

**CARING FOR WOMEN AFFECTED BY
FEMALE GENITAL CUTTING:
STRIVING FOR HEALTH EQUITY**

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Thank you, Mary Malotky, MS, APRN, CNM,
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Caring for women with FGC challenges our current worldview and our systems

The screenshot shows a medical software interface for recording pelvic examination findings. The window title is "Pelvic". At the top, there are buttons for "Mark All Normal", "Clear", and "Mark Unanswered Normal". The interface is divided into two columns of findings, each with a file icon and several buttons representing different clinical observations.

Organ	Buttons
Vulva	Normal, Condyloma, Lesions
Vagina	Normal, Discharge, Inflammation
Cervix	Normal, Lesions, Inflammation
Uterus (wks)	[Input field]
Adnexa	Normal, Mass
Rectum	Normal, Abnormal
Spines	Average, Prominent, Blunt
Sacrum	Concave, Straight, Anterior
Subpubic Arch	Normal, Wide, Narrow
Diag. Conjugate	Not Done, Reached
(cm)	[Input field]
Pelvic Type	Gynecoid, Android, Platypelloid

At the bottom of the window, there are buttons for "Restore", "Close F9", and "Previous". A "Pregnancy Checklist" link is visible at the very bottom.

How would you answer this!
Who gets to define normal?



Outline

- Terminology
- FGC basics – where, why, how
- Complications of FGC
- Working with affected women to achieve optimal outcomes
- Clinical and cultural guidelines

Terminology

“FGM encompasses all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs whether for cultural or any other non-therapeutic reasons.”

World Health Organization, 1997

Terminology

- Terms
 - Female circumcision
 - Female genital mutilation
 - Female genital cutting
 - Client preference
- Philosophical and political dynamics

FGC Basics

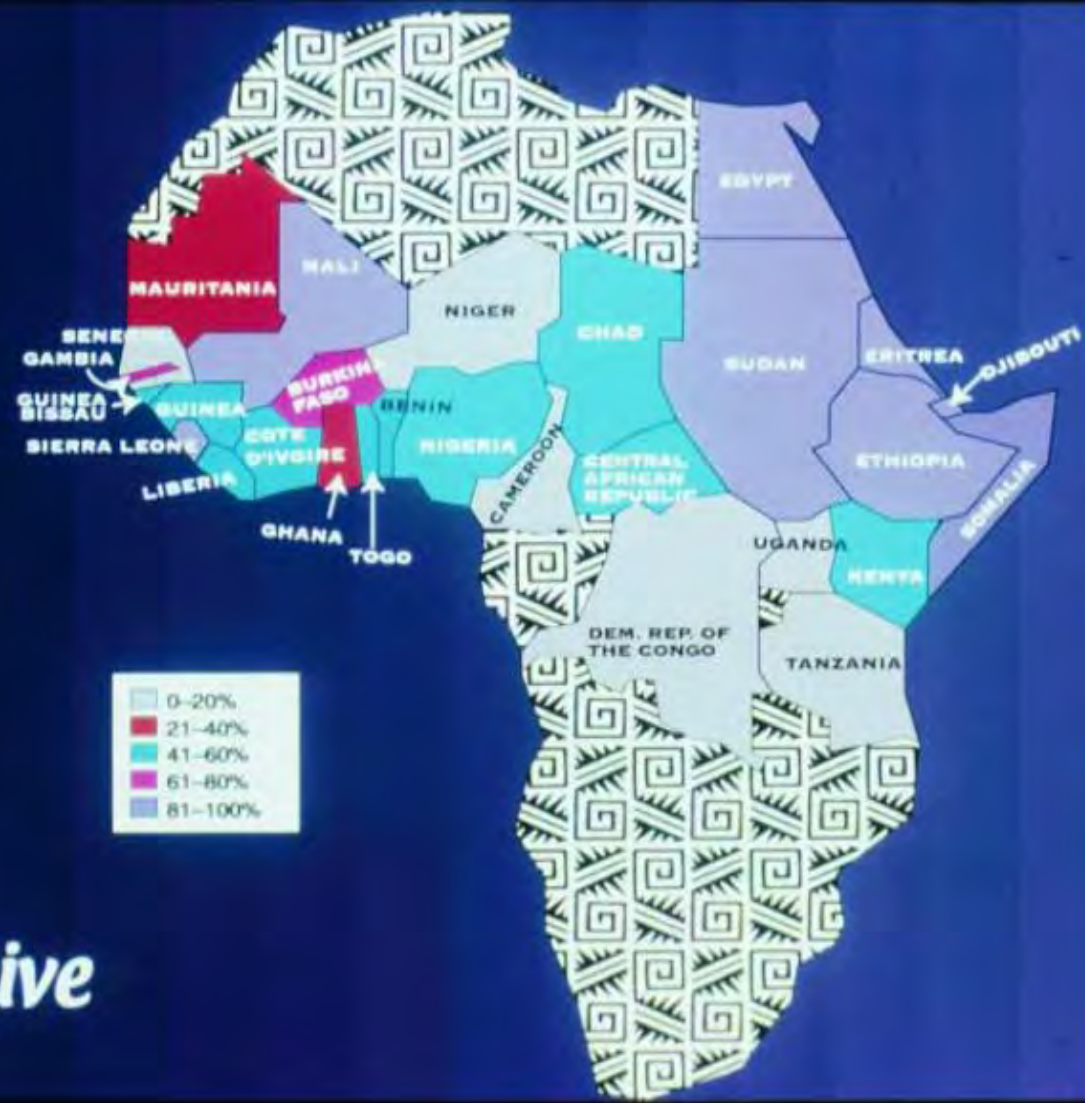
Background

- Practice origins
- History in Africa
- History in the West
- Increased international attention

Where?

- 28 African countries
- Some Middle Eastern and Southeast Asian communities
- Prevalence rates range 5-97%
- Rates often vary within a country
- Highest prevalence found in Djibouti, Egypt, Eritrea, Ethiopia, Mali, Somalia, Sudan

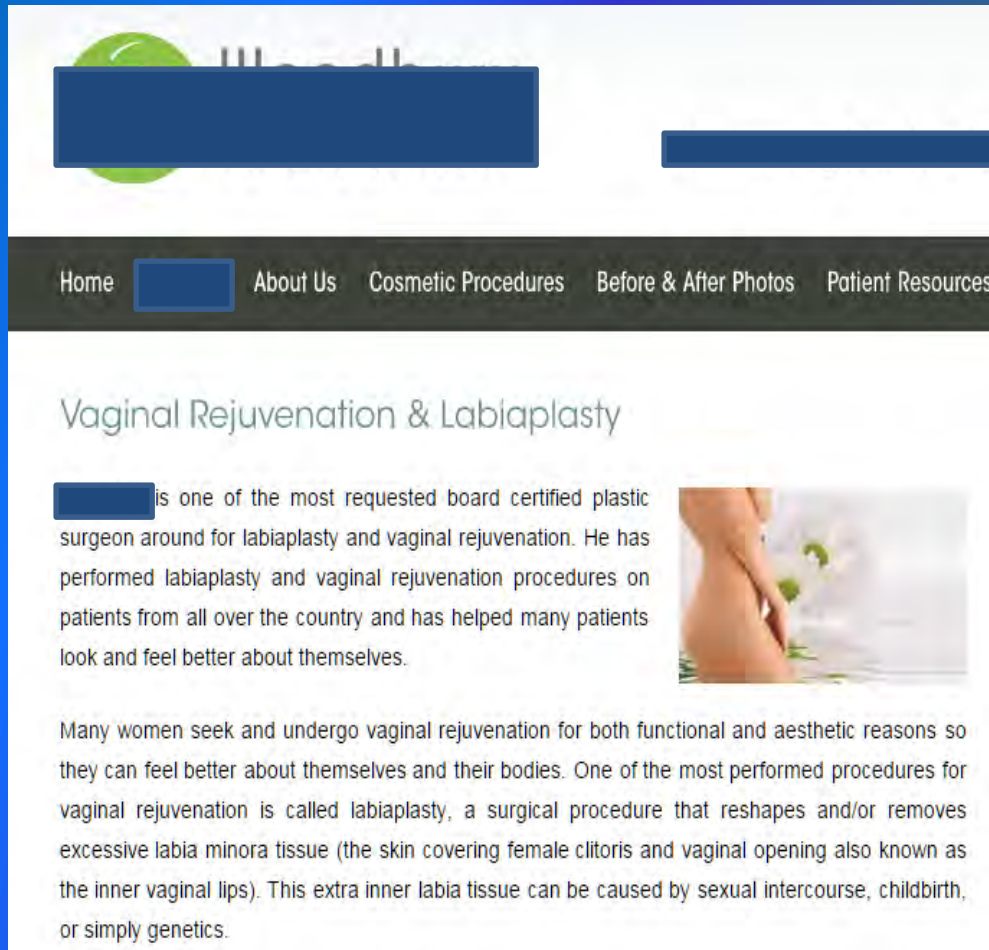
An African Perspective



Areas of affected women in the US



Remember the WHO definition?



The screenshot shows a website for a plastic surgeon. The header features a logo with a green circle and a silhouette of a city skyline. Below the logo is a dark navigation bar with the following links: Home, About Us, Cosmetic Procedures, Before & After Photos, and Patient Resources. The main content area is titled "Vaginal Rejuvenation & Labiaplasty". The text describes the surgeon as one of the most requested board certified plastic surgeons for these procedures. A small image shows a woman's lower body. The text continues to explain that many women seek these procedures for functional and aesthetic reasons, and that labiaplasty is a surgical procedure that reshapes and/or removes excessive labia minora tissue.

is one of the most requested board certified plastic surgeon around for labiaplasty and vaginal rejuvenation. He has performed labiaplasty and vaginal rejuvenation procedures on patients from all over the country and has helped many patients look and feel better about themselves.

Many women seek and undergo vaginal rejuvenation for both functional and aesthetic reasons so they can feel better about themselves and their bodies. One of the most performed procedures for vaginal rejuvenation is called labiaplasty, a surgical procedure that reshapes and/or removes excessive labia minora tissue (the skin covering female clitoris and vaginal opening also known as the inner vaginal lips). This extra inner labia tissue can be caused by sexual intercourse, childbirth, or simply genetics.



The photograph shows a sign for a cosmetic clinic. The sign is white with a teal header and footer. The text on the sign reads: "Complete Your Transformation With These Services". Below this is a list of services: HCG Weight Loss, Vanquish Body Contouring, Laser Skin Aesthetics, Botox/ Juvederm, and Vaginal Rejuvenation/ Labiaplasty. At the bottom of the sign, it says "Look Your Best. Feel Your Best." and "Schedule Today". The sign is located in a hallway with a store named "JOHNSTON & MURPHY" visible in the background.

Complete Your Transformation With These Services

- HCG Weight Loss
- Vanquish Body Contouring
- Laser Skin Aesthetics
- Botox/ Juvederm
- Vaginal Rejuvenation/ Labiaplasty

Look Your Best. Feel Your Best.

Schedule Today

Who? How?

- Practice crosses multiple boundaries
- Age at FGC varies; average 4-10 years old
- Practitioners vary from traditional excisors to trained surgeons
- Tools of the trade – consistent with practitioner
- Use of anesthesia and/or antibiotics

Why?

Myriad of motivations

- Religious
- Cultural
- Aesthetic
- “Necessity” – our version or theirs?



FGC Types

- Type I
Excision of the prepuce with or without excision of part or all of the clitoris
- Type II
Type I plus partial or total excision of labia minora
- Type III
Excision of part or all of external genitalia and stitching or narrowing of vaginal opening (infibulation) (15%)
- Type IV
Unclassified, includes a variety of less common procedures

World Health Organization, 1998

Type II – Area Cut



Type III – Area cut and infibulated



Type III – Area after infibulation



Contributing factors to health inequity

- Increased immigration of affected women
- Lack of information in healthcare curricula
- Poor quality of available literature
- Lack of national or local strategies
- Reinventing the wheel

Complications

Complications

Consistently reported FGC sequelae

- Dysmenorrhea
- Chronic vaginitis
- Urinary problems
- Scars & cysts
- Dyspareunia, apareunia, infertility
- Intrapartum problems

Obermeyer, 1999

Primary care and prenatal concerns

- Vulvar cysts
- Sebaceous and inclusion cysts
- Obstructive keloids
- Neuroma
- Incontinence
- Vaginal obstruction
- Fertility concerns

Primary care and perinatal issues

- Vulvar cysts
- Sebaceous and inclusion cysts
- Obstructive keloids
- Neuroma
- Incontinence
- Vaginal obstruction
- Fertility concerns

Toubia, 1999

Working with affected women:

How a cultural approach
can guide clinical actions
for the best outcomes

Cultural Competency Review

- **Humility**

Opportunity to learn about their culture and view of health as well as to teach about ours

- **Honesty and Respect**

Consider immigrants life experiences which are so much different (and more difficult) than our own.

- **Humor**

A great tool for building bridges, and eventually, trust

- **Flexibility**

Time, tasks, priorities

Misconceptions and Assumptions

(Our patients)

During Pregnancy

- Activity
- Diet and weight gain
- Blood draws
- Prenatal care

During Labor and Birth

- Pain Medications
- Fetal/uterine Monitoring
- Vaginal birth vs. Cesarean
- Provider ignorance/incompetence

(The health care provider)

During Pregnancy

- Knowledge of anatomy and physiology
- That we are trustworthy
- We know more than they do

During Labor and Birth

- Medical interventions represent “advanced” L & D
- We can spare them from a difficult experience
- They are arrogant or belligerent

The Big Hurdle

Muslim (Somali) Culture

Value Acquiescence to Allah as supreme authority

American Culture

Value the supremacy of the individual

The most difficult healthcare decisions and conflicts swirl around these philosophical differences

When to address the topic of FGC

Deinfibulation and repair counseling:

- Annual visit
- Serendipitous encounters
- Problem visits
- As needed unless the woman communicates otherwise

Prenatal Education:

- Opportunity to explore feelings related to first experience of FGC and how those feelings may impact her labor.
- Re: deinfibulation. Give specific details on timing and procedure. Her questions are, “How is my baby going to get out?” and “When are you going to do it?”
- Re: repair. Determine her preference and provider preference. Education. (Is a referral necessary?)

Tips for opening the dialog

- Name it!
- Acknowledge prevalence of FGC and that you know she may not have talked about it before
- Reassure woman of your competency and comfort in dealing with FGC
- Be open to discussion at any time
- Ask open-ended questions



History and assessment

- Multiple visits and building trust will yield best histories
- Identify cutting type if possible
- Inquire about specific problems
 - Urinary complaints
 - Painful sex

History and assessment

Sometimes it's best to leave it alone:

- Client's FGC status may not be a concern for her
- Client may be experiencing physical and/or emotional trauma related to displacement and new environment
- Do not neglect other pressing concerns (Maslow's hierarchy of needs)

History and assessment

- Identify potential need for support if FGC experience was negative for her
- Desire/need for support may vary depending on population:
 - US-raised, school age or adult
 - Nullipara vs. Multipara
 - Recent immigrant
- Local support: Everyday Miracles

History and assessment

- Assess her knowledge about her original anatomy and her status now (visual aids/pictures)
- Sensitivity to the nature of *her* FGC experience

Practice implications

- Discuss how her status may impact ob/gyn health (pictures, teaching aids)
- Caution and explanation prior to invasive procedures
- Don't ask patient to completely disrobe
- Warn patient before taking several tubes of blood

Practice implications

Speculum and bimanual exam challenges and solutions:

- Speculum choice
- Pap smear samples
- Infection work-up
- When to defer or abandon exam effort

Practice implications

- Diagnosis of UTIs
 - No such thing as a “clean catch”
- Sexuality concerns
 - apareunia
 - dyspareunia
 - lack of sexual enjoyment
 - infertility

2001 Canadian study
432 Somali women interviewed
96% Type III FGC

- 78% painful intercourse
- 30% do not enjoy sex
- 37% indifferent
- 20% quite enjoy sex
- 3% enjoy sex very much

Sex is associated with...

- 69% pain
- 30% fear
- 27% endurance

Chalmers, et al.

Deinfibulation

Toubia & Nour recommendations:

- Pre-coitus
- Second/Third trimester
 - Do you need a cathed urine sample?
 - Is client at high risk for difficult emotional birth experience secondary to infibulation experience?
 - Other complications requiring intervention?
- Second stage

Practice implications

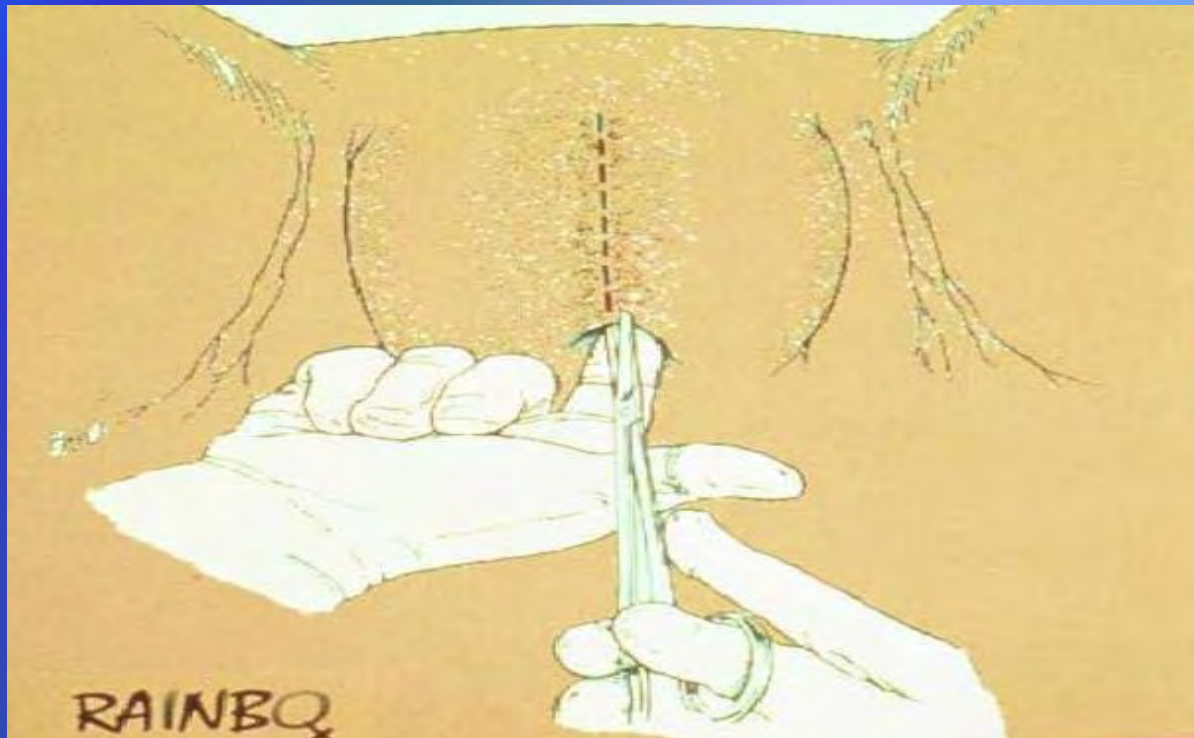
During the birth process:

- Labor and birth as a cathartic
- Role of pain medication- Medical movement toward epidurals: pros/cons
- Provider's facilitative, supportive role
- Support for provider (unfamiliar with deinfibulation and/or repair)

Deinfibulation

Local or spinal anesthesia (Toubia & Nour)

Technique:



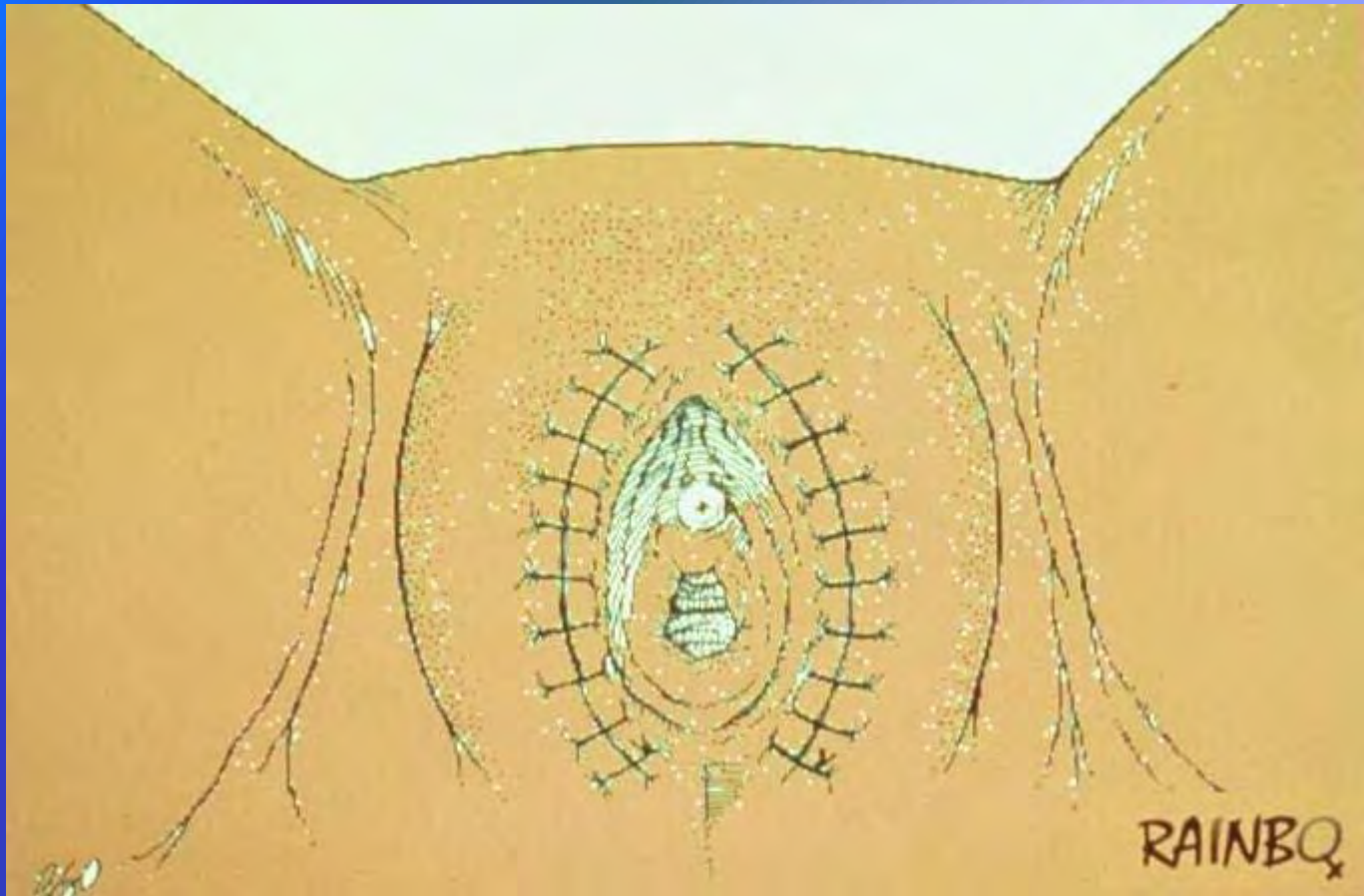
Repairs

Handling requests:

- Determine plan prenatally & document clearly
- Avoid surprise or awkward moments
- Clarify provider intentions
- Family member input – consider cultural differences
- What to do if you've never met her before
ASK HER!
- Leaving woman open/unrepaired is *not* a passive approach
Counsel patient on how things may feel different!

Repairs

Technique



(Toubia)

Practice Implications

- Being aware of your values/biases/boundaries:
- HCMC press spokesperson: "This isn't about respecting someone's culture – it's about being complicit in mutilating women."
- At the same time, the HCMC Nurse Midwife and OB/GYN services were repairing per woman's request



Well Child/Postpartum

- Counseling about children's FGC status
 - Influence of your care for the mother
 - Word gets out to community
 - Responsibility to educate parents about laws
 - Provide written information (RAINBO pamphlets)
 - Can be incorporated in to PNC counseling
- Child spacing vs. Birth control
 - Neighborhood Improvement Project

Provider resources

- Literature – quality and perspective
- References
 - ACOG slide presentation (www.acog.org)
 - RAINBO (www.rainbo.org)
 - Caring for Women with Circumcision: A Technical Manual for Health Care Providers (Toubia, N)
 - slide presentation (www.rainbo.org)
 - WHO (www.who.org)
 - Policy information
 - Publications with care recommendations

Provider resources

- Specialty clinics (MN, Boston, San Diego, UK)
- Department of Health and Human Services
 - Office for Women's Health (regional)
 - FGC Working Group (federal)
- Future possibilities
 - On-line information exchange, forum to ask experienced colleagues for advice
 - Website for providers and clients to share information

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