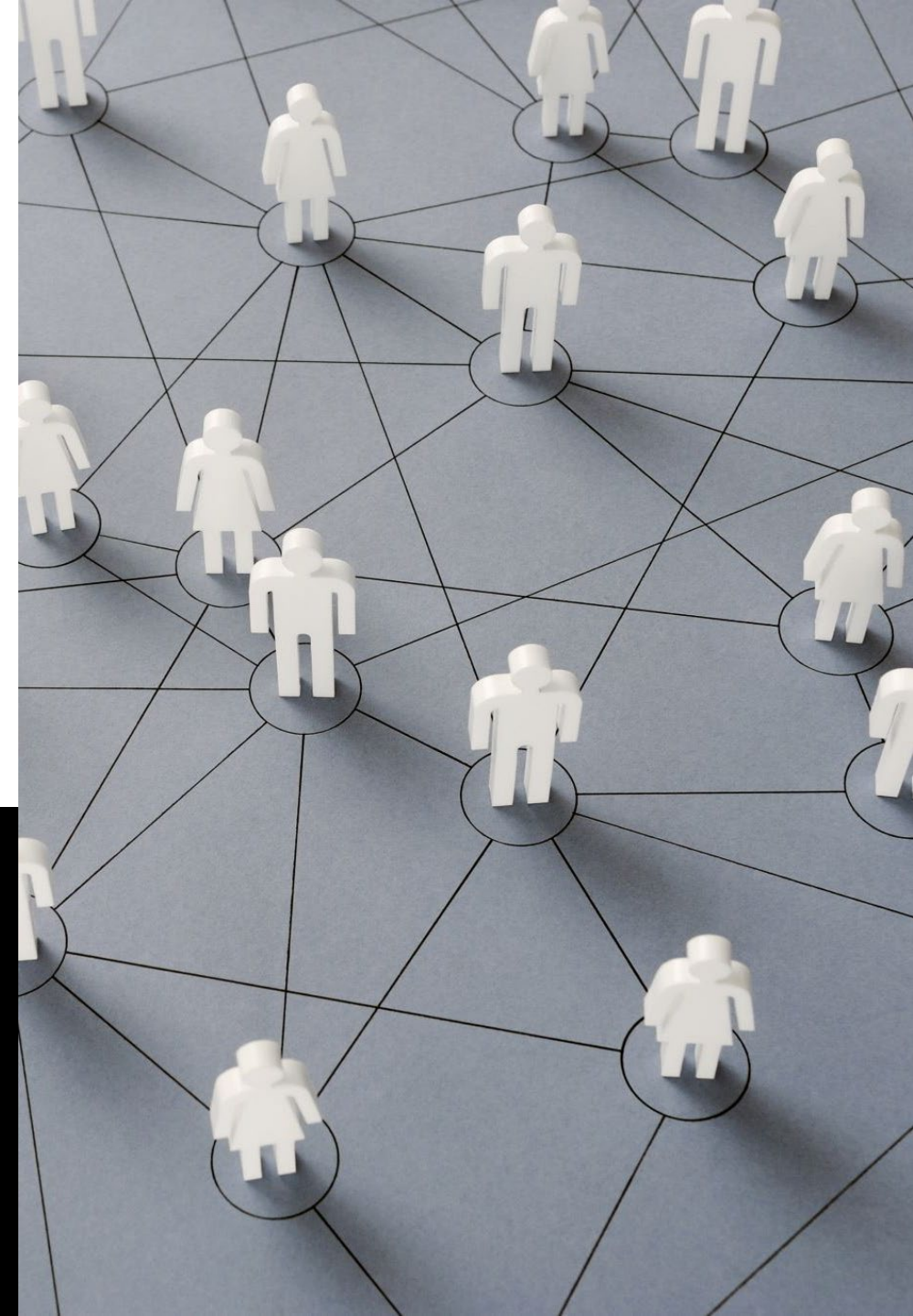


CONSENT AS A LONG-TERM RELATIONSHIP: LESSONS FOR LONGITUDINAL STUDIES

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NO CONFLICTS TO DISCLOSE

TWO ISSUES. . .

Issue 1: Ethics of consent in longitudinal research

Issue 2: Ethics of consent in longitudinal research in aging populations

CONSENT IN LONGITUDINAL STUDIES

- Longitudinal: Observations of the same participants over periods of time (Biobanking, long-term follow-up of interventions, cohort studies, etc.)
- Central Consent Challenges:
 - Informing/choosing in evolving informational landscape
 - Withdrawal/Retention

CHALLENGES TO TRADITIONAL CONSENT

1. Traditional model of consent:

- Discrete event
- One point in time
- Unidirectional information and responsibilities (from active researchers to passive participants)
- Barriers are semantic or environmental

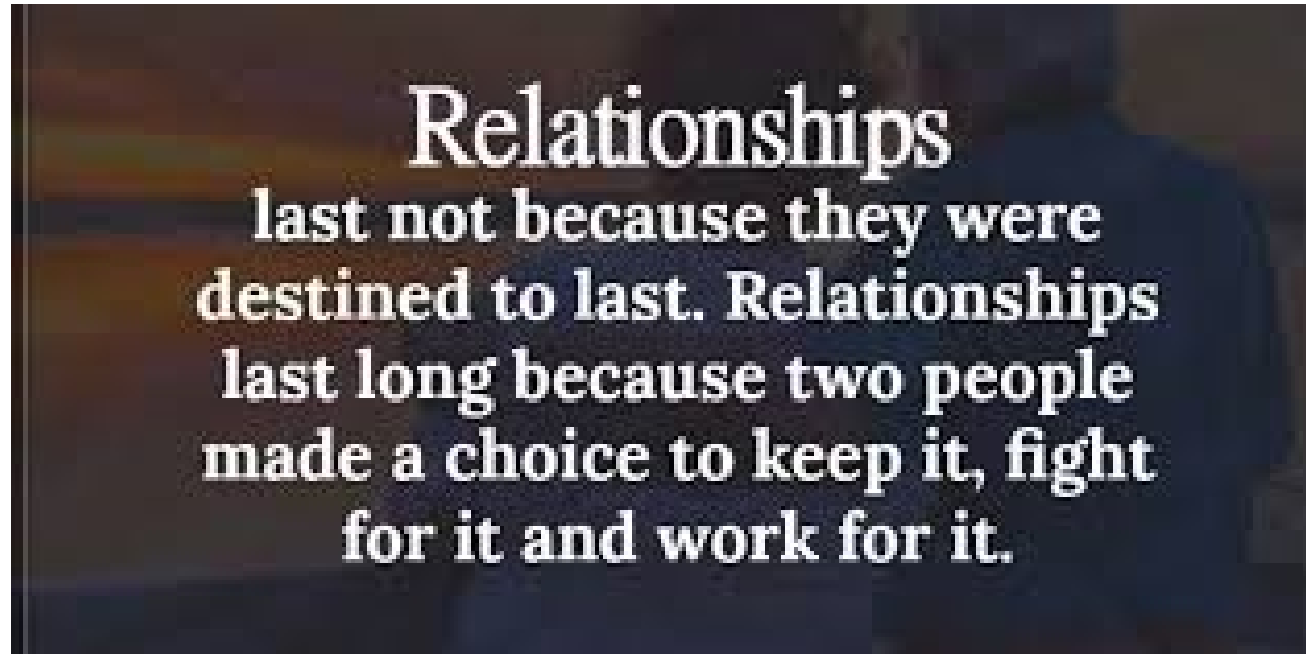
2. This model problematic for longitudinal studies bc:

- Barriers are due to time (informational, psychological, contextual, etc.)
- Requires continuous investment by participants, so cannot be treated as passive
- Current “solution” broad consent, BUT doesn’t solve either problem

BETTER SOLUTION? ALTERNATIVE MODELS OF CONSENT

- Lidz, Appelbaum, Meisel (1988): process model (clinical relationship over time)
- Miller and Wertheimer (2010): Consent transactions (context-based bilateral responsibilities)
- Me (2019): Transaction models of communication (forging relationships, shaping self-concepts, social context)

WHAT DOES THIS LOOK LIKE?



“Self-determination requires “opportunity, capacity, and *motivation*” Moody 1988, 69)

THE GOOD NEWS AND BAD NEWS

- **Good news:** Alternative consent model lessens ethical pressure to make sure all is understood and completely voluntary at outset
- **“Bad” news:** Alternative consent model increases ethical pressure to
 - Establish trusting relationship at the outset
 - ensure access to desired information over time
 - motivate people to continue
 - make withdrawal accessible

STRATEGIES (DEPENDS ON POPULATION)

Issue 2: Ethics of consent in
longitudinal research *in*
aging populations



ESTABLISHING RESEARCH RELATIONSHIPS WITH AGING POPULATIONS

- Do your homework (empirical research, CAB, community consultations, etc.)
 - What would you want available to make your initial decision? (information, people, time, location, etc.)
 - What would motivate you to continue? (ie. updates, education, services, etc.)
 - What would motivate you to stop? (risks, burdens, lack of time, lack of care, lack of health, etc.)
 - How is it best to communicate to you (online, newsletter, phone calls, etc.)
 - How is it best for you to communicate to us? (in case of questions, concerns, or withdrawal)
- Keep in mind
 - Great diversity in the aging population (cognition, interest, desire for involvement, etc.)
 - Great diversity in types of research (risk level, need for active participation, length of study, etc.)
 - Just because participants don't have or understand all the information, doesn't mean that the consent process is unethical, as long as the relationship is ethical

THE ELEPHANT IN THE ROOM

- How does this relate to research regulations and funding?
 - Use “homework” and risk level to argue for nature of initial consent and process of revisiting
 - Build in funding for background work in grant, justified by increased retention (and ethics)
 - Build in funding for continued engagement in grant, justified by increased retention (and ethics)

THANK YOU!

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