

When “Women’s Health” Is Not Inclusive Enough: In Search of Reproductive Justice

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Abstract

When the singular story of “Women’s Health” is the norm, the stories of transgender, queer, non-white patients can be overlooked, misunderstood, or silenced if we do not listen carefully. Three composite stories from a free, comprehensive, primary care clinic for people without health insurance highlight scenarios where providers overlooked patients’ voices. We reflect on how these composites illuminated our assumptions and biases in the field of sexual and reproductive health (SRH), where the narratives of misogyny and preventing pregnancy are dominant. We turn to the construct of reproductive justice to create an inclusive and affirming culture of care. Each reflection led to practice, education, and policy changes within our clinic setting, and these changes center and empower our most marginalized patients as part of a life-long endeavor toward cultural humility.

Introduction

When you research reproductive health centers, you find clinics whose names embody the centrality of womanhood in reproductive healthcare: *All Women’s Health Center*, *Comprehensive Women’s Health*, *A Woman’s Answer Medical Clinic*, *Women’s Health Group*, *Women’s Care*. What is “Women’s Health?” Is this an embracing term, or does it silence the voices of the marginalized? Who does “Women’s Health” include, and who does it exclude? In 1851, abolitionist and women’s rights activist Sojourner Truth asked, “Ain’t I a woman?” because the label of “woman” historically excluded those disempowered by systems of oppression (Truth). The figurative “woman” in the single story of “Women’s Health” is a white, heterosexual, cisgender, female; however, there are many people seeking reproductive health care who do not hold these privileged identities. In order to challenge the underlying racist, heteronormative, cisgendered assumptions that create the single story of “Women’s Health,” we must reconfigure our understanding of how we conceptualize and practice sexual and reproductive health (SRH) to treat those that ask, “Ain’t I worthy of care?”

Clinicians and public health professionals are trained and socialized to provide care in ways that are sometimes incongruent with how people experience and explain illness (Kleinman et al. 140-42). The United States is an increasingly diverse country, with recent census estimates projecting a decline in the nation’s white population - a finding without precedent in history (Frey 1-2) - and an increase in the percentage of Americans identifying as a sexual and/or gender minority (Jones 1). Despite these changing demographics, the education of health professionals does not effectively prepare new graduates to provide care to persons that are not white, middle class, cisgender, and heterosexual (Röndahl 347-48). Patient-centered, inclusive care is built on shared decision-making, but it can be difficult to move

beyond a prescriptive, paternalistic relationship where the “voice of medicine” (Mishler et al. 329) remains dominant in the patient-provider encounter (Nimmon and Stenfors-Hayes 6-7). In many situations, “patients’ voices are not heard, and their own understanding of their problems may be ignored...They [patients, especially those with marginalized identities,] are frequently not recognized as competent reporters” (Mishler et al. 334). Their voices are misheard, ignored, or silenced.

It is easy for providers to lose sight of the personal narrative that accompanies each person entering the health care system. The biomedical model that “treats health as the absence of disease or a physiologic abnormality within the body” (Jaini and Lee 50) has historically characterized Western medicine. This model relies upon objectivity, categorization, and reductionism of individuals to biologic processes (Borrell-Carrió et al. 577). Its practice can pathologize and disembodify patients, and its approach to medical care often overlooks the psychosocial and spiritual factors that can affect illness and health as significantly as physiologic factors (Borrell-Carrió et al. 578; Rozanski et al. 2208-09; Anni et al. 7-8). When the lived experiences of patients are not those of the majority, their stories may be overlooked, misunderstood, or silenced if we do not listen carefully. Further, patients who have had reductionist, negative, or paternalistic experiences with the health system may be less likely to engage in preventive health services or health care (Agénor et al. 728-31; Diamant et al. 2734-35; Doyle et al. 4-5; O'Malley et al. 782-83). This issue is intensified within the field of reproductive health due to the historical marginalization of women and those assigned female at birth (Ross and Solinger, 54-57; O'Malley et al. 782-83)

We at the Mobile Outreach Clinic seek to center the most marginalized patients by “recognizing, absorbing, interpreting, and being moved by” their stories (Charon 4). The Mobile Outreach Clinic (MOC) at the University of Florida is a free, comprehensive, primary care clinic that serves nearly 2,000 uninsured and underinsured patients annually from a retrofitted Bluebird bus. Health disparities describe the disproportionate burden of morbidity and early mortality found among non-majority populations [whether by race, ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location (US Dept. of Health and Human Services)], and they characterize those we serve. Most of our patients identify as members of racial and ethnic minority communities, and close to 20 percent (18.67%) of active patients experience language barriers to care since Spanish is their primary language. Our health providers screen for and address the social determinants of health (SDOH) and over the last decade, the MOC has become a trusted provider of best practice, low-barrier medical services to the residents of underserved neighborhoods.

As an interdisciplinary team, our desire to improve the quality of care and deliver “more than women’s health care” has changed our definition of women’s health, our SRH clinic care, and our approach to public health research. Drawing on the stories of our patients and the transformative outcomes of our quality improvement activities, we lift up three composite narratives and share how they challenged our assumptions about gender inclusivity, patient health goals, and the role of reproductive health care. Reflection on our patients’ experiences prompted structural changes to address our newly-recognized biases. Our new “Reproductive Justice Initiative” provides gender-inclusive and culturally sensitive health care that prioritizes education and shared-decision making.

Methods: Patient Composites and Provider Reflections

In flipping the power dynamic and centering our patients, we focused on their lived experiences instead of projecting our viewpoints and biases. We prioritized narrative knowledge, “a rich, resonant grasp of another person’s situation as it unfolds in time” (Charon 9). Centering this narrative knowledge, we saw our patients “whole—with their bodies, lives, families, beliefs, values, histories, hopes for the future” (Charon 12), and their stories transformed our practice. The stories of our patients sent us on a journey of humility, reflection, imagination, and growth. We created composite narrative examples (i.e. a combination of patient experiences to tell a single story) from MOC that emerged from our mission to center the most marginalized patients, including our mistakes when we missed the mark. We use composites to maintain patient anonymity and privacy, which is of paramount importance in working with our vulnerable population. These stories draw on combinations of patient encounters to communicate themes of our patients’ stories and our reflections on our care. We lift up three composite narratives to show our oversights when our biased lenses tainted our vision and compelled us to adjust our practices.

Composite 1: “Women’s Health” and Assumptions About Gender Identity

After examining the patient, I left the room so the care coordinator could complete the questions that MOC utilizes to screen for and address the SDOH. As I reflected on those important questions that targeted the “non-medical” aspects of life that influence one’s health, I returned to discover that the care coordinator was now using a different gender pronoun and first name than those I had used with this patient. I was stunned! I had provided care to this patient for the last year but it never crossed my mind to ask about gender, and furthermore, the patient never brought it up. For how many other patients did I miss this crucial piece of information? Why had I displaced the responsibility of discussing gender identity on the patient? What else could I have overlooked when delivering “women’s health” care?

Composite 2: LARC-First, Amenorrhea, and Assumptions About Health Goals

I examined the patient, a LatinX woman who came to clinic for a Long-Acting Reversible Contraception (LARC) removal because it had induced amenorrhea, headaches, and “mal estar,” or a general state of feeling unwell or ill. The absence of menstruation is not an uncommon side effect after LARC insertion, but as a LatinX immigrant myself, I understood the culturally significant role of menstruation on one’s identity as a woman in LatinX communities. I listened as she described her desire for menstruation because it made her feel “healthy,” believing her body was purging “old” blood that accumulated throughout the month. When debriefing with the non-LatinX provider following the encounter, they expressed frustration at this request to remove the LARC for “no reason.” I felt stunned by their lack of compassion; not only was this patient experiencing the observable symptoms of amenorrhea and headaches, but her culture-bound concern of “mal estar” was just as substantial to her experience of her contraception. We eventually removed the LARC device, but I began to question our LARC-first approach. Is a “LARC-first approach” the best practice if it does not respond with cultural sensitivity to patients’ health goals? What else should I have asked about her health goals when she first approached us for contraception?

Composite 3: Public Health Research and Assumptions About Reproductive Health Care

I began leading an IRB-approved, de-identified, descriptive research study to identify our patients' interests, beliefs and needs regarding SRH services, with the goal of improving clinic processes and services. We incorporated questions about cultural identity and reproductive justice principles into the survey and were approved to distribute it to any interested "women of childbearing age" attending our clinic. It was exhausting to cultivate a questionnaire that embodied these principles of health equity we hold so dear. However, we soon realized that despite our attention to detail, our carefully constructed survey contained a glaring error: not all people with a uterus identify as a woman. I realized that people access SRH services for a variety of reasons beyond just the prevention of pregnancy, and I did not even consider how gender could affect one's preference for sexual and reproductive health services. How had we allowed our cis-normative views to project onto our patient's identities? What crucial information would our research have overlooked by beginning with inadequate questions?

Lessons Learned

We discovered that our assumptions clouded our care. By organizing a "Women's Clinic," and surveying patients about their preferences for "Women's Health," we assumed that only those who identify as women seek reproductive health care. By strictly adhering to a LARC-first approach to SRH (Committee on Practice Bulletins-Gynecology), we placed paramount value on contraceptive efficacy in assuming that every patient's primary concern was pregnancy prevention. By neglecting to ask patients about their identities, we allowed the single story of "Women's Health" to pervade our clinical direction. We made assumptions, over and over, and they corrupted our provision of health care. Our patients' goals and expectations were not the same as our own.

When we learned how to hear our patients' stories, we discovered a broad spectrum of individual pregnancy plans, contraceptive preferences, and overall definitions of sexual and reproductive wellbeing. We adopted an intersectional framework to examine the relationship between our patients' socially marginalized identities and power, and we turned to the construct of reproductive justice to find language to frame our experiences and make lived experiences visible (Ross and Solinger 10-17; Abrams et al. 2). Since the power of cultural and structural influences on the patient cannot be ranked by importance, we must use intersectionality to determine what matters to the patient at that time (Bowleg 1271-72). Intersectional framework brought clarity to the matrix of multiple oppressions confronting our patients and challenged us to re-define our concept of patient empowerment (Abrams et al. 2; Kelly et al. 5-6; Wilson et al. 9-10). Our attention to intersectionality led us to reproductive justice.

The term "Reproductive Justice" was coined in 1994 by a group of women known as the Women of African Descent for Reproductive Health. Their belief system was built on years of community organizing by indigenous communities, people of color, and transgender persons fighting for equal voice, rights and safety (Sistersong: Women of Color Reproductive Justice Collective). SisterSong, a multi-ethnic organization that is a pillar of Reproductive Justice in Atlanta, GA, advanced the field by creating a conceptual framework focused on access to holistic equitable care. Reproductive justice strives to combine the fields of reproductive rights, social justice, and reproductive health to further the belief that the human right to maintain personal bodily autonomy, "to have children, to not have children, and to

parent the children we have in safe and sustainable communities," is attainable for all (Ross and Solinger 9). Through the comprehensive schema of Reproductive Justice, patients must be centered in their care with a provider that is able to recognize the multifaceted influences on one's health and wellbeing (Kelly et al. 5-6).

Historically, the field of reproductive health has centered contraception and pregnancy avoidance as its primary health goal. Within our own clinic, we heralded LARC as a primary and universal intervention, so much so that when a patient requested it be removed, our team hesitated because it was functioning well in preventing pregnancy. Indeed, SRH scholars are now debating the merits and utility of the long-accepted metric of "unintended pregnancy" (Potter et al. 2-3). Noting methodological and conceptual flaws in the classification of "unintended pregnancy," authors Joseph Potter, et al. (2) explain the natural public health "answer" to the flawed question of "How do we prevent unintended pregnancy?" is widespread use of contraceptive methods with the highest efficacy (i.e. LARC). Instead of making assumptions based upon privilege and power, we should be asking, "How can I best provide for my patients' health goals?" The research and clinical focus should be full reproductive autonomy, not just efficacy. If we convince a patient to use a contraceptive method they did not prefer, we are taking away their autonomy. Even if an 'unwanted pregnancy' is averted, we have failed our patients by reducing their agency in creating and achieving their health goals.

To create an inclusive culture of care with policies and practices that affirm all patients, we normalized questions about gender and culture, understanding that these aspects of identity are inextricably bound to one's health and how one experiences disease and illness (Kleinman et al. 144). As public health researchers and health care providers, we became critical of the questions we formulated, because answers are catalysts that alter public policy and shape clinical practice. We humbled ourselves as practitioners and "said [we] do not know when [we] truly do not know and [we] search for and access resources that enhance care of [our] patient as well as [our] future practice" (Tervalon and Murray-Garcia 119). Inclusive reproductive health care emerges out of a focus on a patient's whole person, including their personal bodily autonomy and their overall sexual and reproductive wellbeing. To provide such care, we must humble ourselves and look for the lessons our patients desperately seek to share.

Toward a Vision of Equity in Sexual and Reproductive Health Services

Our experiences laid bare the fact that our assumptions about the needs of our SRH patients were misguided, but this reflection was only the first step. Cultural humility, coined in 1998 by Melanie Tervalon and Jann Murray-Garcia, is a three-part process that prioritizes self-reflection and self-critique as practitioners, flips the power dynamic of provider-patient interactions through patient-focused and community-based care, and holds institutions accountable to injustices (Tervalon and Murray-Garcia 118). In listening to our patients' stories and recognizing our biases and oversights, we engaged in self-reflection that led to subsequent changes in behavior, practice, and policy to address inequity. In our reflections on the stories of our patients and the principles of reproductive justice, we created policy and programmatic changes to create a more equitable reproductive health care system.

Women's Health to Gender-Inclusive Health Care

The first change was our name. We converted our “Women’s Health Clinic” to the “Reproductive Justice Initiative” to honor the reality that not all who seek reproductive health care identify as women. We strive to be a place where people of all gender identities can find solace and support in a system of healthcare that has not always been a safe space for transgender patients. We want all who desire reproductive health care to feel seen and respected.

Prior to our institutional reckoning, questions about gender identity in our clinic setting were being asked intermittently at best. We surveyed MOC clinician’s beliefs and practices related to LGBTQ+ affirming care to better identify areas for improvement, and from this research, we adjusted and implemented new clinic policies: we reduced cis- and hetero-normative language in our paperwork, patient-provider conversations, and educational materials; we listed preferred gender identities on care coordinators’ nametags; we included gender identity as an intake question asked of every patient; and we organized our electronic medical record system to include a spectrum of gender identities. Through these changes, we created a more gender-inclusive health care system that was accountable to our patients’ experiences.

LARC-First to Patient-Autonomy-Always

Instead of a one-size-fits-all “LARC-First” approach, our SRH services evolved to be sensitive to the historical context of injustices suffered by marginalized communities. We structured our clinic using reproductive justice as a framework that aims to center the patient in their care (Ross and Solinger 64, 239).

We created a seven module, patient-centered Contraception Counseling Training Program to teach shared-decision making within the historical and social contexts in which our patients make decisions. Figure 1 demonstrates the content of each module (Nall 244). By featuring shared-decision making as the core of care, providers “relinquish the role of expert to the patient, becoming the student of the patient with a conviction and explicit expression of the patient’s potential to be a capable and full partner in the therapeutic alliance” (Tervalon and Murray-Garcia 121). Activated patients, or those who understand their role in the care process and feel capable of fulfilling it, experience better health outcomes because they are empowered with the knowledge, skills and confidence needed to manage their health (Greene and Hibbard 524-25). This training program serves two functions: 1) it “activates patients” and increases clinic efficiency by empowering interdisciplinary MOC team members to assess patients’ reproductive goals through shared-decision making, and 2) it teaches health science and pre-health students (our next generation of clinicians) that RJ principles must be central to the provision of respectful and high-quality SRH care. In other words, we adjusted our SRH approach away from a focus on pregnancy prevention and contraceptive efficacy toward a model that centers and emphasizes patient autonomy and shared-decision making.

Acknowledging the longstanding “stigmatization of fertility among young women, poor women, and woman of color” (Potter, et al. 3), we are working to make our preconception and prenatal services more robust to ensure that patients desiring pregnancy are well supported. MOC’s work toward this goal has expanded beyond its initial reach and has resulted in the development of a free, culturally-sensitive, prenatal clinic for pregnant

immigrants, many of whom are ineligible for Florida Medicaid due to their immigration status. In community-based care, physicians “identify, believe in, and build on the assets and adaptive strengths of communities and their often-disenfranchised members” (Tervalon and Murray-Garcia 122). In organizing such clinics, we seek to activate patients, especially those who have been stigmatized or denied health care, and help them realize physical, mental, social, and sexual well-being.

Patient Assumptions to Patient Guidance

When we examined ourselves through the lens of reproductive justice, it became clear that our personal assumptions and biases as providers clouded our clinical judgment and our approach to research. Self-reflection and observation of power dynamics at all levels of health care, including the investigation of research, helped us recognize our position of privilege as public health researchers. These processes are lifelong, and while we made major steps in this reckoning, we created structures to encourage continued self and structural reflection.

To confront these influences and hold ourselves accountable to our patients’ experiences, we are amplifying our patients’ voices. MOC is developing a patient advisory council to empower a diverse group of patients to provide input on MOC policies and procedures. The first of these quarterly patient advisory council meetings will be held in the fall of 2021 with a diverse group of approximately 10 patients. Care was taken to ensure that the location of the council meeting is convenient, safe, and socially distanced for all attendees. The meeting will focus around a moderated, structured discussion on ways to improve the care provided at MOC, with considerable time allotted for all attendees to respond to open-ended questions and make suggestions for improvement. To extend our desire to increase diverse voices, we have been increasing diversity on our staff and volunteer team; we want our leadership team to reflect the diversity of our patient population. It is our hope that this amplification of diverse voices will improve the services we provide and the research questions we formulate.

Conclusion

Out of our research, our patients’ stories, and our mistakes, we reconstructed our provision of SRH care to be more inclusive and person-centered. Informed by the reproductive justice movement, we converted our “Women’s Health Clinic” to the “Reproductive Justice Initiative” and added services to activate and empower patients through education and shared-decision making. Reproductive justice extends culturally sensitive, patient centered and gender-affirming sexual and reproductive care to transgender men and women, non-binary, and gender non-conforming persons of all cultural and socioeconomic backgrounds; it normalizes sexual autonomy and gender freedom, and reduces intersectional oppression. When care is provided in an environment of dignity and respect, shame fades, and a strong therapeutic relationship can form (Ross and Solinger 68-69).

These small steps are huge improvements in our provision of care to our most marginalized patients, and we expect to find oversights as we continue to investigate our assumptions about reproductive health care. The development of cultural humility is a life-long endeavor. Inclusive health care and culturally integrated clinical practice are “defined not by a discrete endpoint but as a commitment and active engagement in a lifelong process that

individuals enter into on an ongoing basis with patients, communities, colleagues, and themselves” (Tervalon and Murray Garcia 118). We are constantly seeking adaptations to be more respectful and intentional about experiences of marginalization and oppression, and we recognize that there is always work to be done in creating a more just, more inclusive health care system. Our goal is to provide equitable SRH care and perform public health research that promotes reproductive autonomy and gender freedom. We hope that in centering the most marginalized patients, we can create better health outcomes for patients on their own terms and in sharing their stories and our listening, other clinics and providers can do the same.

Module 1: Background

- Epidemiology of unintended pregnancy
- Role of contraception
- Barriers to contraceptive access
- Assessing Social Determinants of Health (SDOH)

Module 2: Program Aims

- To build an infrastructure that allows for same-day access to desired SRH services by improving clinic flow and sustainability
- To increase patient self-efficacy and reproductive autonomy by providing education using the Reproductive Justice framework
- To train the next generation of healthcare providers to better understand the historical and social context that influences the health behaviors of their patients

Module 3: Reproductive Justice Framework

- History of SRH and reproductive injustices in the United States
- LGBTQ+ inclusive care

Module 4: Patient-Centered Shared-Decision Making Counseling with Tiered Contraception Counseling

- What is shared decision making?
- Tiered contraceptive counseling
- Using both frameworks to provide best practice care

Module 5: Contraceptive Method Overview

- Progesterone IUD
- Copper IUD
- Contraceptive implant
- Depo-Provera
- The ring, the patch, the pill
- Barrier methods

Module 6: Providing Contraceptive Counseling at the Mobile Outreach Clinic (MOC)

- MOC flow
- Counselor role and expectations

Module 7: Case Studies

- Patient with contraindications to estrogen
- Nulliparous young adult patient
- Transgender male patient seeking amenorrhea

Figure 1: Curriculum for MOC Contraception Counseling Training Program

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