Individualist Autonomy Models & Ableism

Anita Ho

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LAURA GUIDRY-GRIMES

Institutional & Relational Threats to Autonomy

Competing Models: Autonomy

Individualist

- Non-interference is best way to promote autonomy
- Maximize choice
- Inform, let patient decide → duties fully discharged
- Coercion concerns rooted in individual relationships
- Presume patient is free to choose according his/her own wishes

Relational

- Autonomous agency and sense of self are socially embedded
- Evaluate existing and absent choices based on context
- Informed consent is necessary, not sufficient
- Coercion can be structural, political, pervasive
- Freedom to choose can be undermined or distorted depending on context of choice

Autonomous Decision-Making

- Need social conditions that support and maintain capacities and opportunities for autonomous agency
  - Importance of socialization – can be negative or positive force
- Vulnerability
  - Enhanced in healthcare settings – power asymmetry, dependency for knowledge/options/access to services
  - Coercion, domination, exploitation do not always come from individual threats or individual actors
    - "they are also structural phenomena, the intended or unintended product of the actions of many people that shape others' choices" and that can "often foreclose certain opportunities or pre-determine how individuals approach various health-care situations" (Ho 195)

Some Test Cases…

- Jane, 18, grew up surrounded by images of slender and busty women. Her dolls, magazines, and television shows all push unattainable beauty ideals. She believes that no one will appreciate or value a woman who does not have this body type. She now feels horrible about her body and can hardly stand to look in the mirror. She thinks she can start respecting herself if she gets plastic surgery.
  - Can Jane autonomously choose breast augmentation surgery?

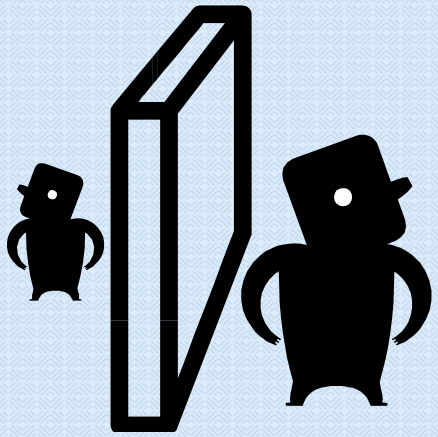
Some Test Cases…

- Jake, 20, has a football scholarship to attend college, making him the first in his family to reach this level of education. After several concussions and brain injuries, however, a physician tells Jake he should stop playing football. If Jake stops playing, he will lose his scholarship, and his family would never forgive him for dropping out of college as a result. If he continues playing, he risks permanent brain damage and disability. His coach has told Jake that professional football requires sacrifice, and Jake's injuries are not all that uncommon.
  - Can Jake autonomously choose to continue playing football at the same level of intensity, as desired by his coach and family?

The Threat of Ableism on Healthcare Decision-Making

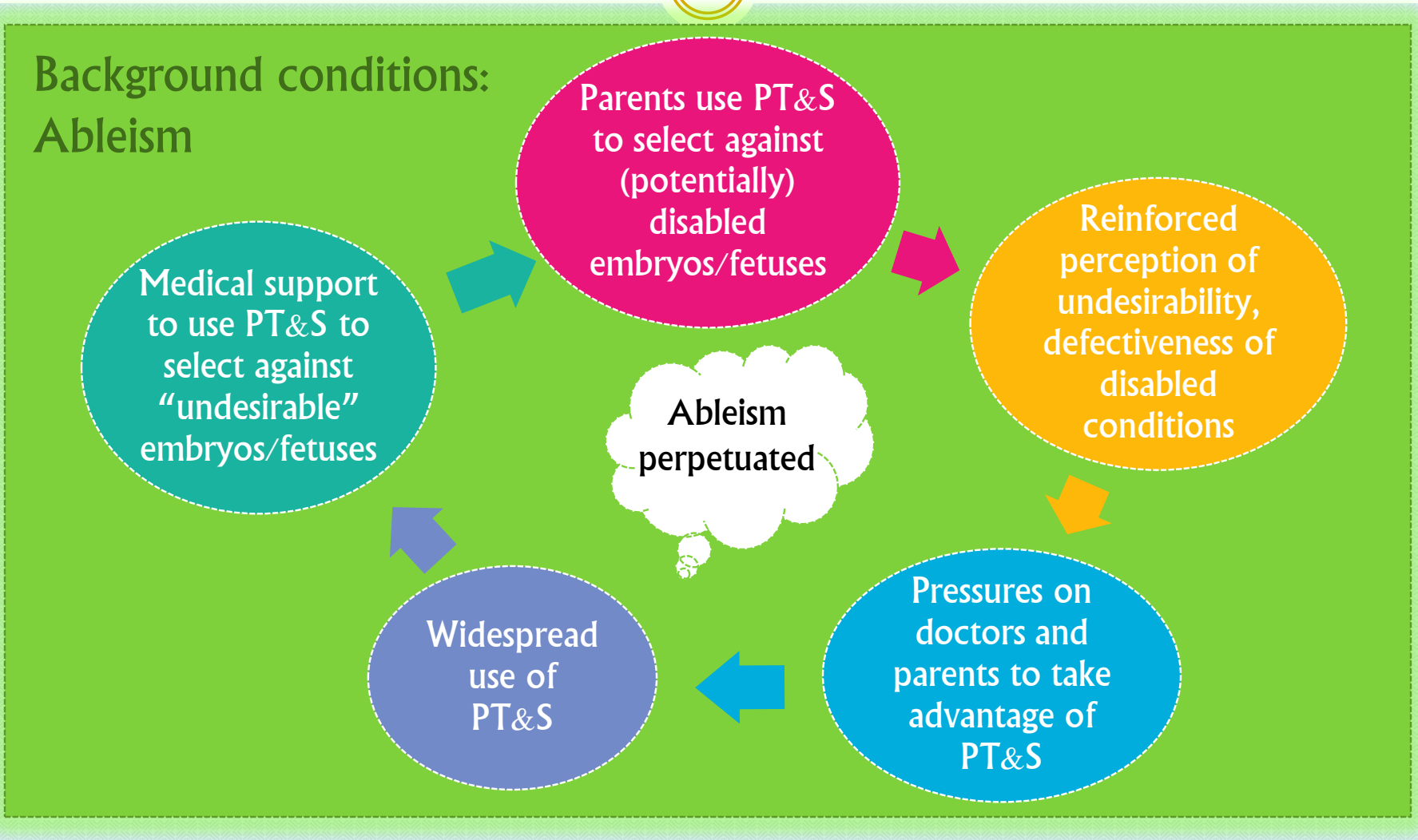
Epistemic Barrier

- **Epistemic barrier** between those who have never experienced disability and those who have/do
  - Insurmountable?
  - Methods for identifying and taking down this barrier?



- Barrier the **result of**
  - Marginalized status
  - Lack of a voice in decision-making (exclusion, disrespect)
  - Paternalistic attitudes ("pathetic, medical tragedies")
- Barrier **perpetuates**
  - Able-bodied, able-minded norms (power privilege)
  - False assumptions about quality of life, agency
  - Lack of accurate information about actual interests, needs

On Prenatal Testing & Screening (PT&S)



Different Questions to Ask

- Can parents autonomously consent to prenatal testing and screening (PT&S)? What are barriers to autonomous consent?
  - Moral differences in types of technology
- Do PT&S perpetuate ableism in families or the larger society?
- Should physicians recommend PT&S for all eligible patients?
  - What are physicians' moral obligations re: these current and future technologies?
- Even if taking advantage of PT&S is morally problematic, is it nonetheless morally permissible?
- Should PT&S be made available to as many prospective parents as possible?
  - What is the **moral justification** for it? What are the **moral costs**?

Ho's Conclusions

- Not suggesting we eliminate technologies, end-of-life options
- Not suggesting that autonomous decision-making is impossible in questions of disability
  - Identifying ways in which free, voluntary, informed consent can be tarnished, distorted, inauthentic, coerced
- "respect for autonomy should be about removal of [oppressive] social barriers or empowerment through social restructuring" (204)
  - Recognize how options are framed, interpreted, and communicated → effects on decision-making
  - More expansive notions of patient advocacy, respecting patient values

Group Discussions

- When it comes to offering prenatal/preimplantation testing and screening to prospective parents, what are some moral priorities?
  - What are some sources of moral conflict?
  - How should genetic counselors advise parents when there is a possibility of physical or intellectual disability?
- If a patient refuses life-sustaining care due to concerns about being a burden or being helpless as a disabled person, what are the moral obligations of the medical team?
  - What forms of paternalism may or may not be permissible?
- Do you agree with Ho that institutionalized policies and practices can coerce patient choice?

Questions?

Comments?