# QUEER BIOETHICS: THE SPIRIT OF THE GOLDEN RULE

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# “QUEER"

Verb: “to employ a non-normative lens to what is taken to be standard and ordinary” (Wahlert & Fiester, 2014, S57)

# QUEER BIOETHICS

- "Mere inclusion" can reinforce cultural wariness and stigma" & "have the power of an imprimatur, legitimating that very stigma"

- "To protect against such liability, we advocate for a queer bioethics … [which] takes utmost care to adequately incorporate the needs, perspectives, cautions, values, and concerns of the population that this new inclusion is trying to assist. It seeks out the 'insider's view' rather than the view from the safe and protected outside."

(Wahlert & Fiester, 2014, S63)

# TRUST

- "A psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behavior of another" (Lewicki et al., 2005)
  - Vulnerability actively avoided to prevent further victimization

(Foglia & Fredriksen-Goldsen, 2014)

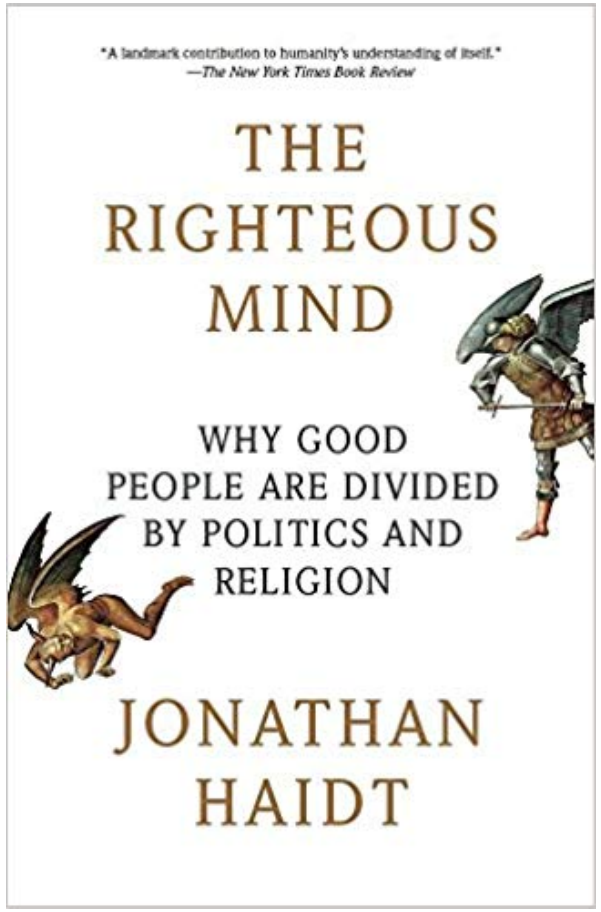
# INSTITUTE OF MEDICINE REPORT (2011)

- Recommendation #3:  EMR data collection on sexual orientation & gender ID
- "Being scrutinized about one's sexuality or gender identity by a HCP carries at least as much potential to bolster feelings of shame or abjection as it does to reduce them"
- "… de facto, a suggestion that [HCPs] press their patients to 'out' themselves without the slightest reflection or awareness about why individuals may choose – and even *need*—to remain closeted"
- "Until minority sexual orientation or gender identity is not socially pejorative and discriminatory, the 'it can't hurt to ask' defense is not only naïve but also revealing: you miss the stakes involved in asking such questions only if you are safely enveloped in the normative fold." (Wahlert & Fiester, 2014, S58)

# RIGHTING INJUSTICE

Rawl's Veil of Ignorance

# COGNITIVE HEURISTICS/ EVOLUTIONARY PSYCHOLOGY





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BIRTHPLACE : EARTH
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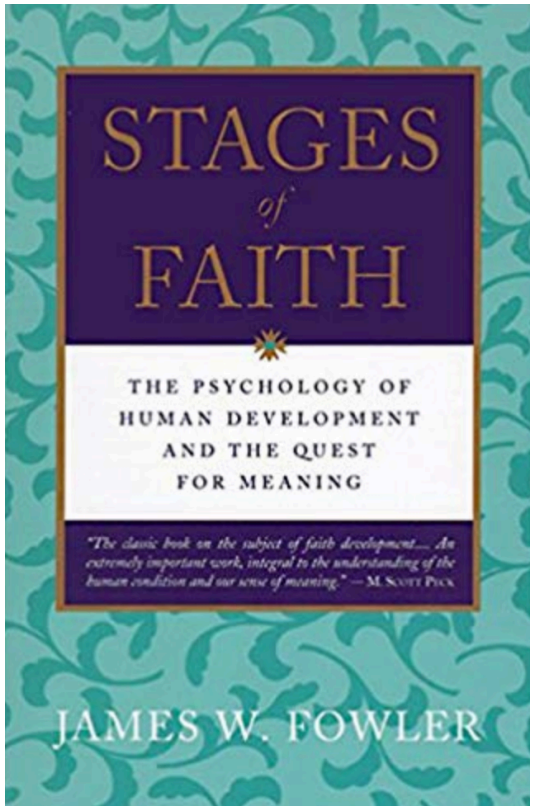
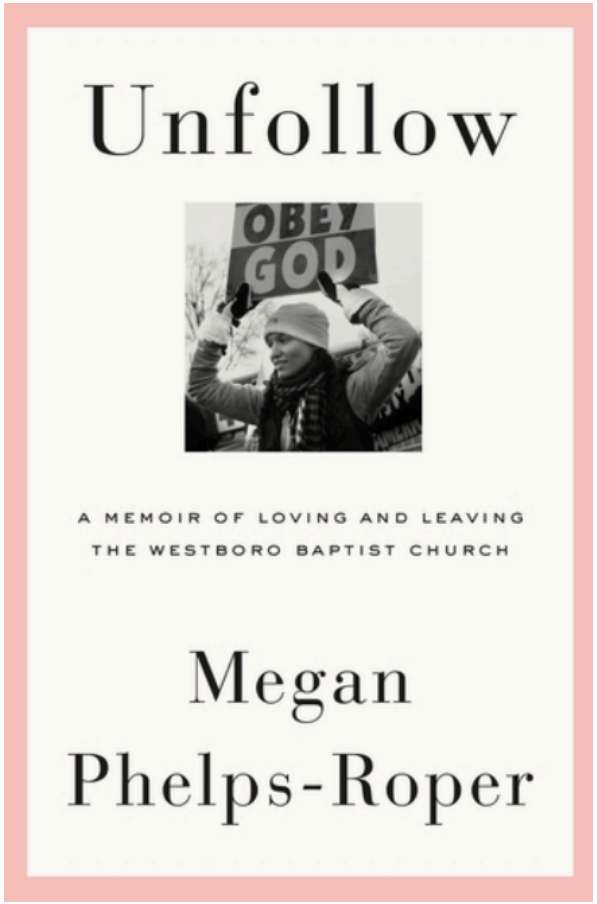
# ETHICS, RELIGION, SPIRITUALITY & FREE WILL/AGENCY/SELF-DETERMINATION






"IT WAS TERRIFYING, THE COGNITIVE DISSONANCE … I ABSOLUTELY BELIEVED THAT MY FAMILY WAS RIGHTEOUS, THAT WHAT WE WERE DOING WAS THE TRUTH OF GOD. WE DEDICATED OUR LIVES TO IT. AND THEN TO HAVE THESE DOUBTS CREEPING IN AND TO START FEELING ASHAMED AND FEELING LIKE … WHAT WE'RE DOING IS WRONG. AND THEN **TO START TO REALIZE THAT THERE ARE THINGS IN THE BIBLE THAT ACTUALLY SHOW THAT WHAT WE'RE DOING IS WRONG** … BOTH OF THEM FELT ABSOLUTELY TRUE, AND THEY WERE IN CONTRADICTION WITH ONE ANOTHER … IT TOOK TIME FOR ME TO BE ABLE TO FINALLY COME TO THE CONCLUSION, THE REALIZATION, THAT, LIKE, **OH, MY GOD, WHAT IF WE'RE JUST PEOPLE? WHAT IF THIS ISN'T GOD HIMSELF COMMANDING US TO DO THESE THINGS?**"

(FRESH AIR INTERVIEW WITH TERRY GROSS, NPR, OCTOBER 10, 2019 - HTTPS://WWW.NPR.ORG/2019/10/10/768894901/HOW-TWITTER-HELPED-CHANGE-THE-MIND-OF-A-WESTBORO-BAPTIST-CHURCH-MEMBER)

# VIRTUE ETHICS

- Intentions not enough
- Self-reflection & awareness critical
- Professional codes of ethics & aspirational care
- Cultural humility and ethical questions to guide care
  - Ask & LISTEN!

# RESPECT FOR AUTONOMY – VALUING DIVERSITY OF EXPERIENCE & CHOICE

- Anti-LGBTQ+ arguments tend to hinge on *behavior > identity*
  - Logical counter is to emphasize innateness ("born that way")
  - BUT: this undervalues diversity of experiences, that people change, & one's identity and sexual orientation can't be reduced to biology or choice
    - 50-80% of identical twins of gay men don't identify as gay (Powell & Stein, 2014)
    - Sexual attraction changes over time for many (though not by choice) (Powell & Stein, 2014)
    - Gender dysphoria in childhood doesn't inevitably continue into adulthood (Drescher & Pula, 2014, S18)

# PRO-CHOICE

- "As a gay person myself, I am troubled that LGBTQ rights are overly contingent on the growing consensus that we cannot change ourselves, which is an experientially strong but ethically weak position." (Solomon, 2014, S5)
- "We reject the argument that a right cannot be vigorously protected if it reflects a choice … it is the right to make choices that reflect the legal equality of those with a same-sex orientation that is under attack, and it is the right to make such choices that we support." (Powell & Stein, 2014, S37)

# RESPECT *CHOICES*

- Engaging in sexual acts w/person of same sex
- Publicly/privately identifying as LGBTQ+ person
- Marrying person of same sex
- Raising children with same-sex partner

# SOCIAL ROUTE

- Erodes “the urgent sense that scientific explanations are required to make being queer habitable for oneself or acceptable to others” (Nelson, 2014, S16)

# JUSTICE

- Civil rights history
- Challenge of translating rights → resources
- Coverage vs. access
  - "…it is strange to imagine telling a young, transgender person on Medicaid that he or she can transition at age sixty-five" (Davis & Berlinger, 2014, S46)

# BENEFICENCE/NON-MALEFICENCE

- How do we minimize harm & maximize benefit to LGBTQ+ persons & those they love?

*"Making sense of oneself is rough enough if your interlocutors are merely ignorant or indifferent; doing so in the face of implacable intolerance is yet worse."*

(Nelson, 2014, S13)

# SCENARIOS

*What went wrong in these scenarios?*
*What ethics violations do you recognize?*
*What are the next steps to fix the problems?*

# CHJ

*CHJ, in her early 60's and in a long-standing same-sex relationship, had scheduled an appointment with an ob-gyn for bleeding likely related to previously diagnosed uterine fibroids. Her prior ob-gyn had recently retired, and all of her patients had been transferred to the care of another doctor. CHJ was somewhat reluctant to be seen by a new ob-gyn but overcame her trepidation because her prior doctor had highly recommended him. She undressed, donned the requisite gown, and positioned herself on the examining table and in the stirrups with the help of a medical assistant. The doctor entered the room and briefly introduced himself. As CHJ was being examined, the physician looked up and asked if she was sexually active. CHJ responded yes and started to feel discomfited, wondering where this line of questioning was going. The physician said, "Change to your fibroid is large. Haven't you experienced quite a bit of pain during sexual intercourse with your husband?" CHJ tensed and simply replied, "No, I haven't experienced any pain."*

(adapted from Foglia & Fredriksen-Goldsen, 2014, S40)

# YVONNE

*Yvonne is a 42 year old trans woman who anticipates her first (top) gender confirmation surgery in a month. She presents to her primary care provider for a pre-op evaluation. A nursing assistant shows her to an exam room, tells her to undress and put on a gown, and gives her a cup for a urine pregnancy test. Yvonne tries to explain, "I'm trans" and the nursing assistant grimaces and says, "You'll have to discuss that with the doctor. I don't think we do that here."*

# NEGATIVE ENCOUNTERS

ALISON REIHELD, PHD, ASBH 2019

- FRONT OFFICE
  - Receptionist & phone call encounters, paperwork
- BUILT ENVIRONMENT
  - Gender-segregated areas
- HUMILIATION, EMBARRASSMENT, SIDETRACKED BY TRANS STATUS
  - "Not part of the human club;" "treated as an experiment;" "chance to learn something" but not seen as patient needing care
- MISDIAGNOSIS
  - Clinician derailed by trans status; not broadly understanding aspects of trans experience; mistrusting patient's own knowledge of their body

# POSITIVE ENCOUNTERS

ALISON REIHELD, PHD, ASBH 2019

- "… involved humble and caring providers who treated the trans patient as other patients in terms of touch, talk, time, research options, staying focused on patient needs."
  - Generally described as "everyone was doing their job."
  - Job descriptions had been "designed to include trans folks in terms of forms, phone etiquette, etc."
- "I would much rather have a doc who says 'I don't know, let me get back to you' than one who I feel super uncomfortable telling them about my gender experience"

# VERNON

*HIV+ man, Vernon, with severe liver dysfunction related to HAART [Highly Active Antiretroviral Therapy] has partner, Trevor, appointed as his health care agent. Vernon previously told Trevor not to disclose his HIV status to his family (mom and sister). Vernon is now critically ill in the ICU, unable to make his own medical decisions. His mom and sister have been at the bedside asking staff for information about his condition. The medical resident overseeing Vernon's care explains to Trevor that it's in Vernon's best interest to include his family in the plan of care by disclosing his HIV status to them. The medical team is feeling distress not being able to directly answer the mom and sister's questions, and they worry about their safety if they are exposed to the HIV virus because they are unaware of Vernon's seropositivity status. Ultimately, Trevor declines to give permission to disclose the HIV+ status.*

# ETHICS CONSULT NOTE

*42 year old man currently in monogamous same-sex relationship previously engaged in sex with multiple male partners. Diagnosed as HIV+ 4 years ago, recently changed his HAART and presented 3 days ago with drug-related effects on liver warranting ICU admission. Currently on ventilator receiving supportive therapies. Medical team is hopeful for recovery although the patient's condition is serious. The patient's partner is acting as his decision-maker. The family (mom and sister) has been visiting and asking questions about the patient's condition, and staff involved believe it would be better for the patient (and safer for mom and sister, given the patient's HIV+ status) if they could all engage in honest conversations about his diagnosis and prognosis. While the patient's partner is his legally recognized decision-maker, it's appropriate to try to persuade him to allow more open dialogue with the family. However, if he desists, he cannot be overruled.*

# QUEER BIOETHICS ANALYSIS

- Person-first?
- Narrow portrayal of LGBTQ+ ethical issues
- Delegitimizes queer family > normative family of origin
  - Vernon merely "acting" as decision-maker
  - Assumes family of origin *should* be involved
    - Disregards history of discrimination & mistreatment toward LGBTQ+
- Unnecessary sexual scrutiny & blame/judgment
  - Sex with multiple partners irrelevant

(Wahlert & Fiester, 2014)

# QUEER BIOETHICS ANALYSIS

"The implicit critique of [Vernon] is that, while he was guilty of the sin of promiscuity in the past (and thereby culpable for his own seropositivity), he has now redemptively joined the normative fold—at least to the extent that a same-sex desiring person can—by his "current" sexual exclusivity" [according to the "hate the sin, love the sinner" mandate]

(Wahlert & Fiester, 2014)

# (NON)CONSCIOUS (IMPLICIT) BIAS & MICROAGGRESSIONS

- Assuming one is married to person of opposite sex
- Asking to complete demographic forms that don't include preferred options
- Unnecessary sexual scrutiny and blame/judgment (e.g., reference to having "multiple sexual partners" instead of "at-risk sexual practices" or when info is irrelevant)
- Directing communication to others; ignoring/isolating life partner
- Joking about patient with other staff; using exclusionary language
  - Particularly high-intensity care delivery sites such as OR & ED
- Negative nonverbal communication
- Asking trans person about their medical history &/or genitals w/out permission
- …

# ORGANIZATIONAL BEST PRACTICES

- Patient nondiscrimination policies inclusive of sexual orientation & gender identity
- Equal visitation
- Employment nondiscrimination
- Encourage diversity among HCPs
- Training on LGBTQ+ patient-centered care
  - Implicit bias training
  - Train patient relations staff in supporting LGBTQ+ patients who report negative care experiences
- Offer lists of LGBT-welcoming HCPs

- EMR adaptations
  - Right to share with clinician and not have status entered into EMR
  - VA: choice of "other" and "individual chooses not to answer" available; mechanism for self-identified gender field, which can be excluded from data-sharing outside VA
  - Monitor data access to prevent misuse to employment/reputation/ breach of privacy
- Educate students at all levels
  - Safe Zone training, Standardized Patients (SPs), Hidden curriculum

Healthcare Equality Index: https://www.hrc.org/hei

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