Patient centered communication in the context of female genital cutting: Implications from the Our Body Our Health research study.

Dean's Lecture Series

Office of Diversity, Equity, and Inclusion

Jennifer Jo Connor, PhD, LMFT

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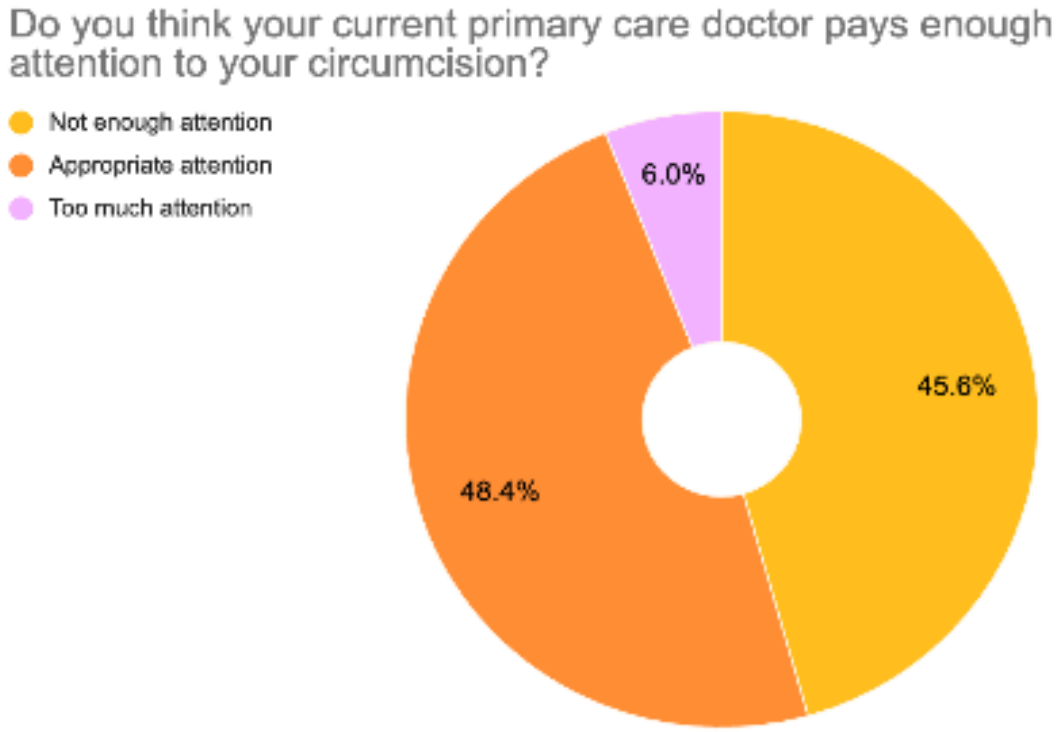
Eli Coleman Institute for Sexual and Gender Health
Department of Family Medicine and Community Health
University of Minnesota, Medical School

My Background

- Institute of Sexual and Gender Health faculty member and clinician - Licensed Marriage and Family Therapist
- Clinical, research, and education interest in how people cope with various forms of genital and sexual pain.
- Over time, research focused on female genital cutting, in particular as it relates to sexual pain.
- Social position – cisgender female, raised in Central MN – Catholic schooling, ancestors migrated from various European countries to the U.S. in the 1700 and 1800's.

Today's Objective: Unpack this research finding and begin to answer this common question.

Common question from HCPs: How do I talk to my patients about FGC?



Female Genital Cutting Terminology

- FGC, FGM, or female circumcision?
- Types – WHO provides 4 general categories
  - 1 & 2 – removal of clitoral tissue, possible excision of labia majora and/or minora (Sunna)
  - 3 – additionally involves closing the vaginal orifice (Pharonic)
  - 4 - other (Sunna)
- Deinfibulation refers to opening the narrowed vaginal orifice; necessary for vaginal childbirth, and alleviates pain, urinary problems, menstrual problems

Health and Social Complications

- No known benefits
- Acute concerns – bleeding, infections, unable to pass urine, missed schooling
- Long-term – obstetric, genital pain, urinary, menstrual, sexual dysfunction, psychological, neonatal health
  - Heterogeneity in findings, points to complexity and diversity
  - Case studies of gynecological problems, such as keloids and cysts

Berg et al., 2014; Bertruit et al., 2021; Hamid et al., 2018; Libretti et al., 2023; Nzinga et al., 2021; Vloeberghs et al., 2012

Our Body, Our Health

- Community-based participatory research (CBPR) with qualitative and quantitative aims exploring sexual pain in Somali women living in MN who have experienced FGC.
  - 75 Qualitative Interviews; ages 20 – 70
  - 300 Quantitative ACASI Surveys; ages 20 – 45
  - About 2/3 Type 3
- Chart review of 100 encounters
  - Used ICD FGM code
  - Majority from East Africa; ages 18 - 79

Connor et al., 2023, 2024; Johnson-Agbakwu et al., 2023; Chaisson et al., 2023; Creger et al., 2024

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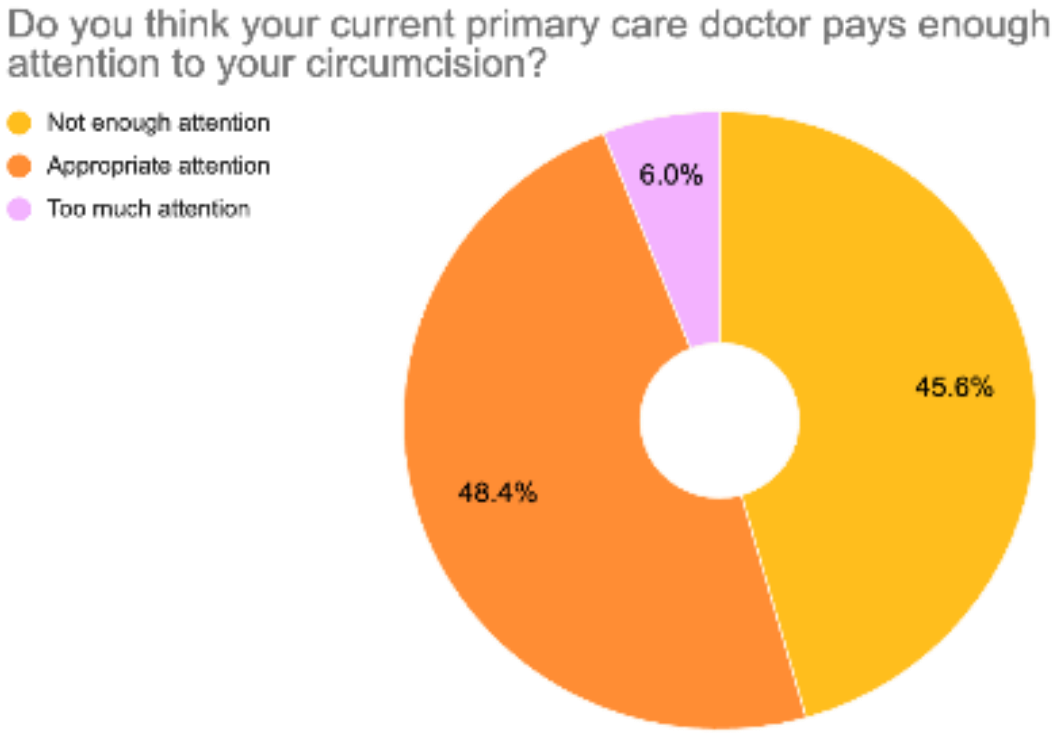
Why?

Knowledge?

Attitudes/Assumptions?

Communication Skills?

Logistics?



Misconception: Women with FGC are not interested in sexual health

- What does the research say?
- Chart Review
  - 31% of encounters addressed sexual health
    - Sexual pain – 23%
    - Sexual arousal – 8%
- OBOH
  - Recruited faster than expected.
  - Participants referred friends and family members.
- OBOH and others
  - Though FGC is associated with a higher odds of sexual dysfunction, it is not a universal experience.
  - Some HCPs denied intervention and overrode patient's request or incorrectly assumed patients were against intervention (see Jordal et al., 2022 and Ziyada and Johansen 2021)

Decisional Conflict Scale (OBOH Survey)

- Subscales: Informed, Uncertainty, Values Clarity, Support from HCPs

- Highest Conflict: Informed (know options)
- Low Conflict: Values Clarity, Uncertainty

Chanda et al., in progress

Healthcare provider knowledge

- **Chart Review Study**
- 11 different terms for FGC were used, with “female circumcision” being the most common. Some appeared to use the wrong terms.
- Notes lacked specificity, such as metric for size of introitus.
- 14 different deinfibulation terms in 64 notes – most were misleading or inaccurate.

- **Other U.S. Studies**
- Levy et al. (2021)
  - 61% of providers worked with a patient with FGC.
  - 14% reported receiving formal training in FGC
  - 47% felt uncomfortable caring for patients with FGC.
- Lane et al. (2019).
  - Survey of 508 professionals specializing in reproductive health across 15 cities.
  - Nearly half did not receive formal training about FGC

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ORIGINAL RESEARCH Open Access

Factors Associated with Health Care Provider Attitudes, and Confidence for the Care of Women and Girls Affected by Female Genital Mutilation/Cutting

Christina X. Marea,[1,2,*,†,‡] Nicole Warren,[1] Nancy Glass,[1] Crista Johnson-Agbakwu,[3] and Nancy Perrin[1]

Table 5. Factors Associated with Health Care Provider Confidence—Multivariable Analysis

	Confidence for clinical FGM/C care ($n=139$)[a]			Confidence in critical communication skills for FGM/C ($n=140$)[a]		
	B (S)	95% CI	*p*	*B* (S)	95% CI	*p*
Awareness of health complications	0.265	0.047 to 0.140	***<0.001***	0.187	0.002 to 0.059	***0.035***
Women's health provider	0.089	−0.365 to 1.389	0.249	0.074	−0.333 to 0.733	0.459
Ever cared for a woman affected by FGM/C	0.340	1.145 to 3.103	***<0.001***	0.142	−0.181 to 1.002	0.172
Ever received training for care of women affected by FGM/C	0.066	−0.408 to 1.182	0.338	−0.012	−0.515 to 0.450	0.894
Female gender	0.178	0.320 to 2.265	***0.010***	−0.110	−0.625 to 0.559	0.755
Person of color	0.161	0.242 to 2.029	***0.013***	0.026	−0.459 to 0.631	0.755
More than 5 years of clinical experience	0.135	0.037 to 1.607	***0.040***	0.034	−0.383 to 0.571	0.696

Bold-italic signifies statistically significant findings.
[a]Participants who were missing one or more of the predictor variables were excluded from the analysis.
B, beta; CI, confidence interval; S, standardized.

Hashim (2017) Patient Centered Communication

- Elicit patient's agenda
- Negotiate the agenda (I would also like to address)
- Open-ended questions
- Active listening skills (clarify, summarize, empathy)
- Assess perspective on what is creating the problem (FGC or other cause)
- Impact (Has your circumcision impacted….)

Interview Quotes: HCP Communication

- *The doctor looked and she just reassured me. She told me that my circumcision wasn't all that bad … I wasn't sewed all the way, so it wouldn't be that difficult, it would be easy, and it wouldn't affect me in any way. Actually, it would help me during intercourse when I do get married. And that just made the decision easier to make at that point.*
- *The doctor mentioned deinfibulation to me. And he gave me a choice to either – to be deinfibulated or not to be deinfibulated. But he did give me the option to do that. I refused to do it because of the pain. I did not want to go through that pain again.*
- *The first doctor that I saw, she could not understand what happened to me, so she called another doctor who was Egyptian and knew about this. The doctor explained to the other doctor what was done to me, and what circumcision was, and she still didn't believe that it was the real thing. She was shocked. She's a white doctor, who has never seen circumcised women before. She suggested that I should have an ultrasound, but the other doctor explained to her what it was.*

Patient Centered Care – Respect, Reassuring – she is not alone, Does not minimize

I've heard so many stories about certain doctors who honestly don't know anything about it or they do know, but they don't treat you as well or they make you feel [badly] about it… she told me that she's done thousands of these procedures and she knows about it. And it affects her people as well, her country. And so that made me even more comfortable to go with her.

Conclusion

- Jacobson et al (2019) refer to “the duality of anti-female genital mutilation discourse: A vehicle for advocacy and stigmatization”.
- HCPs will bring their own perspectives to encounters. It is imperative that we seek education, reflect on our assumptions, listen, and communicate respect.

Resources

Deinfibulation: a visual reference and learning tool by Jasmine Abdulcadir, MD

https://www.youtube.com/watch?v=fbKPqE6Vj_c

Videos for patient education and counseling by GAMS. Available in nine languages: Afar, Amharic, Arabic, Dutch, English, French, Fula, Somali, and Tigrinya.

https://www.youtube.com/channel/UC9osj8btP6Uc6lNCvrfmQdw

Healthcare Provider Toolkit by BRYCS

https://brycs.org/clearinghouse/8149/

World Health Organization. (2018). Care of girls and women living with female genital mutilation: a clinical handbook. https://apps.who.int/iris/handle/10665/272429. License: CC BY-NC-SA 3.0 IGO

A Visual Reference and Learning Tool by Southwest Interdisciplinary Research Center, Arizona State University

https://sirc.asu.edu/sites/default/files/fgmc_booklet.pdf

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Munira Salad, MPH (2018 – 2022; Community Advisory Board member 2022 – 2024)

Zahra Sheikh, BA (2021 – 2022; SoLaHmo member 2023 – 2024)

Fathi Ahmed, BS (2022)

SoLaHmo Community Researchers

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Foos Afey, MSW (2018 – 2022; Community Advisory Board member 2022 – 2024)

Intisar Hussein, LICSW (2018 – 2021; Community Advisory Board member 2022 – 2024)

University of Minnesota Faculty: Family Medicine and Community Health

Bean Robinson, PhD, LP, LMFT, Principle Investigator (2018 – 2024)

Jennifer Connor, PhD, LMFT, Co-Principle Investigator (2018 – 2024)

Nicole Chaisson, MD (2018-2024)

Sonya Brady, PhD, LP (2018 – 2024)

Michael Miner, PhD, LP (2018 – 2022)

University of Minnesota Faculty: Sociology

Cawo Abdi, PhD (2018 – 2024)

University of Massachusetts: Chan Medical School

Crista Johnson Agbakwu, MD (2018 – 2024)

Boston University: School of Public Health

Bernie Harlow, PhD (2018 – 2024)

University of Minnesota Staff

Amy Ash, BS, study coordinator (2018 – 2024)

Muzi Chen, PhD, data manager and analyst (2019 – 2022)

Kalthum Abdikeir, MPH, RN, research assistant (2021 – 2022)

Yiting Li, PhD, data manager and analyst (2022 – 2023)

Zamzam Dini, M.A, LAMFT, research assistant (2023)

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Contracted Artists

Anisa Hagi-Mohamed

Ashley Finch

Robert Kirby

Volunteers (many volunteers were students; degrees below are the degrees they had at the time of work)

Jacinta Anyanwu, B.A 2019

Sadiya Hassan, BSN ,2019

Hibak Roble, BSW, 2019

Jae Creger, B.A, 2022 – 2023

Kyra Kaczmarczik, B.S 2022-2023

Emma Weisner, B.S, 2023

Shreya Chanda, B.S, 2024

Contracted Translator

Lucky Omar, M.A

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