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Shared Decision Making in Mental Health Treatment: Qualitative Findings from Stakeholder Focus Groups

Irma H. Mahone, RN, PhD[Research Assistant Professor],

University of Virginia School of Nursing, 202 Jeanette Lancaster Way, Charlottesville, VA 22903-3388. Ofc: 434/982-1805; Hm: 434/295-1463; Cell: 434/760-0949; Fax: 434/982-1809

Sarah Farrell, PhD, APRN, BC, CNL[Associate Dean for Academic Programs],

202 Jeanette Lancaster Way, Charlottesville, VA 22903- 3388

Ivora Hinton, PhD[Coordinator of Data Analysis and Interpretation],

202 Jeanette Lancaster Way, Charlottesville, VA 22903- 3388

Robert Johnson[Executive Director],

502 Old Lynchburg Rd., Charlottesville, VA 22903

David Moody, MD[Senior Director of Psychiatric/Medical Services],

502 Old Lynchburg Rd., Charlottesville, VA 22903

Karen Rifkin[Research, Evaluation, Grants Coordinator],

502 Old Lynchburg Rd., Charlottesville, VA 22903

Kenneth Moore[Consumer Advocate],

502 Old Lynchburg Rd., Charlottesville, VA 22903

Marcia Becker, PhD[Senior Director of Rural Services], and

502 Old Lynchburg Rd., Charlottesville, VA 22903

Missy Rand Barker, LPC, CSAC[Director of Training]

502 Old Lynchburg Rd., Charlottesville, VA 22903

Introduction

Studies in medication use in mental health have consistently identified insight, side effects, attitudes, psychopathology and therapeutic alliance as related variables (Kikkert et al., 2006; Mahone, 2008). Low adherence to recommended mental health treatment and specifically pharmacotherapy regimens, adversely impacts overall treatment and recovery outcomes for individuals in the community. But mental health providers and researchers are now looking at more than adherence when discussing medication-use in those with serious mental illness. For example, Deegan explored “non-pharmaceutical, personal medicine” including activities that in addition to decreasing symptoms, give meaning to life, raise self-esteem and avoid unwanted outcomes (Deegan, 2005). In a qualitative study of 29 participants, she found that recovery was much more than pill-swallowing; it required “hard work, personal agency, will, vision, hope, fortitude, courage, imagination, commitment and resilience” (p. 34).

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Correspondence to: Irma H. Mahone.

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Similarly, Deegan and Drake have argued that the terms *adherence* and *compliance* “fail to capture the dynamic complexity of recovery for autonomous clients learning to manage their disorders and resolve decisional conflicts” (Deegan & Drake, 2006, p. 1636). Askey, Gamble and Gray also suggest that the iatrogenesis or secondary illness caused by coercive treatments and stigma may be important variables to examine in relation to medication use in this population (2007).

Shared Decision Making

In non-psychiatric long-term illnesses, shared decision making has proven successful in improving the therapeutic alliance between provider and client, treatment adherence, self-care and overall treatment outcomes (Joosten, DeFuentes-Merillas, de Weert, Sensky, van der Staak, & de Jong, 2008; Adams & Drake, 2006). Emerging from a purely medical, disease-focused model in the mid-20th century, through psychosocial and psychiatric rehabilitation, the Recovery Model includes emphasis on values and preferences of the consumer (Frese, Knight & Saks, 2009). Deegan has described mental health recovery as recovering a sense of value after being labeled mentally ill (2007). Thus recovery is both a broadening and an alteration of the medical and rehabilitation approaches of the past (Frese, Knight & Saks, 2009). Hence, shared decision making in medication use is conceptually congruent with person-centeredness and recovery trends in many mental health transformation initiatives.

Shared decision making is a transactional/interpersonal model of communication with which health care providers and patients work collaboratively to select treatment and care that includes patients' health experiences and preferences (Curtis, et. al., 2010). Adams and Drake (2006) note that in shared decision-making “the practitioner becomes a consultant to the client, helping to provide information, to discuss options, to clarify values and preferences, and to support the client's autonomy” (p. 90). This is in keeping with the *New Freedom Commission* vision of greater client “learning, self-monitoring and accountability” (Freedom Commission, 2003), the *2005 US-Institute of Medicine Report* which recommends that “individual patient preferences, needs and values prevail in the face of residual stigma, discrimination, and coercion into treatment” (IOM, 2005), and the position of the *American Nurses Association* which states that “the nursing profession values the promotion of patient participation in their own health care...nurses respect self-determination, independence, and choice in decision making in matters of health” (American Nursing Association, 2010).

The ultimate goal of shared decision making models is to provide health care providers with relevant data and necessary skills, and to empower people with long-term illnesses with the information and confidence to manage their health wisely (Wills & Holmes-Rovner, 2006). The decision-making process refers to how medical, scientific information is combined with personal values to form preferences which in turn shape decisions, behavior and outcomes (Wills & Holmes-Rovner, 2006). Although preliminary studies on shared decision making show mixed results, some positive outcomes that have been demonstrated include improvements in general functioning, illness symptoms, insight, quality of life, health-related quality of life, satisfaction with medication, satisfaction with care, community tenure, patient knowledge, quality of physician/ patient relationship, and attitudes to drug treatment; greater patient willingness to participate and patient perceived involvement; and fewer bed days and side effects (Joosten, DeFuentes-Merillas, de Weert, Sensky, van der Staak, & de Jong, 2008; Mahone, 2008; Hamann, et. al., 2006; Deegan, 2007; Schauer, Everett, del Vecchio, & Anderson, 2007).

Optimal mental health treatment is an individualized process where providers collaborate with service users to tailor the best possible services and supports for that individual, based on the person's needs, strengths, preferences and recovery goals (Adams & Drake, 2006).

SDM is a model that allows consumers *and* providers to assess a treatment's advantages and disadvantages within the context of recovery (Deegan & Drake, 2006), and will likely change the roles of both consumer and provider substantially. SAMHSA's position on SDM is that it is "consistent with recovery-based transformation and the foundation values of choice, self-determination, and empowerment" (SAMHSA, 2007). Shared decision making holds promise as an emerging best-practice strategy to better engage persons with serious mental illness in all aspects of their recovery including decisions about their medications. Although illness self-management strategies is being increasingly accepted as evidence-based practice in mental health (Adams & Drake, 2006; Schauer, Everett, del Vecchio, & Anderson, 2007), reluctance exists by some patients, caretakers and professionals to move forward on self management in medication use (Lein & Wills, 2007).

Seven focus groups were conducted as part of the information-gathering phase of a participatory-action research project related to shared decision making in medication use by persons with serious mental illness. Findings from the qualitative analysis of the focus group transcripts are reported here. A companion article (Mahone, et.al., 2011) describes the Participatory Action Research partnership process.

Methods

Setting

A local mental health clinic in central Virginia, the community partner in this study, is the single point of entry for public mental health services in five counties. Their mission is to create and provide accessible, cost-effective services of the highest quality for persons with mental health needs, so that they can achieve more independent, satisfying and productive lives. This includes supporting these persons on their journey of recovery; helping them build on their strengths, increase their choices and their control in order for them to reach their highest potential and quality of life; advocating for their needs and educating the community to the challenges they face and the gifts they offer; and facilitating the natural supports of family, friends and community. The clinic serves approximately 6000 people each year of whom approximately 1250 persons have a diagnosis of serious mental illness. In the fall of 2008 the clinic implemented an electronic medical record that provides a single, person-centered treatment plan for each individual served.

Design

Using a Participatory-Action Research orientation, a partnership between a School of Nursing at a public university and a public mental health clinic developed around a shared goal of finding an acceptable shared decision making intervention targeting medication use by persons with serious mental illness. One of the goals for the year-long pilot (NIH-NINR grant P20NR009009 RHCRC, Pilot # 5–15) was to solicit input about shared decision making in mental health from various stakeholder groups in the local mental health community. The Partnership Research Team committed to explore shared decision making in mental health using numerous different methods. Although the ultimate goal of the partnership was to identify the most suitable shared decision making intervention targeting medication use for a trial at this clinic, the information-gathering activities also included shared decision making in mental health in a broader sense.

The Partnership decided to use focus groups with stakeholders to gain information on shared decision making about medications, then decided how many focus groups to conduct, what stakeholder groups should be represented, what recruitment methods should be used, who would lead them and where they would be held. Seven different stakeholder focus groups were held with family members, prescribers (psychiatrists and psychiatric nurse

practitioners), other providers (nurses, case managers, support staff), rural clinic staff and three consumer groups. Core group members recommended individuals based on their personal interactions with them in other settings and their knowledge of their work and effectiveness in the local community. The focus groups were co-led by the first author and a clinic partner. The School of Nursing provided \$10.00 Walmart gift cards as incentives and the clinic provided refreshments for focus group participants.

Each focus group started with a brief PowerPoint presentation by the investigator introducing the concept and giving an overview of shared decision making, including definitions and rationales for shared decision making in mental health. Shared decision making was defined as “a process that helps consumers and health care providers work together to make important treatment decisions, that actively involves consumers in their own treatment planning, and that helps health care providers engage consumers in a dialogue.” To providers it was also framed as “a whole new way of doing business and a global re-thinking of the consumer/ provider relationship.” Additionally, to prescribers shared decision making was described as “an emerging best practice in mental health care that is increasingly gaining acceptance.”

This was followed by a distinct set of questions drawn up for each group (see Table 1). The questions were designed to stimulate discussion and key points were noted on a flip chart as the discussion proceeded.

Detailed transcriptions of the qualitative interviews were created. The transcriptions identified all speakers and noted any cases of interruption in speech. The data were verified, de-identified and entered into the qualitative data analysis computer software package NVivo (NVivo, 2008). Content analysis was conducted, identifying, coding and categorizing primary patterns in the data. The text was read and reread to identify significant strips, breakdowns and general themes. Larger categories were identified based on similarities between the themes and organized into most frequent responses. To assess reliability, the transcripts were analyzed independently and compared the coding for degree of agreement. The themes were then shared with a representative from each focus group to ensure validity and accuracy of the analysis.

Approval for this study was obtained from the UVA Institutional Review Board (IRB) for the Social and Behavioral Sciences (#2008016200). All authors certify responsibility for this manuscript.

Results

The focus groups included family members (N=4), prescribers (psychiatrists and psychiatric nurse practitioners) (N= 4), other providers (nurses, case managers, support staff) (N=6), rural clinic staff (N=6) and three consumer groups (N=8,7,9). Consumer groups represented persons attending Clubhouse Program, a residential program for persons with dual-diagnosis, and a peer-run day-support program. A total of 44 persons (34% male) participated, representing every level of education, income, insurance coverage, and marital status, and including both Caucasian and other races. Themes identified across all focus groups included implementation barriers, consumer factors, information-exchange issues, new skills needed, and outcomes expected.

Provider Barriers

The question was asked: What practical barriers do you foresee in implementing shared decision making in mental health? Barriers identified by providers included the long tradition of basing treatment on the “doctor/diagnosis-driven medical, disease-focused

model.” Other related issues included the obligations of mental health professionals to society, the risks of harm to self or others, legal liabilities related to responsible prescribing and moral obligations. Prescribers focused primarily on their legal obligations and the responsibility they have always had for medication decisions. Lack of system support and the need for “every part of the mental health clinic” being committed to recovery was identified as another barrier.

“For example, if I as a case manager am making my consumers aware of this new model, this new way of doing things, it’s going to take years. ...So I think that there’s got to be more than just service providers. There has got to be agency awareness.”

Reference was also made to “certain expectations” of persons from other agencies who made referrals to the mental health clinic. Providers noted that the whole system is “learning how to re-immense ourselves in persons.” They agreed that mental health emergency situations presented special challenges to shared decision making and making Wellness-Recovery-Action Plans (WRAPs) and advanced directives could be used more effectively when persons were “no longer able to make informed, intelligent choices” or “the point where rational thought isn’t there.” Providers were worried about potential risks to self or others. Also, prescribers noted the disconnect between inpatient and outpatient prescribing practices, with outpatient prescribers generally more in tune with the realities of living in the community.

“The insurance company makes the decision. I’ve had a number of decisions about meds be totally thrown overboard when they go into the hospital. So I think that’s a practical barrier -that there are more forces here than you’d think that control what is prescribed.”

Family members raised the issue of legal obligation - “because of the law of the land, how far can he compromise his recommendation and still be a responsible physician?” On the other hand, this group acknowledged that “from a sales standpoint, if you sell someone the wisdom of an idea, you’re much more likely to be successful than issuing an edict.” Family members described the potential for danger in practicing shared decision making without sufficient history, such as past medication use, benefits and side effects.

Consumers described the traditional medical, disease-centered model as “the professional would make all the decisions,” “the whole idea was that you just take what I give you,” “nobody talked to me about my meds,” “presented to me as a black-and-white situation,” “docs don’t learn about alternatives when they go through med school,” “someone is mandating what you must do and you have absolutely no say-so in that,” “they always say there is no hope,” and “condescending ...how I would discipline my kids.” They said that many times they felt a need to “please the people giving them service” and to “keep the peace” rather than convey honest information.

“You know what I believe, why people have so much problem getting involved with their care is because they’ve had so many people for so many years answering that care for them. It’s like you’ve been making this decision for me for so long, why start now making my own decisions, when sometimes in certain situations they make the decision for you anyway?”

Consumers discussed the permanence ascribed to them as clients once they began receiving services in public mental health. “I don’t think that the current system - it’s almost like once you start seeing a psychiatrist, that’s your prognosis forever.” Another consumer mentioned that for her, as much help was obtained through informal networks as through the formal mental health treatment system. Other consumers experienced the system as very rigid, “and you know they’ve got the level system all written out in black-and-white; and you know

there are no options.” Consumers acknowledged the challenges of shared decision making in crisis. “In the community when I’m not in crisis, I do have more options.” One consumer shared a positive experience of being offered choices when in crisis.

“Recovery had never entered my mind, let alone when I was having a crisis. That meant so much to me that even in a moment of crisis, I was given the choice of whether I wanted to recover.”

Consumer barriers

Consumer-related barriers in shared decision making included competence, insight, literacy preferences, fears, and trauma from past experiences. Providers envisioned practicing shared decision making as “changing expectation, setting the bar higher for consumers.” Concerns were voiced about the ability of persons with “severe cognitive impairment” to participate and about the unique needs of persons with a borderline personality disorder diagnosis. Providers believed that lack of insight, memory deficits, and fears of failure, and fear of getting better would affect the practice of shared decision making. Also, persons who cannot read or write would have difficulty using printed decision aids. Providers thought older clients with longer histories of passivity would have a more difficult time adjusting to this new paradigm - “they want you to make decisions for them.” Providers acknowledged however, that “the goal is to help consumers achieve their goals.”

One consumer factor identified by prescribers was the illness process itself - “...the biologic process, whatever the brain abnormality is, with something like schizophrenia.” Prescribers also said that some consumers were totally closed-minded to taking any medication: “There are some people, even if they can hear all the pros and cons, they just don’t want medicine in their body, and that one overwhelms the rest.” Prescribers agreed that consumer insight (or lack of it) was a significant factor in successfully practicing shared decision making.

“I think the question of insight is different. I wasn’t bringing up cognitive impairment. I was bringing up insight and I think that is something separate. So we have to be careful not to equate those two in terms of a concern because insight is not accepting that you even need to be in the office, meeting with the provider at that time, because you have nothing wrong with you, so why should you even be there?”

Prescribers identified the value of connecting with the consumer.

“And so some of that joining might occur outside the realm of medications. So thinking in a process way then it might be that something like this would occur later down the road with them if we join with them successfully around the non-medication issue.”

Consumer readiness to participate and developmental issues were also discussed by providers.

“Providers will need to learn what their capabilities are.”

“I think that’s a growth opportunity for some of our patients who are saying right now, ‘Oh you just tell me what to do.’ Doesn’t mean we just stop there and we never work with them on that. Like, as when they are out of the hospital longer, and increasing self-esteem and feeling a little bit better about themselves.”

Family members pointed out the difficulty of reasoning when sick: “When a person is mentally ill, and particularly when they’re seriously psychotic, it [shared decision making] would be more challenging,” and they questioned the notion of viewing the consumer as an “expert.”

Some consumers noted their fears of “dealing with some of the feelings” and of “disapproval from the prescriber.” Other consumers shared the view that shared decision making was “so basic to human dignity - to have a say in your own choices in your own life. You know, it’s not brain science.” Consumers also noted the problem of being considered incompetent once they had a mental illness.

“that a person, once they have a schizophrenia, bipolar, schizoaffective or any of those, there is something about their brain that can’t think correctly. And so other people have to think for them. And even though they won’t acknowledge it, there are a lot of providers that just assume a certain level of incompetency.”

Consumers also acknowledged the need to respect their own expertise. “I know my body and my mind better than you do.” Consumers felt that they should convey the information to the prescriber when medications were interfering with accomplishing their goals.

“Well, what are your goals? That’s been a very big shift but it’s very empowering and to me it promotes recovery. Because I am being asked, ‘What is important to me? What do I want to work on that’s going to improve the quality of my life? What is that, you know, I want to do?’”

Consumers also identified trauma from past coercive treatments as a significant factor to consider, because “we do have forced treatment, you know, when you have mental health issues.”

“If you don’t take your medicine they inject you with medicine. You know, it’s like every single choice is taken away from you. And why is that suddenly OK, as an adult? Why is it OK for all my choices to be suddenly taken away from me?”

“When I went in there, there was no shared decision making. They said, ‘Here, you need to take this and if you don’t take it, we’ll strap you down and make you take it.’ That’s the way it was. And they started me on medication.”

“I remember when I was young, my mother forced me to take my medicine because the doctors said I had to take it. It took me 30 years to get un-negative about that.”

Information-exchange issues

Prescribers noted that some consumers are more knowledgeable than in the past because of access to the internet, yet other consumers still look for the prescriber to be the only source of medication and treatment information. Prescribers shared experiences of consumers’ positive responses to being presented advantages and disadvantages. There were concerns expressed about adequate preparation and training of both sides - providers and consumers, prior to implementing shared decision making at the clinic.

Family members questioned whether persons engaged in shared decision making have the “self-awareness, self-knowledge, and willingness to explore....I have to know what’s important to me.” They also questioned whether the consumers could ever be viewed as valuable experts, even though they would be most knowledgeable about their preferences and lived experiences: “expert status implies knowing what’s important.” The view was expressed that a consensus decision could be a compromise to the degree that there was willingness to compromise. The issue of the danger of this approach without sufficient information exchange was also raised.

Consumers expressed concern that antipsychotics have serious side effects: “I was given a piece of paper with information about my medication I’m currently taking and it specifically says that it destroys your immune system.” They also expressed concern that they are not always given adequate information about the antipsychotics prescribed for them.

“The doctor should inform you of your medicines because it’s something that your body is going to go through and you have to be apprised of these things so you’re not in shock or anything.”

“The reality is, a lot of these anti-psychotic medications, not so much the newer ones but older ones have, you know, undesirable effects taken after a long period of time. I don’t think that’s made upfront to everybody. But I think the more you know about your medicine the more you can make an informed decision: is this the best medicine for you?”

“You would like more information about side effects and whether what you’re experiencing is a side effect of the medicine or not, whether it’s something else.”

“At this point I’m considered diabetic. So, you know, I go to the doctor and I’m like, you know, nobody ever mentioned to me that this could be a link and I was very angry and I was like, you know, I want to get taken off this medication immediately. And I felt like if I would have been equipped with all the knowledge, now I’m not saying I wouldn’t have taken the medication, but I would have taken better care of myself as knowing that I should probably try to get my blood sugar taken regularly or things like that.”

Some consumers looked for things other than medicine from their prescribers.

Consumers also expressed a need for more two-way conversations and openness to their suggestions.

“...they should prescribe some *hope* to you that one day you may not always have to be on medication, that you’ll have tools and other things to be able to use to move forward in your recovery.”

“You know, it’s like if I was told some other things that I figured out like, after a ten year span how to regulate my sleep, it might have nipped it in the bud in the beginning. And I wouldn’t have went through like ten years of sleep medicine.”

“...my desire was for us to find a common ground and it seemed like it was presented to me as more like a black-and-white situation.”

“If they agree with you of course they’re going to, you know, support you but if you’re going to try and step out and do something that they don’t think you’re ready for, even though it’s your decision, they’re going to discourage you and make it a little more difficult for you to do it, you know? And that’s unfortunate because you would want people kind of like on the sidelines saying, you know, ‘Go Mary! Do whatever you want to do.’ But, it’s not always like that.”

Consumers expressed the view that sometimes doctors do not have enough information prior to prescribing medications; and only the consumers themselves have information about how the medications are affecting them, and how their responses are different from the medication inserts.

New skills needed

Providers expressed amazement at how well-functioning computer systems in health care settings have the ability to make all the needed information available at the right place at the right time. They suggested that electronic decision aids may be able to interface with electronic medical records to refine this even more. They pointed to a need for ongoing coaching on person-centered, person-first language (emphasizing that they are people first and the disability second), and active listening (“listen to our consumers and hear their preferences”), including “changing expectations, setting the bar higher.” The need for

negotiating and motivational-interviewing skills was mentioned, as well as the need to assess stage-of-readiness prior to engaging a client in shared decision making. Providers also pointed to a need to acknowledge the learned helplessness experienced by many clients. The potential for shared decision making to create a safe environment for clients to try decreasing their dose or going off their medication was discussed by providers. They recognized that providers are not the only experts and with shared decision making they are not in control to the degree they were earlier. Providers expressed confidence that “building that partnership” was a skill that could be learned. They, however, felt that many case managers needed to further develop skills in speaking to clients in respectful ways and respecting client choice, and they thought this would require relinquishing some control and promoting more peer advocacy. Prescribers expressed the view that shared decision making was actually an extension of person-centered planning, which they already did. They said a decision aid would give them a more concrete way to facilitate the interaction and record mutual decisions.

Family members expressed the view that a key component of shared decision making would be how to negotiate a compromise and the “basic debating of understanding.” Providers would need to develop the ability to discern “when it is OK to honor the consumer’s preference.”

Consumers expressed the view that shared decision making “puts consumers at a place where their voice is being heard and their preferences are being respected in the process.” They felt there would be a need for providers to learn greater listening skills.

“I know I have my own personal ideas and thoughts and feelings about the way that I want to live my life. And then the question in my mind is how often does the doctor really listen and hear everything I have to say before making the choices about medication and treatments.”

“A lot of doctors do have good interpersonal skills.”

“You do find doctors who are very non-listening. They haven’t been taught proper listening skills, or call it communication skills.”

Outcomes

Providers said advance directives could be helpful in giving “steps to follow should somebody start to have severe mental health.” They felt that shared decision making offered the

“How can they recover when control is taken away?”

“The goal is to try and help the consumer achieve their goals.”

“It gives them more enthusiasm to actually want to recover. If you force them they’re not going to give it their all.”

“The goal is to get them to the highest level of independence.”

“My job is, I feel, to help them acquire those [recovery] skills.”

potential for greater consumer participation and self-management. They acknowledged that “It’s all about relationships” and voiced the hope that shared decision making would provide “that time needed to develop rapport with the consumer.” They also expected that there would be greater effectiveness of treatment plans because “if people understand, there would be more follow-through.” Finally, providers believed that with more shared decision making more consumers would recover.

Prescribers suggested that patient satisfaction with treatment would be a good outcome to measure, along with larger issues such as quality of life. One observed that greater client involvement results in clients' being "a whole lot happier" and "a whole lot easier to work with."

Family members suggested that number of hospitalizations and time between hospitalization could be used by consumers themselves as practical benchmarks. Also they felt that independent living and not being dependent on the system year round, would be a good outcome measure to consider, as well as socialization skills and development of a social network. Given the brief medical appointments consumers are offered in the mental health system, they felt that "if they know that person, it goes a long way to get to what the outcome is that you want." shared decision making was seen as a way for "the patient to become an integral part of the treatment team" and "a specific model to implement Recovery."

Consumers thought that shared decision making was consistent with Recovery principles.

"Recovery is unique for every person. The whole idea that you can participate and shared decision making kind of reinforces a recovery model in that no one can tell you what your goals are in life but you. No one knows what you want to strive for. You can have a doctor and a clinician deciding that these are the things you want to work on, but they might not even be what is important to you in your life. That may not be what moves you forward in your recovery. So I think it's important to be at the table when, you know, decisions are made and to feel like there's some mutuality there like you guys are on the same level."

"Well, what do I want to work on? Well, what are my goals? That's been a very big shift but it's very empowering and to me it promotes recovery because I am being asked, 'What is important to me? What do I want to work on that's going to improve the quality of life? What is it that, you know, I want to do?'"

Consumers noted that even in crisis situations there are often choices that could be offered to consumers. Some consumers felt that to be "more of a team with the many people that work with you - that's one of the mile markers." They felt that consumers may need fewer appointments at the clinic and when they leave, "consumers would feel valued," "everyone respected us more," and feel "treated like a person." Other consumers spoke of the best outcome being to "want to move on with the rest of my life, man" and a good outcome measure may be "the degree to which you feel that you're in control of your life." Another outcome of shared decision making predicted by consumers was greater self-management and initiative - "to start to take care of yourself," with providers cheering them on when they were ready to take risks.

Discussion

The mental health providers were very concerned about community, cultural and political issues. Their primary focus was on the need to change the attitudes, expectations and language of the community, agency and consumers. The outcomes they expected from shared decision making about medications included consumer empowerment, consumer involvement, faith in them as providers and higher expectations for all. These rural providers focused primarily on issues concerned with improving the system, dealing with consumers' limited access to resources, and addressing consumers' fear-of-failure. They say there is a need to foster respect and teamwork among providers and encouragement to speak out against inappropriate attitudes and language. They also say there is a need to foster consumers' independence, goal achievement, skill acquisition and sharing with the provider. Many prescribers felt that a more formal system of shared decision making could help

promote person-centeredness. Their concerns had to do primarily with legal concerns, fulfilling their responsibilities as prescribers and finding the time to learn and implement a new system.

Families valued shared decision making but were concerned about the capability of the consumer and had difficulty seeing the consumer and provider as equals. They saw shared decision making as hampered by time limitations which providers face rather than knowledge that providers lack. They also put a great deal of emphasis on measuring outcomes they considered relevant, particularly social skills, independence, happiness, and quality of life.

The three consumer focus groups stressed consumer rights, being back in the community, and getting on with the rest of their lives, and they wanted providers to recognize their strengths and talents. Consumers welcomed greater shared decision making while articulating fears of higher expectations and greater responsibility for them in their own recovery.

Conducting focus groups with different stakeholders yielded valuable information in planning for implementing this approach in public mental health. Although the focus-group methodology is generally effective for exploring new concepts, particularly when the researcher uses open-ended questions, one limitation of using this method is that the voicing of group norms may silence individuals with dissenting views.

Conclusion

Provider barriers to shared decision making include the history of the medical, disease-centered model, mental health crises, lack of system support, and time. Consumer-related barriers include competence, fears, insight, literacy and trauma. Information-exchange issues include consumer passivity, whether consumers can be viewed as experts, and the importance of adequate history and past treatment information. New skills needed to practice shared decision making include provider knowledge of alternative treatments, mastery of person-first language and listening skills; consumer ability to articulate their information, and computer skills for both. Outcomes that can be expected include greater power-sharing, greater follow-through with treatment plans, greater self-management on the part of consumers, and improved therapeutic alliances.

Findings from these focus groups support that medication use by persons with serious mental illness is a complex, dynamic process requiring consumers to continually navigate decisional conflicts as they learn to self-manage their disorders; and shared decision making is a model that allows consumers *and* providers to assess a treatment's advantages and disadvantages within the context of recovery (Deegan & Drake, 2006). Implementing shared decision making in public mental health will impact consumers, their families, providers, prescribers and administrators. Shared decision making trials in public mental health are needed to identify other barriers and facilitators of this practice, perhaps looking at first-episode consumers, using peer specialists as decision-coaches, methods to integrate this concept into transformation initiatives, and exploring sustainability issues.

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Table 1**Focus Group Questions**

Focus Group	Questions asked
consumer groups	What does “recovery” mean to you? How important is “recovery” when it comes to making decisions about how you live your life? Do service providers honour and respect your choices? Would you like to be more or less involved in the decisions that affect your treatment? Have you ever felt coerced (forced) to “go along” with a treatment that you preferred not to? Have you ever heard of shared decision making in mental health services? What do you think is meant by this term? Do you feel that you are always fully informed about your treatment options? If not, what information did you learn later that you wished you had been told about? Do you want to fully participate in the decisions that affect your treatment? Or do you prefer that others make the decisions for you? How do you think your full participation in, and sharing in the decisions about your treatment, would affect your “recovery”?
Family members	What does “recovery” mean to your family member? How important is “recovery” when it comes to making decisions about how your family member lives their life? Do service providers honour and respect your family member choices? Would you like to be more or less involved in the decisions that affect your family member treatment? Has your family member ever felt coerced (forced) to “go along” with a treatment that your family member preferred not to? Have you ever heard of shared decision making in mental health services? What do you think is meant by this term? Do you feel that your family member is always fully informed about their treatment options? If not, what information did your family member learn later that they wished they had been told about? Does your family member want to fully participate in the decisions that affect their treatment? Or does your family member prefer that others make the decisions for them? How does your family member think their full participation in, and sharing in the decisions about their treatment, would affect their “recovery”?
Mental health providers	In your opinion, does shared decision making align with Recovery concepts? What practical barriers do you foresee in implementing shared decision making in mental health? What new skills would you need to learn to be comfortable implementing shared decision making effectively? Do you believe your consumers could be taught to participate more? What changes would need to take place system-wide for shared decision making to be successful?
Rural mental health providers	Same as for “Mental Health Providers” above, and: Does being a rural clinic make this easier to implement? Why or why not?
Prescribers	In your opinion, do the positive outcomes of shared decision making outweigh the disadvantages? What practical barriers do you foresee in implementing shared decision making at this mental health clinic? What research design should we use and what outcomes should we measure? What unique considerations/ modifications should we include for rural people?