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## The Role of Patient Activation in Psychiatric Visits

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## Abstract

**Objective**—This study identified ways that consumers of mental health services are active participants in psychiatric treatment.

**Methods**—Self-reported activity in treatment and observations of audio recorded psychiatric visits were examined. Four providers (3 psychiatrists and one nurse practitioner) and 10 of their consumers with severe mental illness (40 total) were recruited. Consumers completed questionnaires on patient activation, illness self-management and medication attitudes on the day of a psychiatric visit. The visit was audiotaped, transcribed, and thematically analyzed. Providers reported diagnosis, substance abuse, and medication adherence.

**Results**—Self-reported patient activation was positively related to illness self-management and negatively related to substance abuse. Consumers were active in partnership building, seeking and displaying competence, and directing treatment; however, there was little relationship between self-reported activation and observed behaviors.

**Conclusions**—Consumers are active in a variety of ways; but, similar to other populations, the relationship to self-reported desire for involvement is not direct.

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Living successfully with chronic health conditions requires active collaboration in managing illness -- consumer and health care provider working together to identify problem areas, set goals, learn self-management skills, and participate in follow-up (1). An active partnership is critical because the majority of time spent managing chronic illnesses takes place when the consumer is on his/her own in the community rather than in the provider's office. Further,

reviews have shown that positive, relationship-centered approaches translate into higher levels of trust, satisfaction, reduced emotional burden, and improved biomedical markers such as blood pressure and blood sugar control (2). Relationships in which patients are activated to take greater control in treatment appear to be particularly important predictors of physical health (3).

National policy supports an active role for consumers of mental health services, and research indicates that people with severe mental illnesses such as schizophrenia want to take a role in making decisions about their care (4). Shared decision-making is gaining more attention (5) and interventions are being developed to improve activation and shared decision-making in this population (6). Unfortunately, tools to assess active participation are lacking (5).

In the general medical field, the Patient Activation Measure (7) has been successfully used in a variety of chronic health conditions including diabetes, arthritis, and high blood pressure. The scale assesses an individual's knowledge, skill, and confidence for actively managing illness and has been associated with a variety of self-management behaviors including diet, exercise, nutrition, self-monitoring, and reading about medications. Patient activation has also been associated with service utilization, medication adherence, satisfaction with services, and quality of life (8).

To better understand patient activation in people with severe mental illness, we conducted a cross-sectional, mixed-methods, descriptive study assessing self-reported and observed patient activation. We hypothesized that self-reported activation would be positively related to illness self-management, positive attitudes towards medications, and provider-rated medication adherence. We explored ways consumers were active during visits by identifying themes of activation and rating each consumer's overall activation. We hypothesized that observations of activation would be related to self-reported activation, i.e., people who endorsed high levels of activation on a questionnaire would be rated as more active in the visit.

## Methods

The study took place between March and July, 2008 at a community mental health center in a medium size Midwestern city serving children and adults with severe mental illnesses at 200% of poverty level or below. The agency organizes treatment teams around the assertive community treatment (ACT) model serving consumers who have a prior hospitalization history, homelessness, and/or incarceration. We contacted prescribers who served adults, and the first four we approached (of five possible) agreed to participate (three psychiatrists and one nurse practitioner). A research assistant scheduled days to recruit 10 consumers per provider. During recruitment, agency staff introduced the assistant who described the study and reviewed the informed consent statement. Consumer participants completed a brief packet of surveys prior to (or just after) the visit and were paid \$10. Providers allowed us to audiotape the visit and provided diagnosis and ratings of substance abuse and medication adherence; they were not paid for their participation. All procedures were approved by IUPUI's Institutional Review Board.

We approached 43 consumers to gain a sample of 40 (a 93% participation rate). Two declined citing lack of time, and one declined for personal reasons. Participants had a mean age of 43.5 ±15.2 years, were predominantly Caucasian (31, 78%), and most had at least a high school degree (28, 70%). About half were female (21, 53%). Diagnoses included schizophrenia/schizoaffective disorder (25, 63%), bipolar disorder (4, 10%), major depression (8, 20%) or other (3, 8%). Six (15%) had a co-occurring substance abuse disorder. Most were being served on state-certified ACT teams (29, 73%).

Activation was assessed with the short form, mental health version of the Patient Activation Measure (7). The 13 items refer specifically to “mental health,” rather than “health” (e.g., “I know what each of my prescribed mental health medications do”). Scores have a theoretical range of 0 (least activation) to 100 (highest activation). Internal consistency was good (Cronbach’s alpha = .83); scores ranged from 40.1 to 91.6, with a mean of 57.7 (SD=12.5). See on-line appendix for sample distribution.

Illness self-management was assessed with the client version of the Illness Management and Recovery Scale (9). The scale consists of 15 items rated on a 5-point behaviorally anchored scale and include: progress toward goals, knowledge about mental illness, involvement with significant others and self-help, time in structured roles, impairment in functioning, symptom distress and coping, relapse prevention and hospitalizations, use of medications, and alcohol and drug use. The scale has demonstrated adequate internal reliability, good test-retest reliability, and convergent validity (9).

Medication attitudes were assessed with the 10-item Medication Adherence Rating Scale which has been shown to have adequate internal consistency, test-retest reliability, and positive correlations with related measures (10). This measure includes items such as “I take my medication only when I am sick” and “My thoughts are clearer on medication.”

Provider ratings were given for medication adherence (1 = rarely/never, 2 = half the time, 3 = usually, 4=always/almost always). Providers were asked the diagnosis for each consumer and whether the individual had co-occurring substance abuse.

Observations of activation came from the 40 visits (one per consumer) that were audiotaped, transcribed verbatim, reviewed for accuracy, de-identified, and imported into Atlas-ti. Through an iterative, consensus-building process, we listened to and reviewed transcripts to identify emergent themes related to activation. Initially four of us reviewed a transcript independently to identify points where the consumer was active (or not active when expected) and what led to this identification. We met as a group to discuss our findings and repeated this process on several transcripts until we had a set of defined codes. Then three of us coded transcripts in blocks of three (two independently and the third in common) to maintain inter-rater reliability. We met weekly to compare coding of the common transcripts, resolve discrepancies and refine coding through consensus. We also rated each transcript on the extent to which the consumer 1) was active in the negotiation about treatment, 2) seemed interested in the management of his/her mental illness, and 3) was involved in controlling his/her mental illness, based on research in diabetes management (11). However, we used a cruder rating scale (0 = not at all; 1 = a little; 2 = somewhat; 3 = a lot) because we did not have the history of prior data for more fine-grained levels of activation.

We examined Pearson correlations among all measures, and categorical variables (e.g., substance abuse) were dummy-coded as 0 or 1 to indicate presence or absence of the variable. We used correlations to test the hypotheses that self-reported activation would be related to self-management and medication adherence, and to examine whether self and provider ratings would predict coder ratings of activation. Thematic analysis identified ways in which consumers were active.

## Results

Background characteristics (age, gender, race, education and diagnosis of schizophrenia) were unrelated to self-reported activation, illness self-management, medication attitudes or medication adherence. As shown in Table 1, self-reported patient activation was related to higher levels of illness self-management ( $r = .46, p < .01$ ) and less substance abuse according

to provider report ( $-.35, p < .01$ ). However, activation was not significantly related to medication attitudes or provider ratings of medication adherence.

The mean length of visit was  $19.0 \pm 6.0$  minutes (ranging from 9.0 to 32.2). Length of visit was not significantly related to activation, illness self-management, medication attitudes, prescriber ratings, or coder ratings of activation. Coder ratings of active involvement based on the transcripts were not significantly related to self-reported activation, illness self-management, medication attitudes or medication adherence (Table 2).

Thematic analyses revealed four broad types of consumer activation: partnership building, seeking and displaying competence, directing treatment, and missed opportunities.

Partnership Building included praise opportunities, activity outside the visit, and self-disclosure. Praise opportunities occurred when consumers called attention to positive affect or efforts, often placing themselves in a positive light along the path to recovery, e.g., “And my math is getting better...I’m working on it every day.” Activity outside the session involved consumer reports at improving mental health (e.g., adhering to a medication regimen) or broader life improvement, e.g., “I’m going back through the job training program. I have a meeting on that today.” Self-disclosure involved revealing new information containing a moral or affective component, at times prompted by the provider (e.g., asking if a consumer was taking illicit drugs), and at other times unsolicited: “I have a lot of anger toward people, a lot....To be honest with you, it is very, very embarrassing.”

Seeking/Displaying Competence was evident when consumers asked questions, often related to medication dosage, side effects, and new or unusual symptoms. Consumers frequently displayed understanding of illness (e.g., when symptoms are better or worse) and treatment (e.g., knowing timing and dosage), or deeper understanding, e.g., recognizing consequences of behaviors such as substance abuse, exercise, and taking medication as prescribed. Another degree of competence emerged when consumers took responsibility for their behaviors: “I’m a responsible adult...I can’t be acting like a teenager.”

Directing Treatment varied from more passive strategies, such as voicing a concern, to expressing opinions about treatment, to specific requests of the provider. Expressions of concern included mental health symptoms, medication side effects, physical symptoms, and general life concerns e.g., job stresses, worries about obtaining a high school diploma, and saving for retirement. Consumers offered evaluations of how the treatment was working (or not) and sometimes discussed how they felt about the treatment, e.g., “I still don’t like the way it makes me so tired at night. Cause after I take ‘em I can’t go out...I slur my speech.” At the most active end of the spectrum were direct requests. A few consumers asked for a particular medication, a change in dosage or timing, or specifically that no changes be made. For one consumer, medication was interfering with her work “I... I think...is there any way you could start me out right now on a lower dose to get me adjusted because it pretty much leaves me comatose, really.”

Missed Opportunities, the final theme, referred to missed opportunities on the consumer’s part to become more involved in treatment. Usually this occurred when the consumer responded minimally to provider questions, only to bring up concerns later. In one case the provider was trying to engage the consumer in a conversation about goals, but the consumer responded “Uh...my goals...I don’t remember.” (To be fair, this provider had also forgotten: “Well, I can’t remember exactly what they were, but I bet you’re a lot closer to them now than what you were a year ago.”)

## Discussion

This is the first study we are aware of that explores the role of patient activation in people with severe mental illnesses. The Patient Activation Measure had good internal consistency and correlated with self-management and substance abuse in meaningful ways. Consumers high in activation rated themselves higher in illness self-management and recovery, and were less likely to be identified by the provider as having a substance abuse problem. Activation was not significantly related to medication attitudes or adherence. However, correlations were in the expected direction and the small sample size restricted our ability to detect anything other than moderate to large effects. Further validation is needed, but this initial examination appears promising for use with people with severe mental illnesses.

Activation was not related to coder ratings in terms of negotiation, interest in managing the illness, and involvement in controlling the illness. Even considering the small sample size, the magnitude of the relationships was very small. The lack of relationship may reflect a general lack of concordance between attitudes and behaviors; what people think and how they actually behave are different things. Other studies of healthcare communication have found that patient ratings of involvement have not correlated with actual behaviors (12). Similarly, doctors often overestimate their own behaviors, such as the amount of time spent in giving information during encounters (13). Additionally, we may have observed visits in which highly activated consumers simply did not have issues to bring up at that particular visit and, therefore, did not appear active. Of course, it is also possible that our coding scheme was not sensitive or was tapping into the wrong areas.

Thematic analysis of the transcripts revealed numerous behaviors reflecting consumer activation. Some of these behaviors were expected, such as asking questions or displaying knowledge, common indicators of patient activation in other chronic illnesses (14). Basic knowledge about the medical condition and its treatment are fundamental to being an active participant. By contrast, direct requests, perhaps the most active form of behavior, were evident in only a few transcripts. Consumers were generally more indirect or passive, offering opinions and more frequently statements of concern. In the absence of specific coaching for consumers, providers may need to be primed to look for ways in which consumers ask for help. Also, because in-session behavior may not accurately indicate consumer preferences for involvement, providers may need to have more focused discussions about preferences and decision-making.

Another interesting set of behaviors involved partnership building, in which consumers talked about how they were active outside the session, provided opportunities for praise, and disclosed personal or sensitive information. This latter behavior, in particular, may indicate the consumer's trust in his or her provider, which in turn may help facilitate the two parties working together to make decisions that are most beneficial to the consumer. These attributes are fundamental to the concept of relationship-centered care and the role of reciprocal influence in the provider-consumer relationship (15).

This study was based on a small non-representative sample from one agency and may not be generalizable to the population of individuals with severe mental illnesses. Additionally, because this study was cross-sectional, with one visit per consumer observed, it provides only a window into the consumer's overall experience. We were not able to assess the development of relationships over time, nor did we gather information on how long the two parties had been working together or other aspects of the consumer-provider relationship that may influence communication. Despite these limitations, this study provides a more complete picture of patient activation by measuring this construct quantitatively while simultaneously looking for manifestations of activation in actual consumer-provider interactions. Furthermore, while

healthcare communication research tends to focus on the provider role in interactions, this study provides a view of the interaction and activation from the consumer's perspective. Future analyses will focus on the interactions of both consumer and provider, essential in fully understanding shared decision-making processes. Future research should also examine the relationship between activation and meaningful clinical outcomes, for example, reduced relapses or improved work or other functional indicators. Finally, it would also be interesting to examine the relationship between patient activation and the much broader concept of consumer empowerment, the former being a potentially important component of the latter.

## Conclusions

Patient activation is an important construct in collaborative care for chronic illnesses. Although further validation is needed, the patient activation measure appears promising for use in consumers with severe mental illnesses. In addition, activation may take different forms, with consumers displaying a range of behaviors that are related to being an informed, active collaborator in the recovery process.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Correlations between background measures, self-report and prescriber report

Variables	Patient Activation Measure	Illness Self-Management	Medication Attitudes	Prescriber Rated Medication Adherence	Prescriber Rated Substance Abuse
Patient Activation Measure	-				
Illness Self-Management		.46**		.26	-.35*
Medication Attitudes			.22**	.04	-.09
Prescriber Rated Medication Adherence			.44**	.39*	.13
Prescriber Rated Substance Abuse					-.19

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).



**Table 2**

Correlations between self and prescriber report and observer ratings of activation

<b>Variables</b>	<b>Active in Negotiation</b>	<b>Interest in Mental Illness Management</b>	<b>Involved in Controlling Mental Illness</b>
Patient Activation Measure	.07	-.01	.08
Illness Self-Management	.14	.11	.27
Medication Attitudes	-.08	.08	.20
Prescriber Rated Medication Adherence	-.16	-.11	-.05
Prescriber Rated Substance Abuse	.15	.27	.17