TRANSITION AGE YOUTH AS ACTIVE PARTICIPANTS IN MEDICATION DECISION MAKING: A THOROUGHLY RELATIONAL APPROACH

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Acknowledgements

The Transitions RTC aims to improve the supports for youth and young adults, ages 14-30, with serious mental health conditions who are trying to successfully complete their schooling and training and move into rewarding work lives. We are located at the University of Massachusetts Medical School, Worcester, MA, Department of Psychiatry, Center for Mental Health Services Research.
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Key Definitions

- **Young adults:** people between ages 16-30
- **Serious mental illness (SMI):** "a diagnosable mental disorder resulting in functional impairment which substantially interferes with or limits one or more major life activities." For this study defined as:

  -having been on governmental disability benefits within the previous five years and/or

  -having been hospitalized at least twice in the previous ten years.
- **Transition Age youth:** Young adults with SMI
- **"Active" participation** is the use of one's knowledge, skills, and beliefs to manage his/her health, and more specifically to exert influence over decisions about his/her treatment

TAY as a special population

- Services research findings regarding adults with SMI do not necessarily apply to TAY
  - Major disruption to vocational and educational development
  - Housing; Homelessness, Criminal justice involvement
  - Period of unsettling turbulence
  - Parental guidance
  - Restrictive setting as adolescents for some
- Dearth of research on service needs and effectiveness re TAY

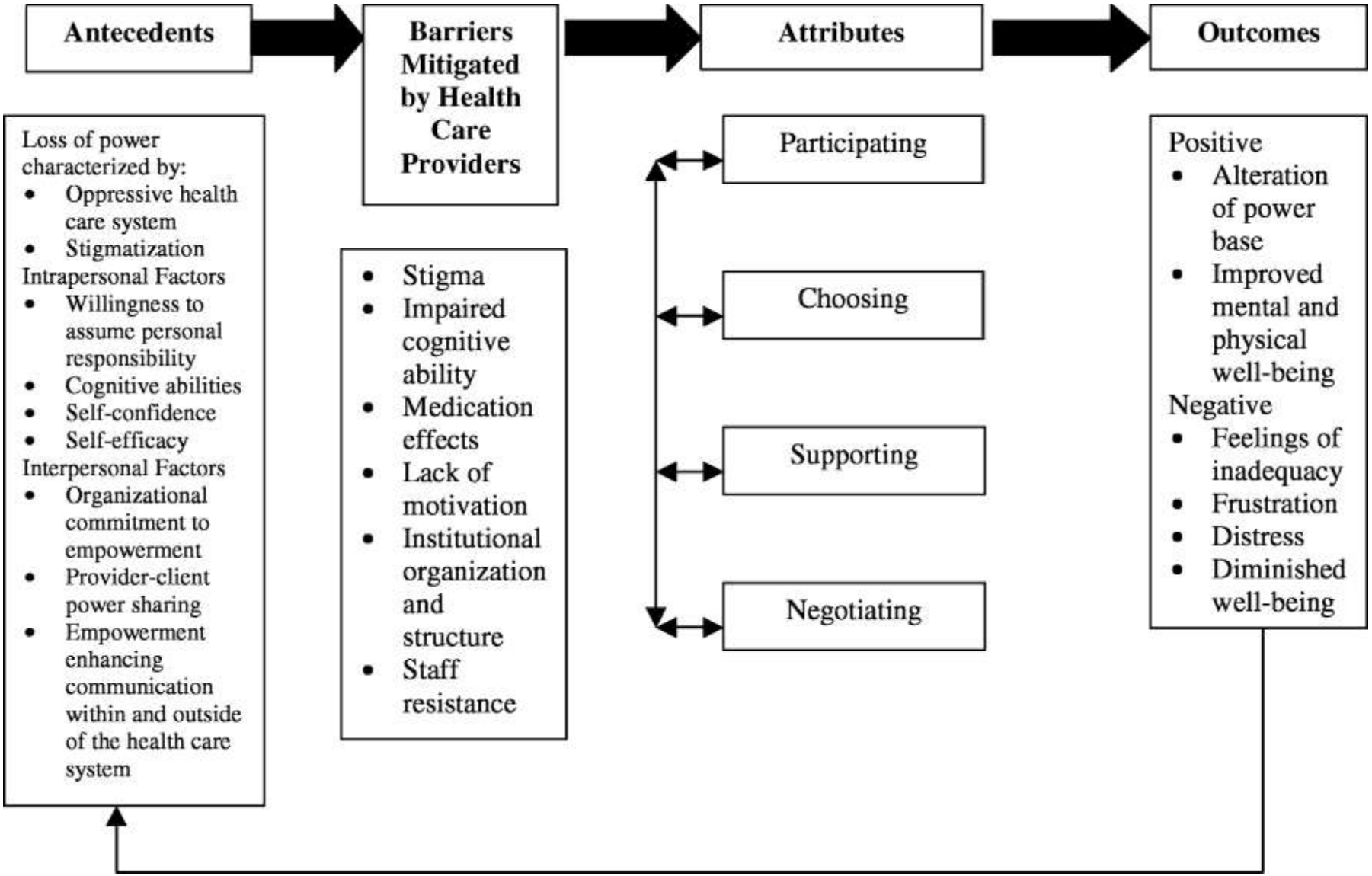
Study purpose/questions

- Purpose: To describe the experience of young adults with TAY as active participants in making medication decisions with their psychiatrists.
  - How can the stages (or levels) of client activation in the decision making process best be described?
  - *What are the key features the medication decision-making process where the client is an active participant?*
  - What are the barriers and facilitators to the active participation of TAY in making medication treatment decisions with their psychiatrists?

Significance

- Benefits of active participation
  - Preference-sensitive decision
  - Adherence
  - Outcomes, satisfaction
- Most studies find minimal involvement
- Very few studies on the nature of active participation
- *"[T]he [psychiatric] patient's subjective evaluation of the relationship, rather than the therapist's actual behavior, has the greatest impact on psychotherapeutic and clinical outcomes."* (Cruz & Pincus, 2002 p 1258)

Finfgeld Empowerment Model



Study Methodology

- Semi-structured Interview guide per Finfgeld
- 24 in-person interviews
- Audio-recorded and transcribed
- Analysis: Inductive analytic approach
  - Coding
  - Constant comparative analysis
- Eligibility
  - TAY (ages 19-30)
  - Seeing an outpatient psychiatrist for medications
  - Active participant

Sample demographics

- Mean age: 24 years (range = 19–30)
- 67% were female and 33% were male
- Most were white
- All living in the community and many working part-time
- All had been hospitalized psychiatrically at least twice after 16 years of age
- Most had started treatment before age 16.
- Most receiving Medicaid; i.e., low income.
- Most saw a therapist regularly (along with a psychiatrist)
- Avg. visit time with psychiatrist: 15 minutes

Findings Part 1:
The three levels of client activation

Formulating- Clients not only share information, but also ask questions about medications and/or request medication changes based on dissatisfaction with how they are feeling.
Choosing- Clients express feelings about an option/choice and/or assertively select that option.
Negotiating- Clients and psychiatrists express different opinions on a treatment option, and then engage in a "back and forth" process by which they reach a compromise.”

Negotiating

S*(M, 23): I upfront told her that I wanted to try to see if I could* ***cope off my medication*** *because of the weight gain issues and the blood sugar issues … I didn't want to deal with those, permanently. …it was kind of put off… For a couple of months she... basically wanted to know what my symptoms were, and to get to know me and tell me about my blood levels.* ***And, eventually, she helped me lower my medication****. But it was like, every one or two or three months, she'd lower it 25 mgs?*

FINDINGS PART 2:
A) Respondents' experience of active participation

Psychiatrist is seen as knowledgeable

http://www.youtube.com/watch?v=dlVL1ebnxIQ

Psychiatrist is seen as nice and respectful

Psychiatrist demonstrates his/her interest in the client's mental health

The relationship is built on mutual trust

The relationship is ongoing

FINDINGS PART 2:

B) The active participation experience: themes applying only to “choosing” and “negotiating” clients, but not “formulating”

- Psychiatrist is seen as interested in the client’s perspective on treatment, and often encourages participation

http://www.youtube.com/watch?v=NYftQdWobGk

- Psychiatrist is available immediately outside of their meeting format if there are medication problems, and follows through on that promise

Psychiatrist immediately accessible outside of their regular meeting format

- Psychiatrist informs client of a specific way s/he can be reached
- Will usually get back in touch with client within 24 hours of contact, and decide with the client whether there should be a change in dosage or medication, and/or whether s/he should come in for an immediate appointment
- Increase the frequency and/or length of future meetings, even where there are additional hurdles set up by the payer insurance company.
- Goes beyond the basic "trial and error" (not waiting until the next meeting)

Psychiatrists and the most active clients (Choosing/Negotiating)

Finfgeld (2004) p. 47:

"Health care providers are urged to accept the trial-and-error approach, provide meaningful feedback if needed, and be prepared to rescue clients when necessary. This attitude echoes Gibson's and Ryles's suggestion that empowerment of clients entails risk taking and courage on the part of nurses (emphasis added)."

Findings part 3: Barriers & Facilitators

Category	Barriers	Facilitators
Psychiatrist attributes and relationship with client	Psychiatrist resistance to client perspective	Psychiatrist's openness to and/or direct interest in the client's perspective on treatment
Organizational and structural factors	Lack of time for meetings	Support of other mental health providers
Client confidence efficacy, willingness to assume responsibility	Limited self-efficacy http://www.youtube.com/watch?v=7EAsAfKlRg4	http://www.youtube.com/watch?v=ziU-9VezptQ • Personal Growth leading to greater participation • Self-confidence

Discussion

- Active participation seen by clients as more relational than rational
- Psychiatrist holds the power
  - They report that they favor collaboration, but when push comes to shove… maybe not
  - Psychiatrist seen as all knowing
  - Training needs
- Opportunities for activation when psychiatrist is ambivalent or neutral
- Client Self-efficacy
  - Formal education and health literacy
  - Personal growth, maturation and confidence
- Decision supports; the Internet
- Parents
- Other providers

Implications for Practice

- Training for psychiatrists
- Increasing the availability of advanced nurse practitioners (certified prescribers)
- Improved ability of PCPs to prescribe meds to people with SMI
- Psychiatric Office Teams, through which psychiatrists share clinical support staff (Torrey & Drake, 2010) Decision support tools prior to visit
  - Peer specialist.
  - Computer interface kiosk
  - Implementation challenges
- Decision support tools do not have to be office-based; **Internet** was popular source of health information for our TAY respondents,
- Inter-professional team-based approach (e.g., medical homes) to maximize client contact time (Légaré, F. et. al. 2011)
  - Collaboration
  - Economies of scale

Implications for Research

- Follow-up qualitative studies on the experience of active participation:
  - Interview psychiatrists who see clients at various levels of activation
  - Video/audio of clinical interactions
  - Client interactions with other prescribers, e.g., PCPs, nurses
- Additional research topics/questions:
  - How are some psychiatrists able to promote higher levels of activation despite systems limitations (e.g, busy clinic, insurance restrictions)
  - Factors contributing to a psychiatrist's capacity and willingness to 1) take a sincere interest in the client perspective, and/or 2) make themselves accessible as needed.
  - Roles of family members and decision Supports
- Develop participation measures sensitive to the higher levels of activation, and measures of access to psychiatric care
- Impact of integrated treatment teams on client activation

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Questions and Comments

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