RELATIONSHIPS AS THE FOUNDATION OF SHARED DECISION MAKING: THE EXPERIENCE OF YOUNG ADULTS WITH MENTAL HEALTH CONDITIONS

Jonathan Delman, JD, PhD
Commonwealth Research Center
Reservoir Consulting Group

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 an individual's development and use of his/her own capacity (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?

Clinical Significance

- Benefits of active participation
  - Preference-sensitive decisions: No “best” choice from clinician’s perspective
  - Adherence
  - Outcomes, Satisfaction
- Capacity and desire to be active participants
- (Un)Likelihood of active participation
  - Psychiatrist
  - Client
  - Environment

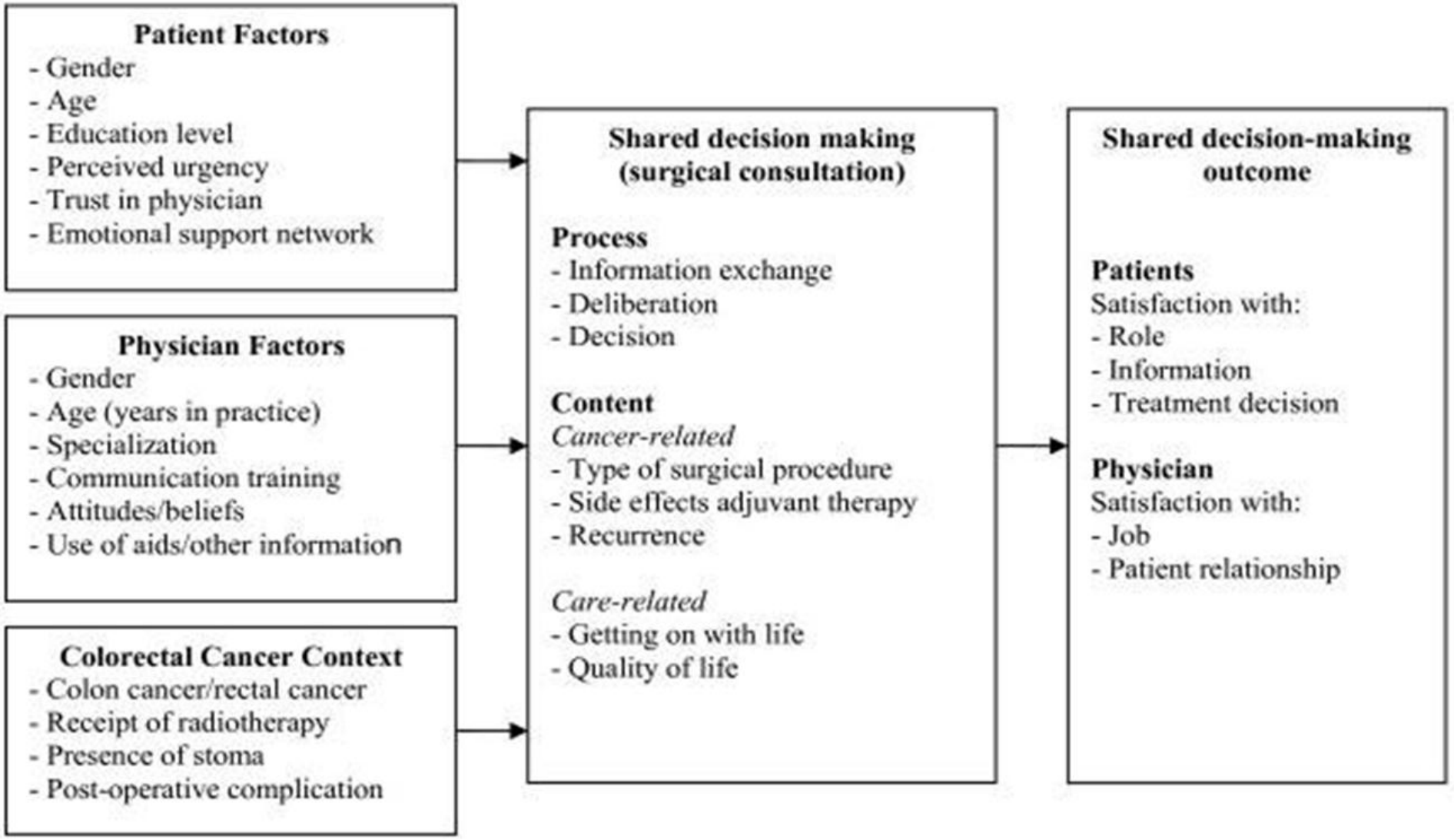
Research Significance

- 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)

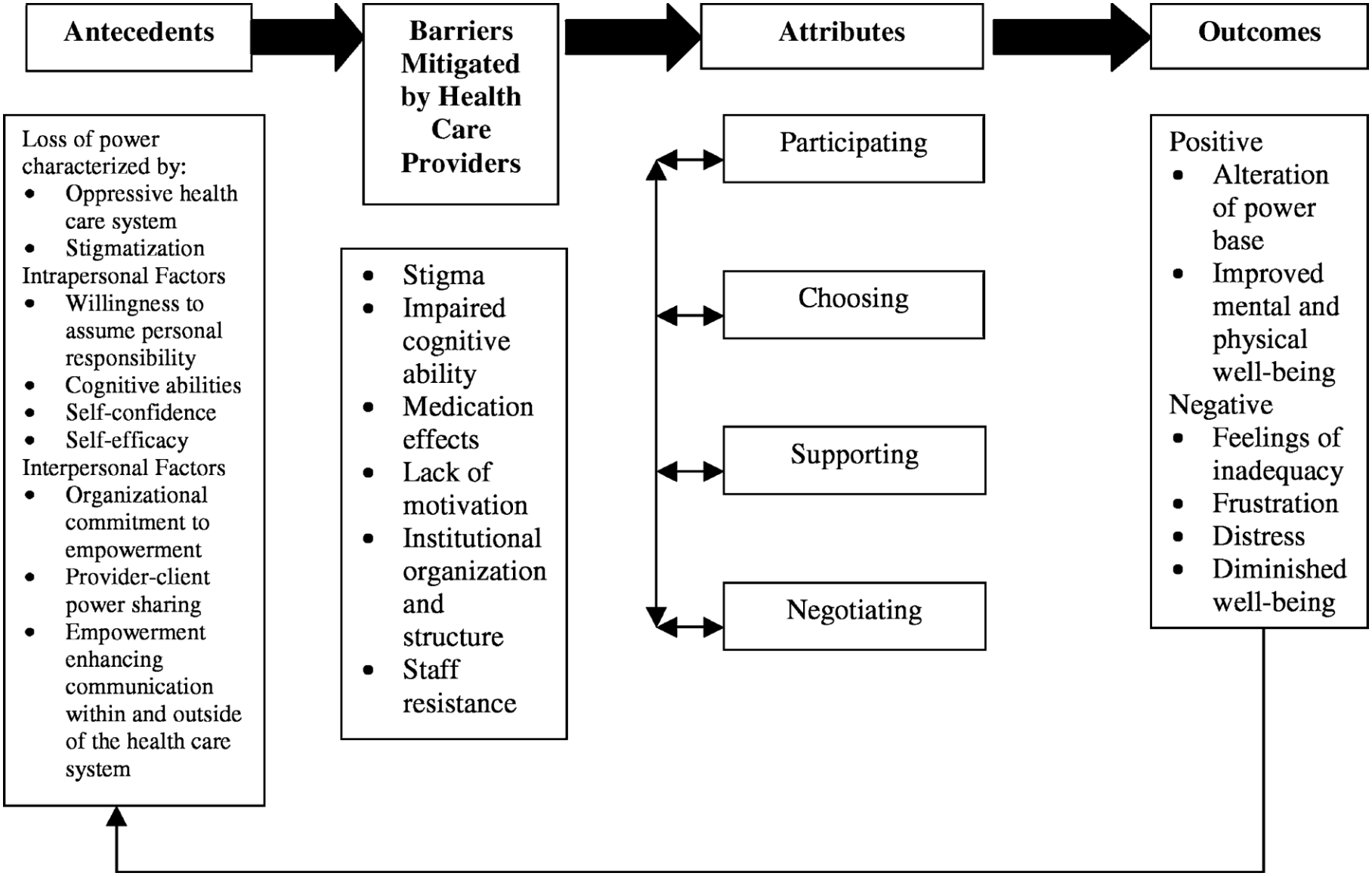
Shared Decision Making

- Patient and physician communicate information and values and make decisions together.
- Physicians are seen as having the most accurate information regarding the illness, treatment options and side effects
- Patients are seen as the experts on their health history, values, treatment preferences, and treatment goals

SDM Conceptual Model



Finfgeld Empowerment Model



Study Methodology

- Semi-structured Interview guide per Finfgeld
- 20-25 in person Interviews; Audio-recorded, & transcribed
- Field notes
- Analysis: Inductive analytic approach
  - Coding
  - Constant comparative analysis
  - Singular analyst

Eligibility

- TAY (ages 19-30)
- Seeing an outpatient psychiatrist for medications
- English speaking
- **Active Participant** (required a “yes” answer to all questions below)
    - 1) Have you provided information about your mental health issues to your psychiatrist?
    - 2) Has your psychiatrist explained to you the potential benefits and side effects of those options?
    - 3) Have you understood the benefits and side effects of those options
- Phone Screening

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 four levels of client activation

Number of respondents	**Findings**: Levels of Active Participation	Finfgeld levels of active participation
3	"**Communicating"-** Clients share information with the psychiatrists about their clinical condition, including symptoms, the effects of medications, and psychiatric history, all of which are used by the psychiatrist to make clinical decisions."	Participating
8	"F**ormulating"-** Clients not only share information, but also ask questions about medications and/or request medication changes based on dissatisfaction with how they are feeling.	
8	**"Choosing"-** Clients express feelings about an option/choice and/or assertively select that option, *regardless of whether the psychiatrist presents option(s).*	Choosing
5	**"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

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?*

The TAY client experience of decision making: Themes/Features

Psychiatrist is seen as knowledgeable
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
Psychiatrist is seen as interested in the client's perspective on treatment, and is not merely a good listener
Psychiatrist is available immediately outside of their regular meeting format if there are medication problems, and follows through on that promise

Knowledgeable

S*(F, 23): He knows what he's doing, I have confidence in him. He's a big chief.*
Interviewer: Oh, he's a big chief.
Subject: When I sit in his office he has different plaques and stuff like that, and his family, so... it's really, um, really nice.

S *(F, 27): She's nice... she knows what she's talking about, she's educated on the medication, all the different things like that. Uh, she's very educated on my specific diagnosis and symptoms, 'cause the majority of the people she sees have the same diagnosis and are on the same meds as me.*

Nice and Respectful

S *(F, 21): She's, she's got a vibrant personality, she's very gentle, soft-spoken person, Um... she's very considerate and very compassionate. It's a nice feeling, to feel as though… my opinion matters. And she's a very fair and respectful person. People even brought paintings in, to thank him.*

She doesn't treat you like a little kid, um, who doesn't really know anything. She treats you like an adult. She's got, you know, when you have something to say that's kind of like... she gives you the impression that it's important to her that she listen.

Interested in Client's Mental Health

S*(F, 24): Um, if it's new, she just tells me about it, tells me some of the side effects… Um, "It's time to change," um, or, if... if there's just a medication that isn't really taking, she might suggest a change to somethin', that may not be new... she's there to help. So, she doesn't just leave me on medications that aren't working. I mean, she calls the day before every appointment I have?*

- *Interviewer: She does?*
- *Subject: To remind me, yeah. She had, she asked me awhile ago if that would make it easier for me to... to remember to be there. And I said, "Yes." So, every, every time she sees me, the day before, she calls.*

Mutual Trust and Ongoing

S*(M, 25): The decisions were made by actually trusting in him and trying it... I'm a bit hesitant because again, a couple years ago, um, I gained sixty pounds in a summer from a prior doctor. ... I usually go along with whatever he says.*

I: Why?

S: Because I've known him for so long.

Interested in Client's Opinion

S *(F, 22) She didn't change my diagnosis… She didn't change my medications. She just said, "**I'd like to see you again and get to know you a little bit better."** And she said, um... "What do YOU think you have?" (Chuckles) And I said, "WHAT?" She said, "Your diagnosis right now is PTSD. Do you think that that's the correct diagnosis?" … I said, "I DO!" **And she said, "Well, you know, I just met you. I don't know any better. So," she said, "I think that's the correct diagnosis, too!" "So, if that's what YOU think, that's what I think.** And, previous to that there had been nineteen other different diagnoses"*

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 next meeting

Psychiatrist accessibility

- *I: And, what do you typically email him about?*
- ***S**(M, 28): Medication. Like if, when I have an emergency, that my pills were not workin"… I was gonna take an extra sleepin' pill to go to sleep… I hadn't slept the night before... I was like going paranoid... So, because of that**, I told him that I wanted to take an extra pill, and he agreed to it.***

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)."

Discussion I

- Relational perspective rather then the process of information sharing
- SDM framework is not the most appropriate lens:
  - Psychiatry's history of coercion and paternalism; necessity of encouragement to participate
  - Low client education and confidence; maturation process to be nurtured
  - Psychiatric illness often an ongoing condition
- Finfgeld empowerment framework is reliable, but does address the process of decision making

Participatory v. *Shared* decision making

Ruiz-Moral (2010, p. 41):

"*Even if a consultation meets the formal criteria for objective Shared DM, it does not ensure that the DM process will be subjectively collaborative … share means divide, distribute things in equal parts, share out in a fair evenhanded manner… Instead, participate means take part in something (in whatever way) and communicate (something).*"

- Relationally driven encouragement for client to share information and offer opinions
- Trial and error: gather information as they go, not just one meeting

Discussion II

- 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

Implications for Research

- Qualitative studies: Methods and Triangulation
  - Interview psychiatrists who see clients at variety of levels of activation
  - Video/audio of clinical interactions
  - Client interactions with other prescribers, e.g., PCPs, nurses
- Qualitative research topics
  - How some psychiatrists are able to achieve 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

Implications for Practice

- 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,
- Training for psychiatrists
- Inter-professional team-based approach (e.g., medical homes) to maximizing client contact time and thus promoting active participation in decision making (Légaré, F. et. al. 2011)
  - Collaboration
  - Economies of scale
- Increasing the availability of advanced nurse practitioners (certified prescribers), particularly for clients who are more stable.
- Improved ability of PCPs to prescribe meds to people with SMI

References

- Cruz, M., & Pincus, H. (2002). Research on the influence that communication in psychiatric encounters has on treatment. *Psychiatric Services, 53* (10):1253–1265.
- Davis, M. (2003). Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health*, 30, 495–509.
- Drake, R.E., Deegan, P.E., & Rapp, C. (2010). The promise of shared decision making in mental health. *Psychiatric Rehabilitation Journal: 34*(1), 7-13.
- Finfgeld, D.L. (2004). Empowerment of individuals with enduring mental health problems: Results from Concept Analyses and Qualitative Investigations. *Advances in Nursing Science*. *27*(1): 44-52.
- Légaré, F., Stacey, D., Gagnon, S., Dunn, S., Pluye, P., Frosch, D. et al. (2011). Validating a conceptual model for an interprofessional approach to shared decision making: A mixed methods study. *Journal of Evaluation in Clinical Practice*.,17(4), 554-564.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills: Sage Publications
- Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder, G., Ridd, M., & Kessler, D. (2009) ‘‘Medication career’’ or ‘‘moral career’’? The two sides of managing antidepressants: a meta-ethnography of patients’ experience of antidepressants. *Social Science and Medicine*, 68, 154–168.
- Ruiz-Moral, R. (2010). The role of physician-patient communication in promoting patient-participatory decision making. *Health Expectations, 13*, 33–44.
- Torrey, W. C., & Drake, R. E. (2010). Practicing shared decision making in the outpatient psychiatric care of adults with severe mental illnesses: Redesigning care for the future. *Community Mental Health Journal,* 46, 433–440.
- Woltmann, E. M., & Whitley, R. (2010). Shared decision making in public mental health care: perspectives from consumers living with severe mental illness. *Psychiatric Rehabilitation Journal*, *34,* 29–36.