 was provided.[28] In ongoing consultation with two physician experts in FGC (first and fourth authors), these anatomical drawings were painted in watercolor by Ashley Finch, an artist who specializes in illustrating genitalia for sexual health education and research. A complete description of the development of these illustrations and the full set of illustrations are discussed and shown in the accompanying article in this issue (Chaisson et al., this issue). To minimize confusion between FGC types and subtypes, visual imagery included illustrations of an uncut vulva (for comparison purposes), FGC type 1b, FGC type 2b, and FGC type 3b.

In order to maintain cross-cultural equivalency, Somali transcripts were translated *conceptually*, rather than literally word for word in a two-step process by the interviewer(s). In *step 1*, the interviewer listened to the Somali audio recording while digitally recording their verbal translation of the interview into English. In *step 2*, translations were back-checked by both a bilingual Somali intern and a bilingual CAB member; few corrections were needed. Then, a professional transcription service transcribed all the English and Somali-translated English digital audio files. Transcripts were organized using a qualitative data analysis software (Dedoose version 9.0.17).[29]

Interview discussion about self-assessment of FGC type

At the beginning of each interview, interviewers tried to create a safe and comfortable environment for the women to discuss their experiences by introducing themselves and getting to know something about each woman. As part of the informed consent process, a written consent form (in English or Somali) was reviewed with the participant. Interviewers gave an overview of the study and purpose and reviewed interview procedures, making sure to allow time for participants to ask questions and request clarifications and demonstrate their understanding of the study before signing the consent form. Women were able to take breaks and pause if needed at any time during the interview. Upon completion, each participant received a $75 gift card.

The interviews started with less sensitive questions to build rapport and put participants at ease before asking the following more sensitive questions about FGC. Participants were asked to describe and discuss their recollection of their original circumcision including the procedure itself. As part of this discussion, anatomical drawings of an uncut vulva and vulvas displaying FGC type 1b, FGC type 2b, and FGC type 3b and a description of FGC type 4 were shown to the female participants to assist them in more precisely identifying their FGC type. For comparison, the first drawing displayed an uncut vulva. Interviewers spent a few minutes discussing this drawing by pointing out all labeled anatomical parts to orient each woman to the appearance of an uncut vulva. Next, interviewers reviewed drawings of FGC types 1b, 2b, and 3b by reading the description aloud while pointing at the altered parts (eg, parts that were cut, removed, or sewn together). Type 4 was represented by a list of words describing possible type 4 procedures such as piercing, pricking, incising, scraping, or burning/cauterization that may have occurred without removal of genital structures. After this informative discussion, women were asked to choose which image they thought best represented their original circumcision type. This iterative educational process involved moving back and forth

from image to image, allowing each circumcised woman to ask clarifying questions and to spend additional time, as needed, reviewing the images at their own pace and thinking about their own original FGC procedure. At the end of this process, each participant chose the image they thought best represented their anatomy at the time of original circumcision (ie, before any anatomical changes due to deinfibulation, sex, and/or vaginal childbirth). If a participant was unsure or unable to determine their circumcision type, the interviewer asked probing questions (eg, what parts do you think were cut, were you sewn together, etc.) to help her arrive at a type.

Procedure for assessing concordance between participant self-assessment and "expert" panel assessment

Interview transcripts and interviewer field notes regarding the participant's self-assessment of FGC type using visual illustrations, as well as additional relevant information helping to determine FGC type (eg, if any anatomical parts were removed, or sewn together) and experience with defibulation, chronic sexual pain, childbirth, or menstrual and urinary complications were entered into an Excel spreadsheet. The three female assessors, the experts in FGC who were discussed earlier (obstetrician/gynecologist [first author], family physician [fourth author], and our most experienced interviewer [third author]) *independently* reviewed the deidentified interviews, spreadsheet, and field notes to determine the FGC type for each woman. After their individual FGC-type assessments were completed, the assessors met together as a 3-member panel to review their determinations and arrive at a consensus regarding the FGC type for each participant—which they did. Once the panel reached consensus, concordance or discordance between participant self-assessment and panel assessment of FGC type was evaluated using percentage of agreement and Cohen's κ statistic.[30]

Sociodemographic characteristics of the FGC self-assessment subsample

Sociodemographic characteristics of the FGC self-assessment subsample are shown in Table 1. All 50 participants identified their ethnicity as Somali and their religion as Islam and were on average 35.1 ± 5.3 years old (range, 21-45 years). Education levels varied widely: 36% of participants ($n = 18$) had less than a high school diploma, 18% ($n = 9$) had a high school diploma, 32% ($n = 16$) had completed some college or an Associate's degree, and 14% ($n = 7$) had a Bachelor's or a Master's degree. Most women (82%, $n = 41$) worked outside of the home full or part time. Women had a median household income of $15 000–$30 000 (range <$15 000 to >$60 000). About two-thirds of the women ($n = 34$) were married; 28% ($n = 14$) were divorced. On average, women had lived in the United States for 13.4 ± 7.5 years; range, 1.5-26.5 years), and 42% ($n = 21$) had lived in a refugee camp before arriving in the United States. Most participants (74%, $n = 37$) could speak both English and Somali, but 64% ($n = 32$) chose to be interviewed in Somali.

Table 1. Participant demographic information ($n = 50$).

Variable	No.	%	Mean	SD
Age*			35.1	5.3
Ethnicity				
Somali	50	100		
Religion				
Islam	50	100		
Education				
No school	2	4		
English as a second language	1	2		
Elementary school/some high school	15	30		
High school diploma	9	18		
Some college/Associate's degree	16	32		
Bachelor's degree/Master's degree	7	14		
Employment status				
Part-time	27	54		
Full-time	14	28		
Homemaker	5	10		
Unemployed/disabled/student	4	8		
Income				
<$15 000	10	20		
$15 000-$30 000	22	44		
$30 000-$45 000	7	14		
$45 000-$60 000	5	10		
>$60 000	6	12		
Marital status				
Married	34	68		
Divorced	14	28		
Widowed/never married	2	4		
Lived in a refugee camp				
No	29	58		
Yes	21	42		
Years in the US			13.4	7.5
Born in the US	1	2		
≤5	12	24		
6-10	7	14		
11-15	10	20		
16-20	12	24		
≥21	8	16		
Language spoken				
Both Somali and English	37	74		
Somali but not English	12	24		
English but not Somali	1	2		

Results

Circumcision experiences

Eighty-seven percent of women in the sample were circumcised between the ages of 5 and 11 years, the majority in Somalia (89%), as most women were born in Somalia (92%, Table 2). Participants were usually circumcised at home or in someone else's home/neighborhood (61%), or in a hospital/doctor's office (15%), by a traditional circumciser (55%), or by a doctor/midwife/person with medical training (45%). Although 45% of women were given anesthesia or pain medication before circumcision, only 20% were given pain medication afterward and 18% were treated using traditional practices to heal (eg, smoke from burning traditional herbs, ice, warm water with salt).

Concordance between self-assessment and panel assessment

The most common type of circumcision reported by both participants and assessors was type 3 ($n = 27$ self-assessment, $n = 33$ panel assessment), followed by type 1 ($n = 17$ self-assessment, $n = 12$ panel assessment). Types 2 and 4 FGC were more infrequently reported (Table 3). Overall, there was substantial agreement between participants' self-assessment of their FGC type after the participants viewed the visual images and the panel assessment of their FGC type (kappa = 0.64,

Table 2. Participant circumcision information.[a]

Variable	No.	%
Birth country ($n = 50$)		
Somalia	46	92
Ethiopia	1	2
Yemen	1	2
Kenya	1	2
United States	1	2
Age at circumcision, years ($n = 47$)[a]		
1-4	4	9
5-11	41	87
12-13	2	4
Where circumcised–country ($n = 46$)		
Somalia	41	89
Ethiopia	2	4
Kenya	3	7
Where circumcised–specific place ($n = 46$)		
My home	16	35
Someone else's home/neighborhood	12	26
Hospital or doctor's office	7	15
Refugee camp	1	2
Other[b]	10	22
Circumciser ($n = 33$)		
Traditional circumciser/a local woman	18	55
Doctor/midwife/person with medical training	15	45
Pain medication before circumcision ($n = 44$)		
Not given pain medication	24	55
Given anesthesia or pain medication	20	45
Pain medication after circumcision ($n = 40$)		
Not given pain medication	25	62
Not given pain medication but used traditional healing practices	7	18
Given pain medication	8	20

[a] When n was not 50, participant responses were "I don't remember," or "I don't know," or data were missing. [b] "Other" included: Somalia (no details; $n = 7$); Mogadishu, Somalia ($n = 3$).

Table 3. Participant self-assessment, panel assessment, and concordance between self- and panel-assessment by FGC type ($n = 50$).

	Self-assessment, No.	Panel assessment, No.	Concordance, No. (%)
Type 1	17	12	11 (92)
Type 2	6	3	2 (67)
Type 3	27	33	27 (82)
Type 4	0	2	0
Total	50	50	40 (80)

$P < .001$, observed agreement 80%, $n = 40$).[30] Extent of concordance varied by FGC type, with the highest agreement between the participants and panel for type 1 (92% concordance), followed by type 3 (82% concordance), then type 2 (67% concordance), and no concordance for the two type 4 cases (Table 4). Among the 10 discordant cases, 70% ($n = 7$) of participants who assessed themselves as type 1 or type 2 were rated by the panel as having undergone type 3. The 2 discordant cases that were rated as type 4 by the panel were assessed by the participants as type 1.

Table 4 displays illustrative quotes demonstrating the iterative discussion process used to review the drawings and discuss the woman's FGC, as well as what that the discussion process looks like for concordant and discordant assessments. As shown, a typical description of type 1 referred to *sunna* (vs *pharaonic*) and described involvement of the clitoris only, with

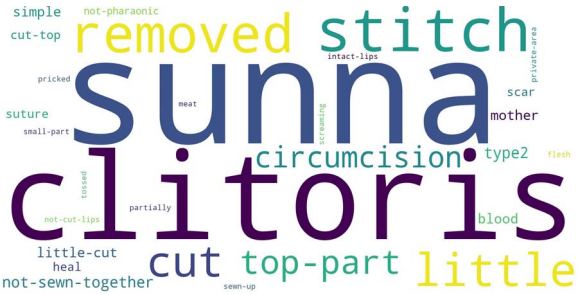

Figure 1. Word cloud of Participants' FGC Type 1 Descriptions.

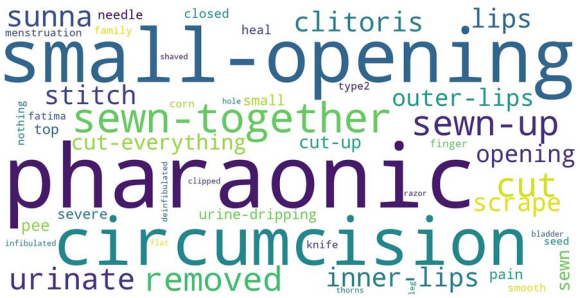

Figure 2. Word cloud of Participants' FGC Type 3 Descriptions.

no involvement of the labia/lips. A typical description of type 3 (*pharaonic*) included words that indicated sewing and space only left for urine. In the example of a discordant assessment, the participant used words that suggested type 3, despite her self-assessment of type 1. The interviewer did not point out the discrepancy but could have clarified that further with the participant — perhaps eliminating that discordance.

Participant description of types 1 and 3: word clouds

We created word clouds to depict types 1 and 3, as displayed in Figure 1 and Figure 2. The three panel assessors noted that certain repeated phrases and words (ie, buzz words) emerged from the data that were characteristic of FGC types 1 and 3. After irrelevant words (eg, "the," "a") were deleted, a dictionary of words and counts was generated and plotted using a programming language called Python (2012).[31] Words in larger fonts emerged more frequently from participants' descriptions than those in smaller fonts. For the type 1 word cloud, the top 10 frequent words included were the following: *sunna* ($n = 26$), *clitoris* ($n = 20$), *stitch* ($n = 18$), *removed* ($n = 14$), *little* ($n = 10$), *cut* ($n = 9$), *circumcision* ($n = 5$), *top-part* ($n = 5$), *not-sewn-together* ($n = 5$), and *little-cut* ($n = 4$). For the type 3 word cloud, words with a frequency of at least 10 included: *pharaonic* ($n = 43$), *small-opening* ($n = 41$), *circumcision* ($n = 32$), *sewn-together* ($n = 31$), *sewn-up* ($n = 22$), *cut* ($n = 21$), *removed* ($n = 20$), *urinate* ($n = 16$), *sunna* ($n = 15$), *clitoris* ($n = 13$), *inner lips* ($n = 12$), and *outer lips* ($n = 10$).

Discussion

To our knowledge, this study is the first methodologic undertaking of a novel, iterative process that triangulated the integration of FGC visual imagery with women's self-reflection describing their lived embodiment of FGC, alongside vulvar anatomical education and a comparison of FGC type-specific

Table 4. Illustrative quotes of participants whose self-assessment was concordant or discordant with the panel assessment.

Concordance		Discordance	
Self-assessment *after* seeing drawings Type 1	**Panel assessment Type 1**	**Self-assessment *after* seeing drawings Type 1**	**Panel assessment Type 3**
Interviewer: *This third picture shows the clitoris is removed and the inner lips are also removed. There's no sewing and there's nothing else removed from this picture. This fourth picture shows another type of circumcision and if you can see, the clitoris is removed, the inner lips are removed and the outer lips are sewn together. There's a small opening left and this last picture shows the clitoris also removed, the inner lips are also removed and the outer lips are sewn together and the opening got very small. Which type or which one of these pictures best describe your circumcision?* ***MS48:*** *My Sunna is this picture, type 1 on this picture. My clitoris was removed and they did a little bit of suturing to heal the scar where the clitoris was removed. My lips are still intact. I have nothing else removed from me and I was not sewn up together.*		***Interviewer:*** *Please, look at these pictures. Which one do you think you looked like before you got married?* ***FA1:*** *This one.* ***Interviewer:*** *Type 1? So, how much was cut?* ***FA1:*** *The whole clitoris was cut. They did it like this and then that was it. They cut it and then they sewed it up.* ***Interviewer:*** *They scraped it?* ***FA1:*** *They scraped it. They scraped it and then they sewed it up. That's it.* ***Interviewer:*** *How much did they sew?* ***FA1:*** *Do you see the place that you were made from? [Referring to vaginal opening] That's all that was left. The little thing was all they left. But the whole thing, they scraped, they scraped, they scraped, cut, scraped, they scraped. Then took a needle and sewed it up. The only place that was left was the place that you urinate from. That was all that was left.*	

self- and expert reporting. While there have been other studies which have incorporated visual imagery to facilitate the accuracy of FGC self-reporting,[22,32] we have proposed a novel approach whereby women's self-perceptions of their FGC status were integrated with patient-informed and culturally relevant visual imagery and descriptors and discussed iteratively to develop descriptive and shared language that could be used to get agreement on FGC type based on WHO typology.

From this exercise, a panel of words and phrases were derived to characterize FGC types 1 and 3, which achieved consensus across a panel of cultural and health experts, improving our ability to apply WHO typology. The addition of visual imagery and understanding of common language—words and phrases used to describe the experience of FGC—may serve to strengthen the rigor of community-based or large population-based cohort studies, which must rely on a woman's self-report of FGC status in circumstances where performance of verifiable clinical genital exams is neither feasible nor desired.

Consistent with the global literature, Somali women in our study underwent FGC at a young age in nonmedical settings, without adequate analgesia. The vast majority of participants were circumcised in childhood at ages 5-11 years (87%).[33,34] Recent evidence suggests that a woman's personal experience with FGC (the physical and psychological effects at the time of the cutting), and her specific recollection of the actual event, may influence health services use more than the extent or severity of cutting itself.[35] This finding may have important implications for targeting psychological therapeutic interventions.[2]

There was substantial agreement between participants' self-assessment of their FGC type after viewing the visual images and the 3-member panel assessment of their FGC type. However, among the majority of the 10 discordant cases, the consensus panel assigned a more severe type than the participants, suggesting social desirability bias or cognitive dissonance on the part of participants. Perhaps participants felt inclined to downgrade their FGC status by not admitting or perceiving they had undergone type 3, especially in the US context where FGC, especially type 3, is stigmatized.[36] This tendency to pick a less extensive FGC type may also reflect shifting attitudes in Somalia in the 1980s toward the more extensive types of FGC – with girls still experiencing type 3, but being more likely to be told they were *sunna* (type 1).

The word clouds highlighted buzz words used by many participants, which helped distinguish type 1 from type 3, such as *sunna* vs *pharaonic* and *little cut* vs *small opening*. Such specific descriptors were useful for coding the extent and/or location of tissue cut or removed. In addition, the action of reapproximating tissue was distinguishable for types 1 and 3, with descriptors for type 1 designating "stitching" to achieve hemostasis, whereas "sewing" was used to designate type 3 as a closure bringing tissue edges together to "close" or "sew up." Use of these buzz words, as displayed in the word clouds, may inform how future researchers elicit information about FGC status without requiring a clinical exam. Word clouds were not assigned for type 2 and type 4 due to low frequency of these types hindering our ability to assign adequate and distinct descriptors—but future research may lead to the development of similar descriptors.

Strengths and weaknesses

There are several strengths of this study, namely the incorporation of patient-informed, culturally relevant, artistic, and anatomically accurate visual imagery of FGC types and subtypes, which provided an educational opportunity for participants to learn more about their vulvar anatomy and FGC. By incorporating qualitative descriptors through iterative discourse augmented by artistic visual imagery, the accuracy of women's self-reports may be enhanced. As previously mentioned, there was substantial interrater agreement ($\kappa = 0.64$,) and a high level of concordance (80%) of assigned FGC type, which emerged from key qualitative descriptors generated during the interview process and panel assessment.

These findings must be interpreted with caution. Given the nature of this community-based study, performing clinically verifiable genital exams was not feasible. Without such clinically verified genital exams, we cannot conclude that the women and panel members accurately assessed FGC type. We propose that future research explore the accuracy of this enhanced method of FGC self-assessment using the "gold standard" of clinically verifiable genital exams. One final

caution is that FGC is also practiced by Christians in other areas of the world,[14] and therefore the buzz words of *sunna* and *pharaonic* used by this sample of Muslim women will not apply to all who have experienced FGC.

Clinical implications

Our study has important implications for future validation of the use of visual imagery alongside FGC type-specific qualitative interview questions and descriptors to enhance the standardization and accuracy of FGC self-reporting in community-based or population-based cohort studies where clinically verified genital examinations are not feasible. In the clinical environment (both medical and mental health) there is a role for visual imagery of FGC typology, not only as an educational tool for patients, but as an aid for healthcare providers treating circumcised prepubertal girls[15] and/or in low volume settings with limited exposure to FGC-affected patients—particularly the less extensive forms of FGC (types 1 and 4).

Women who have experienced FGC may want to seek advice about how to address their sexual concerns.[37] Yet, despite the documented impact FGC can have on sexual function,[38] there is little guidance within the academic literature on best practices for addressing these concerns through educational or psychological interventions; the literature has been primarily focused on surgical interventions.[39] Several experts recommend that psychological and sexual counseling be utilized to address sexual functioning.[40,41] The type of circumcision will affect a woman's experience and has diagnostic and treatment plan implications. Finding a sensitive and culturally informed, yet reliable, means of interviewing a female patient about which type of FGC she experienced will be necessary for health professionals who do not physically examine patients or have immediate access to medical records (eg, psychologists, sex therapists, community health workers). The method described in this paper can be utilized as a means of eliciting this information.

The WHO typology was originally designed for use by clinicians and researchers to have greater consistency in reporting on FGC types visualized during clinical pelvic exams to achieve standardization in reporting. In this study we are applying the WHO typology to participants' own self-assessment of FGC cutting status, which is novel. As noted by Earp and Johnsdotter, [19] the WHO FGC typology is not without problems, including the use of imprecise language and oversimplification of the diversity of procedures used across cultures and geographic regions. We suggest that the integration of visual imagery alongside common words or phrases used by FGC-affected communities, as shown in our word clouds, to self-describe their own FGC status without using stigmatizing, value-laden language or requiring an invasive clinical exam, can assist in bridging the language differences between affected community members and healthcare professionals familiar with the WHO typology. This method is particularly salient during healthcare encounters where FGC-affected women and girls may be prone to experiencing implicit bias and othering as racialized and religious minorities.[17]

Future directions

To validate our findings, future research conducted in clinical settings should be performed to examine concordance between the self-assessments of FGC-affected women, both with and without the use of visual imagery. In such research participants may discuss or draw how they think they appear anatomically and their own self-representation of "normality" before they view any imagery. Participants' knowledge before and after visualization of the graphic imagery could thereby be assessed. Thereafter, a clinically verified genital exam may be performed by medical providers blinded to the participant's self-assessment. Thus, the degree of concordance across both patients and providers alongside visual cues of FGC typology and then the scalability of this procedure can be evaluated for use in larger population-based cohort studies, for which clinically verified exams would not be feasible. It would also be critically important to include a sample from the general population for comparison purposes to assess whether those participants who consent to genital examination possess varied anatomic and/or physiologic comprehension and/or have voiced concerns pertaining to the impact of FGC on sexual pain compared to the general population, who may or may not derive similar knowledge, concerns, and/or possess the fortitude to voice such concerns before and after visualization of FGC imagery. In these studies, it would be important to train medical providers to specifically ascertain the historical type of FGC that was originally performed, particularly if the original FGC is different from the patient's current vulvar appearance, and accurately reflect this distinction in the medical records. When women have undergone prior defibulation and infibulation procedures, numerous pregnancies and laceration repairs, and other procedures (eg, vulvar repair of epidermal inclusion cysts, clitoral reconstruction, etc.), it becomes increasingly difficult for both clinicians and patients to assign the correct FGC-type designation. We believe the iterative, bidirectional, open dialogue between the patient and clinician discussed in our study, infused with FGC visual imagery, may enable a deeper understanding of the evolution of women's vulvar anatomy across time and space, resulting in a more accurate assessment of FGC status.

There is growing interest in the application of 3D web-based applications comprising pelvic prototype models illustrating genital anatomy and physiology across FGC types and subtypes.[42] Such innovative technology would greatly enhance the accuracy of women's self-reporting as well as provide robust opportunities for women's education and counseling by their healthcare providers, which would inform not only research, but also clinical care and shared decision making between patients and their providers when considering surgical interventions.[43] This would be particularly salient for women with limited health and anatomic literacy who may not otherwise be equipped to make informed choices about medical and/or surgical treatment plans. In addition, psychotherapy and sex therapy may be greatly facilitated by women's enhanced understanding of their vulvar anatomy, genital sensation, and overall sexual function.[42] Data collection efforts should also include an examination of sociodemographic characteristics correlated with FGC self-assessment according to key variables such as migratory patterns, age, educational attainment, length of time in host country, and degree of cutting. The role of acculturative processes in influencing negative attitudes toward more extensive forms of FGC, thus potentially infusing social desirability bias into women's own self-reporting, warrants further exploration. In addition, future efforts should be made to assess FGC-affected women's perception of the visual aids

themselves in terms of its cultural appropriateness and anatomic accuracy.

Conclusion

We propose a new method for the patient-informed and culturally relevant multidimensional integration of anatomically accurate visual imagery and iterative self-reflective discourse with education. This method holds promise for assessing self-reported FGC status according to mutually understood, type-specific terminology that has been designed for use in clinical, community, and/or population-based cohorts. Our model reflects a culturally informed process for investigating sensitive topics and provides guidance for clinicians seeking to provide more patient-centered, culturally informed care for patients who have experienced FGC.

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Supplementary material

Supplementary material is available at *The Journal of Sexual Medicine* online.

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Conflict of interest

None declared.

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Data availability

Plan for Data Sharing and Dissemination of Findings. Currently, we are conducting data cleaning and data analysis. The final dataset will be stripped of identifiers prior to release for sharing. However, we believe that there remains the possibility of deductive disclosure of subjects with unusual characteristics. Thus, we will make the data and associated documentation available to users only under a data-sharing agreement that provides for: (1) a commitment to use the data only for research purposes and to protect the identify any individual participant; (2) a commitment to securing the data using appropriate computer technology; and (3) a commitment to destroying or returning the data after analyses are completed. A long-term data sharing and preservation plan will be used to store and make the data publicly accessible beyond the life of the project. The data will be deposited into the Data Repository for the University of Minnesota (DRUM), http://hdl.handle.net/11299/166578. This University Libraries' hosted institutional data repository is an open access platform for dissemination and archiving of university research data. Date files in DRUM are written to an Isilon storage system with two copies, one local to each of the two geographically separated University of Minnesota Data Centers. In addition, DRUM provides long-term preservation of digital data files for at least 10 years using services such as migration (limited format types), secure backup, bit-level checksums, and maintains a persistent DOIs for data sets, facilitating data citations. In accordance to DRUM policies, the (DE identified) data will be accompanied by the appropriate documentation, metadata, and code to facilitate reuse and provide the potential for interoperability with similar data sets.

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