FEMINIST AND NARRATIVE ETHICS: DECONSTRUCTING AND REBUILDING AN ETHICAL FRAMEWORK FOR INCLUSION

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For most of history, Anonymous was a woman.

— Virginia Woolf —

AZ QUOTES

LEARNING OBJECTIVES:

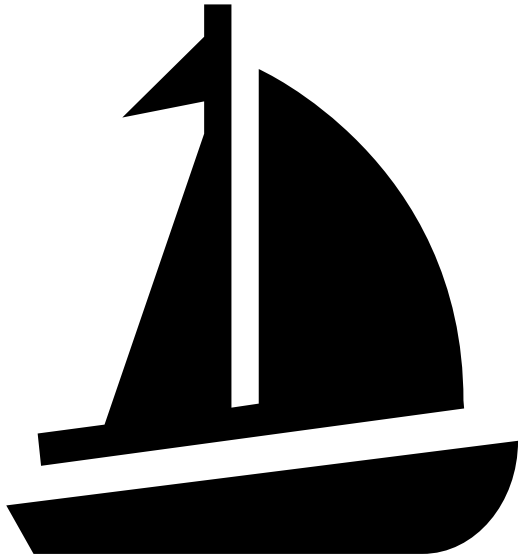
1. Explore feminist and narrative ethics as alternatives to dominant bioethical models, focusing on power dynamics and marginalized voices.

2. Analyze how power and privilege shape ethical decision-making in healthcare.

3. Understand the ethical importance of storytelling and lived experiences.

4. Discuss prioritizing inclusion, relational autonomy, and justice to ensure healthcare practices are equitable, culturally safe, and reflective of diverse.

ETHICS: FROM COULD TO SHOULD (THE TRADITIONAL MODEL)



COULD **SHOULD**

Political Power | Financial Power | Cultural Power | Academic Power | Narrative Power | Spiritual Power

THE DOMINANT BIOETHICAL MODEL:

THE 'THEORETICAL-JUDICIAL MODEL' OF MORAL PHILOSOPHY

MARGARET URBAN WALKER

- Traditional Western/Eurocentric moral philosophy (we are familiar with).
- Universal, generalizable rules and principles aka the "Principle Based Ethics" Model
- THE AUTONOMOUS MAN: Assumes Power/Privilege
  - Financial
  - Political
  - Cultural
  - Spiritual
  - Narrative
- COULD
- Exclude *'extraneous' factors* such as special relationships that might cause a person to act *irrationally* and *external barriers* or considerations that impact the way people are forced to navigate the world.
- Non-relational and based on privilege

Urban Walker M. *Moral Understandings: A Feminist Study In Ethics*. Second. New York: Oxford University Press; 200

I'M NOT IMMANUEL KANT, PLATO OR ARISTOTLE…

There is one right answer

If you could remove all of these 'extraneous factor' that everyone would come to the same conclusion/answer

Universal, generalizable principles/guidelines to make decisions. An equation you can use.

This assumes we have the same access to resources, support systems, the same things are important to us as the 'Autonomous (white, straight, wealthy) man

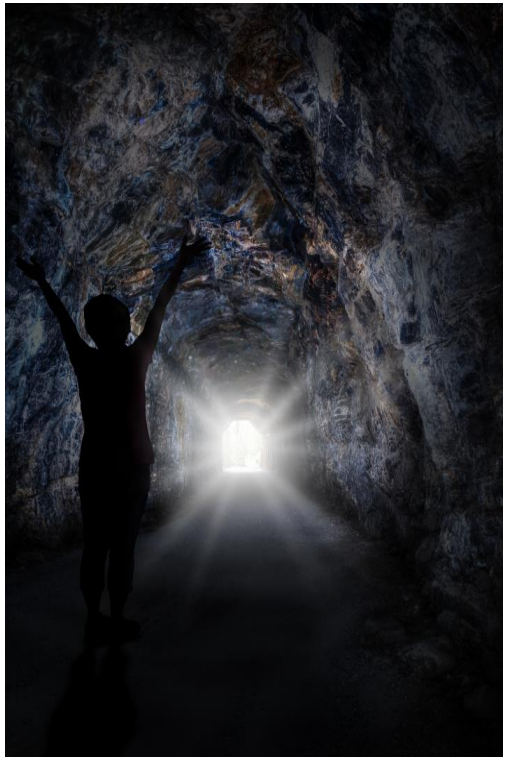
Over history, in medical decision making, it was the white, male, doctor that was determining what was right for their patients that may have been a women, POC, queer, disabled, impoverished…

This isn't true – my reality is not your reality and the what is right for me isn't right for everyone

The only way you can truly come to that conclusion is through significant privilege

That's not my truth

This assumes that male knowledge, male decision-makers get to determine what was right and wrong.



Life is Messy

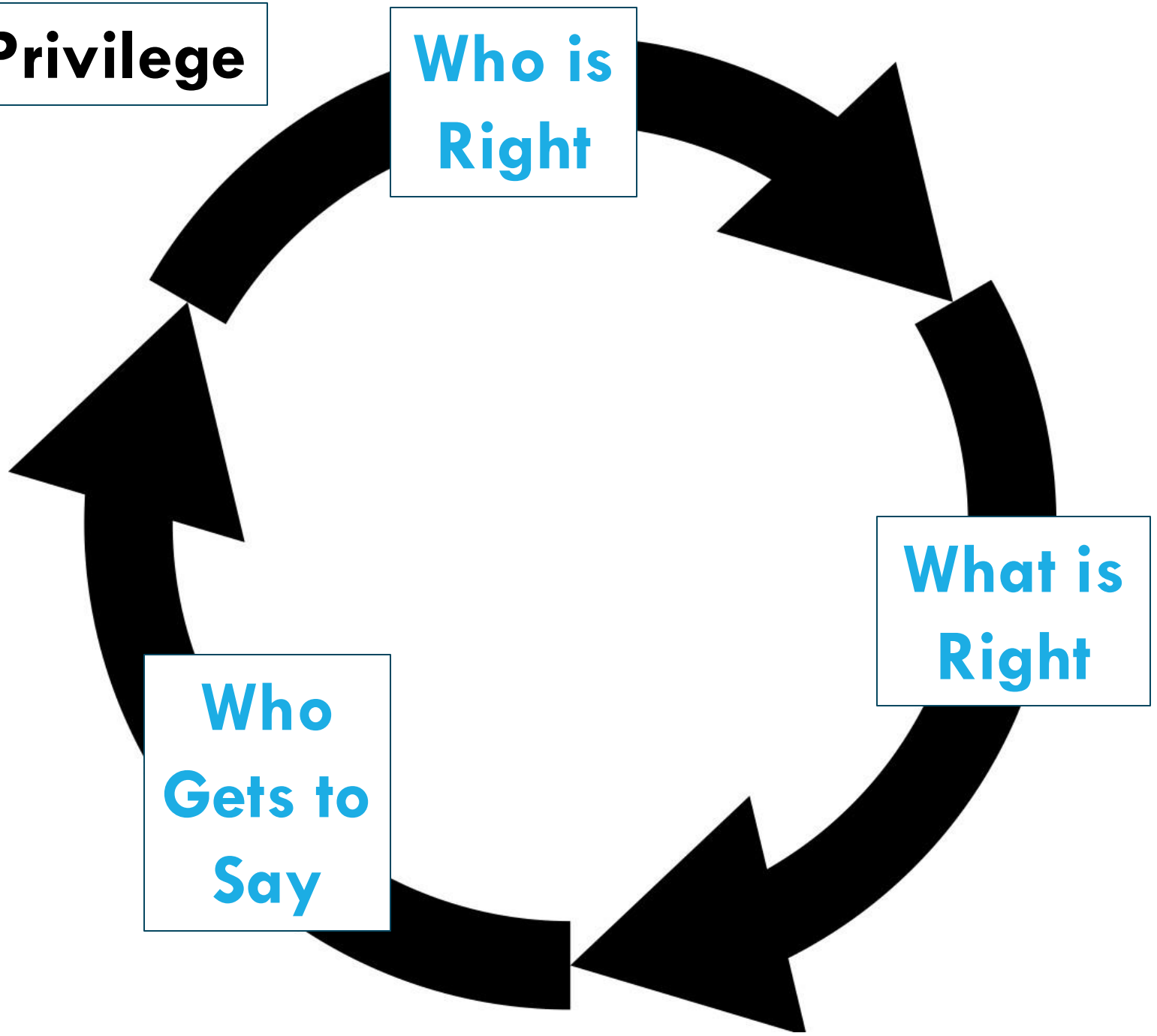
Why don't we consider that (enough)?

WHO HOLDS THE POWER TO PRODUCE AND TELL KNOWLEDGE AND TRUTH?

Feminist lens: "Who knows? and Who gets to say?"

Urban Walker M. *Moral Understandings: A Feminist Study In Ethics*. Second. New York: Oxford University Press; 200

Power and Privilege



Power Is…

"'Who knows?' and 'Who gets to say?'" (Margaret Urban Walker)

- "the ability to take part in whatever discourse is necessary to action and the right to have one's part matter."[54]
- "described as asymmetric control of resources in social relations, or a more diffuse force that flows through all interactions, generatively shaping individuals by, among other things, impacting their perception of truth and knowledge."[55]

"Not everyone is allowed or enabled to tell just any life (or other) story. The stuff of lives to be told, the discursive means available for telling them, and the credibility of storytellers are apt to differ along familiar lines of class, gender, and race, and perhaps along other lines, even rather local ones, as well."[40] (P.132)

The narrative that has dominance is a function of the power reflecting the social location and privilege of those who construct the narrative.

KNOWLEDGE PRODUCTION — DETERMINING WHAT ARE FACTS, WHAT IS TRUE, WHAT IS 'RIGHT' AND WHO GETS TO KNOW?

Who Knows and Who Gets to Say? Knowledge Production – The Professionalization of Medicine (and marginalization of women)

- **Who Knows? (Feminists: WHO IS LEFT OUT?)**
  - Who gets to know?
  - Who chooses what knowledge matters?
  - Who chooses how we measure the validity/truth/importance of that knowledge?
  - Who investigates/pursues producing that knowledge?
  - Who is the knowledge about?

- **Who's gets to say? (Feminists: WHO DOESN'T?)**
  - Who is seen?
  - Who is listened to?
  - Who is believed?
  - Who interprets those stories?
  - Who determines what matters in those stories?
  - Who shares those stories?
  - Who are they sharing them with?
  - Who gets to say what stories are told, how they are told and who can hear/see them?

WHO HOLDS POWER = KNOWLEDGE PRODUCTION

Who produces knowledge, who has access to the knowledge, who is the knowledge about and for?

Medicine/physicians control and produce most knowledge about health/disease – function of their power

Patient and family data is mostly only available in less-valued forums or through the lens of clinicians

Who is producing knowledge?

- **Physicians**
  - 41% of licensed physicians in Canada are Female
- **Philosophers/Ethicists**
  - ~30% faculty are female
  - "Male-coded authors account for 82.5% of authors of all articles inspected." (Cole Murdoch, Prof. Kathryn Norlock – Journal of Moral Philosophy)
- **NIH Funding** - ~30% Female
- **Publications in Medicine**
  - ~ 37% Female 1st authors
  - 17.5% Female Editorial Board Members
- **Leadership Roles in Medicine**
  - 21% Female Full Professors (even when accounting for factors that affect promotion)
  - 15% Female Department Chairs
  - 16% Female Deans

KNOWLEDGE - MEASUREMENT IS AN ETHICALLY SIGNIFICANT CHOICE AND PRODUCT OF POWER

Power: What is measured, is what is of value, and what is of value, is what is measured.

> **Power -> What/Who is of value -> What is Measured -> What is Known/True -> Who/what is told**

- What physicians choose to do with the power that knowledge production gives them has impacted not only the science of medicine but the experiences of patients and families. What is chosen as an area of importance can be just as important as what is *not* chosen

- **Measurement Alters What is Measured and What is Considered Good and Important**
- The Observer Effect states that just the act of watching or monitoring, has the potential to change people's behavior. (Mitchell)
  - Because you are watching/measuring, it must be important, so I will focus and improve in that area.
  - **Measurement -> Value -> Behavior and Effort -> Improvement**
- Value, or what is understood as 'good' healthcare, can then be determined by what is measured.
  - Improvement (of the measure) becomes the objective
  - "focus on areas that are easier to change - such as food, the built environment or booking systems - rather than more intractable areas - such as communication and information provision." (Mitchell et al.)
- Women's experiences and health are not being measured, and because they're not measured, they can't be valued.

POWER = WHAT DO WE GET TO KNOW?

What is good/known/acceptable = What is good/known/acceptable for men…

What and Who: No Data or Bad Data: *Women were "Confounding and more expensive test subjects because of their fluctuating hormone levels." (Liu)*

Drug Trials:

- Inequality: "Overall, just 0.32% (534) of all active registered studies were Pregnancy Drug Trials" (Scaffidi) or there are no trials.
- Dosage = 70kg Man (Lippi)
  - "In 2014, the U.S. Food and Drug Administration (FDA) initiated distinct weight-based dosing for women and men.10 At that time, zolpidem was the only medication to have dosing based on sex." (Liu)
- Minimal safety/efficacy data
  - Adverse events are only picked up in the post-marketing phase of the drug." (Lippi)
  - 2x Side Effects (and 8/10 withdrawn were more likely to caused greater risks to women – Liu)
- **Duty to exclude -> duty to include:** "Policy guidelines are now in place to include women and minority groups in clinical research appropriate to the scientific question under study so that the results can be generalizable to the whole population." (Lippi) – Passed in 1993

Scaffidi J, Mol BW, Keelan JA. The pregnant women as a drug orphan: a global survey of registered clinical trials of pharmacological interventions in pregnancy. BJOG 2017;124:132–140.

Lippi D, Bianucci R, Donell S. Gender medicine: its historical roots. Postgrad Med J. 2020 Aug;96(1138):480-486.

Liu KA, Mager NA. Women's involvement in clinical trials: historical perspective and future implications. Pharm Pract (Granada). 2016 Jan-Mar;14(1):708. doi: 10.18549/PharmPract.2016.01.708. Epub 2016 Mar 15. PMID: 27011778; PMCID: PMC4800017.

WHO/WHAT IS MISSING?

Quantitative vs Qualitative – The Lived Experience, the Narrative is Missing

- 4.1% of General Medical Publications were Quantitative (up to 40% now?)
- **Qualitative:** 'Objective', binary, (easily) measurable
  - Is that what matters to people?
- **Quantitative:** Subjective, Narrative, Non-binary, Difficult to Measure
  - Is it what matters to people?
    - The outcomes or the experience of getting to/through those outcomes?
    - The experience of living with, surviving or dying from that disease?

Communication, comfort and care

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FEMINIST AND NARRATIVE ETHICS/MORAL PHILOSOPHY

- **"Critical examination of the social definition and distribution of discursive resources, credibility, and dominant conventions of intelligibility. These determine whether and *how lives can be told, to whom they can be told, and what effects their telling has*.**

- **Available ways of telling lives in stories, and their social intelligibility and prestige for certain audiences, raises questions. *Who's kept quiet? What's left out*?"[40] (p. 135)**

- ***Situated Knower* – one's 'social location' cannot be separated from their conceptions of 'x'[53]**

- **Feminist perspective: "…why and for whom knowledge is sought."[63]**

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THE ALTERNATIVE: THE 'EXPRESSIVE-COLLABORATIVE (FEMINIST/RELATIONAL) MODEL' OF MORAL PHILOSOPHY

PERSON AND CIRCUMSTANCE SPECIFIC, RELATIONAL AND CAN CHANGE OVER TIME

- Feminist, intersectional approach to moral philosophy.
- Person, community, and circumstance specific, varies over time with the same.
- "moral knowledge produced and sustained *within communities*."[19(p. 66)]
- A **negotiation** and "equilibrium… between people over ***their responsibility*** for things open to human care and response."[19]
- "A picture of morality as social *negotiation in real time*, where members of a community of roughly or largely shared moral beliefs try to refine understanding, extend consensus, and eliminate conflict among themselves. 'We' are the members of some actual moral community, motivated by the aim of going on together, preserving or building self- and mutual understanding in moral terms." [19 (p. 71)]
- **Relational, community-based, intersectional**
- The Autonomous Woman?

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WHO AND WHAT DO WE KNOW AND HOW DO WE COME TO KNOW? NARRATIVE ETHICS – THE EXPERIENCE OF ILLNESS

The use of storytelling/listening to understand and resolve ethical conflicts, *create and understand moral communities*.

"In telling stories…we both create and reveal who we think we are as moral agents and as persons; in granting these stories uptake—that is, in *giving them epistemic credibility*—we help to mold and sustain the moral identities of others, as well as our own."

https://iep.utm.edu/fem-e-n/#:~:text=A%20narrative%20approach%20to%20ethics,and%20structure%20our%20moral%20universe.

SEXIST ETHICS: '**CRITICAL ISSUES' VS 'HOUSEKEEPING ISSUES'** - VIRGINIA WARREN

GIVING POWER TO LIVED EXPERIENCES

Housekeeping issues "refer to one's everyday life and to on-going relationships," [64] (p.80) where "the problematic situation is on-going, rather than resolved once and for all; and decisions need to be made continually."[64] (p.79)

Housekeeping issues "commonly require us to reassess large parts of our lives: our character traits, how we think about ourselves, and how we relate to others. Their impact is thus felt long after a particular crisis is past."[64] (p.79)

HOUSEKEEPING ISSUES: THE LIVED AND DAILY EXPEREINCES THAT INFORM THOSE CRITICAL ISSUES *AND* THE LIVED AND DAILY EXPEREINCES AND CONSEQUENCES THAT RESULT FROM THOSE DECISIONS

THEORY → REALITY

Warren VL. Feminist directions in medical ethics. *Hec Forum*. 1992;4(1):19-35.

LISTEN TO THEIR STORY…THE WHOLE STORY…WITHOUT INTERRUPTION

- "Physicians interrupt patients' opening statements after a mean of 18.2 s."
- "If uninterrupted, patients' opening statements are a mean of 45.9 s long."
- "The mean difference between uninterrupted and noninterrupted is 27.7 s."

Narrative – Storytelling

How we make sense of what is happening/has happened

Reflects what we value (or want to value) and believe to be true

External Narrative

Those in power - dominant/official narrative: What is 'truth' and what represents 'our' interests*

"When these representations of moral life are put forward authoritatively as truths about 'human' interest, 'our' institutions, 'rational' behavior, or 'the' moral agents, they do not just say what is false. Rather they uncritically reproduce the represented positions and locations as normative, i.e., as the central or standard (if not the only) case." [40] (P.60)

Listening is Powerful: What is the story they tell about their illness and what does that tell us?

- Transfer of Power
- Opportunity to gain deep understanding about:
  - What they understand
  - What they value
  - Their experience and potential traumas, mistrust etc.
  - Foundation for their 'illness narrative'
  - 'Treasures' for later discussions

MORE WORK WITH NARRATIVES – BUILDING TOGETHER

- **Continuous and coherent narrative** – moving forward together
- **Cultivate intentionality concerning pursued actions**
  - "Intentional actions require plans in the form of representations of the series of events proposed for the execution of an action…*it must correspond to the actor's conception of the act in question*, although a planned outcome might not materialize as projected."[12]
  - **Prognostic awareness (hope & reality) and goal-directed care**
- **Authentic decision making**
  - "Authenticity is the degree to which an individual's actions are congruent with their beliefs and desires, despite external pressures."[59]
    - Requires discussion and understanding of the expectations and values patients and families have, and how those expectations and values inform their understanding and decision making
    - ***Value/goal-based decision making (vs slippery slope/clinical momentum)***

AUTONOMY: THREE CONDITION THEORY

Understanding: "In our account, an autonomous action needs only a substantial degree of understanding and freedom from constraint, *not full understanding or a complete absence of influence.*"

--- What you think/understand will happen

Intentionality: "Intentional actions require plans in the form of representations of the series of events proposed for the execution of an action…*it must correspond to the actor's conception of the act in question*, although a planned outcome might not materialize as projected."

--- What you *mean (**want**)* to happen

Non-control: "…that a person be free of controls exerted *either by external sources or by internal states* that rob the person of self-directedness."

--- What *you would choose* to do with the above

Beauchamp, T. L., & Childress, J. F. 2013. *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

QUICK GUIDE: HOW WE CAN DO BETTER

1) **WHAT WE NEED TO KNOW**
   - WHO IS MISSING
   - WHAT IS MISSING
   - WHAT MATTERS
   - WHAT IS THEIR STORY
     - WHO THEY ARE OUTSIDE THE CLINICAL SETTING
     - THEIR PATIENT EXPERIENCE
     - WHAT THEY VALUE
   - WHAT IS IMPACTING/INFLUENCING THE ABOVE

2) **HOW CAN WE COME TO KNOW IT BETTER**
   - LISTEN TO THEIR STORY
     - ASK MORE QUESTIONS ABOUT THEIR STORY, EXPERIENCE, VALUES AND NEEDS
   - PRACTICE IT AND ASK FOR FEEDBACK
   - STUDY IT!

3) **HOW CAN WE SHARE WHAT WE KNOW BETTER**
   - CHALLENGE THE DOMINANT NARRATIVE/CULTURE
   - TELL THEIR STORY AND THE VALUE IT HAS
   - PUBLISH IT

THE BACKGROUND

FEMINISM & THE MALE/FEMALE EXPERIENCE

The Male Experience: 'The Rational Man'

- I matter (most)
- I know (most/everything)
- I can (belief and agency)

The Female Experience: The Irrational Woman

- I don't matter *(belief and fact)*
- I don't know (even about myself)
- I can't (belief and agency)

Feminism Asks:

- *Who and what don't we know about?*
- *How do we come to know about them/it?*
- *What do we/they value and how do we build and re-build that together?*
- *What do we need to know/do to alter those things and help people make authentic choices?*