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Effective Mental Health Consumer Education: A Preliminary Exploration

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Abstract

People with serious mental illnesses are increasingly becoming more active participants in their treatment and recovery. At times, their participation may be limited by incomplete, unclear, or insufficient information. The authors used a grounded theory approach to look at the unmet informational needs described by consumers. Participants in this study called for materials appropriate to their level of understanding, assistance with interpreting and comprehending information when necessary, and information on policies that affect the treatment they receive. Ultimately, an informed consumer is one empowered to make decisions about the course of his or her recovery and participate meaningfully in the patient-provider relationship.

Mental illnesses are defined as medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others, and daily functioning, including diagnoses of major depression, schizophrenia, and bipolar disorder.¹ People with serious mental illness are encouraged to become "consumers" of health services as they navigate their recovery processes.^{2–5} To counter barriers to treatment participation in a way that supports recovery, education about mental illness and treatment options has emerged as a primary need among mental health consumers.^{6–8} This manuscript provides an exploratory look at consumer perspectives about the specific types of information needed and the best ways to provide consumers with this information.

Obtaining accurate information is consistent with recovery from serious mental illness in several ways. Knowledge can be a resource that fosters teamwork and eases adaptation to living with the illness.⁹ A patient who understands treatment options and is collaboratively active in the treatment process is more likely to engage in behaviors that effectively manage physical chronic illnesses.¹⁰ When consumers are able to communicate with their providers and obtain information they need, they are more satisfied with treatment: increased patient-provider communication is associated with positive health outcomes of emotional health,

symptom resolution, functional and physiologic status, and pain control.¹¹ Well-informed consumers may also better exercise power in this relationship; for example, when they understand the options available and have the ability to decide between them.¹²

Consumers, especially those who are active participants in their treatment, also seek out information beyond what their providers give them, including through the Internet and through peers. Fox reported that 79% of American Internet users have searched for health information; about 21% of these people have specifically looked for information on depression, anxiety, stress, or mental health issues.¹³ Although their training varies widely, peer support specialists may share a wealth of resources and advice based on their own experiences.^{14,15}

Given the benefits of information to increase patient–provider communication and consumer outcomes, as well as consumers’ ability to obtain information about mental illness from multiple sources, this paper presents views of mental health consumers about (a) the kinds of information they seek about their health care conditions and treatments, (b) processes for obtaining information from providers and other sources, and (c) how the information-seeking process may contribute to or inhibit their recovery.

Methods

Study design

This study used grounded theory methods^{16,17} to interview mental health consumers about their perceptions of the role of information in their experiences of mental health conditions and recovery. Grounded theory is a systematic method of conducting research that begins with an inductive approach, involves engaging in simultaneous data collection and analysis, emphasizes constructing an analysis, and aims to construct theories.¹⁶ Grounded theory method includes the use of an emergent design, theoretical sampling, axial and open coding, saturation, and concurrent data collection and analysis. This method differed from grounded theory in two ways: (1) researchers used purposive rather than theoretical sampling, and (2) researchers were unable to reach complete saturation on all concepts due to study constraints. Purposive sampling involves the deliberate sampling for heterogeneity¹⁸ on factors designated as important to the concepts being studied (e.g., gender, treatment status). Saturation is achieved when no new information is being received on the study concepts.¹⁹ Despite divergence from grounded theory methods, these findings offer a unique exploratory perspective on information needs of mental health consumers.

This paper is part of a larger study of mental health treatment providers that assessed their views of evidence-based practice for serious mental illness. The larger study addressed providers’ acceptance of specific evidence-based practices²⁰ and capacity to implement them.²¹ The consumer portion of the study was initially designed to obtain consumers’ perspectives of evidence-based treatments, but through an emergent design process,¹⁶ it became more focused on consumers’ information preferences. The research protocol and study activities were approved by the Oregon Health & Science University Institutional Review Board.

Participants and setting

Researchers used purposive sampling from multiple sources^{18,22} to obtain a broad sample of consumers. Recruitment letters were mailed to potential consumer participants recommended by advisory board members from the larger project. In addition, interviewers contacted the state chapters of the National Alliance for Mental Illness (NAMI) and Mental Health America (MHA) via email or telephone and asked them to distribute the recruitment

letter. Respondents were mailed an information sheet about the study, and interviewers scheduled appointments for phone interviews.

At the beginning of the phone interview, interviewers explained the study and obtained verbal consent to continue. The IRB did not require written consent due to the low-risk nature of the research (i.e., a one-time phone interview) and the desire to maintain confidentiality (the consent form would have been the only link between participants and responses).

During the 12-month study period, 83 invitations sent via email yielded 12 completed interviews from 11 states. Eleven participants were female; one was male. Age, race, and other demographic information were not requested to increase confidentiality and participation; all participants confirmed having a serious mental illness (e.g., schizophrenia, bipolar disorder). A \$5 gift card was mailed to each participant following the interview.

Data collection

Interviewers used a semi-structured interview guide to ask participants about their experiences with their providers, opinions of evidence-based practices, and satisfaction with opportunities to be involved in treatment decisions, among other topics. Specific questions included: Can you tell me about systems in place to involve consumers and their families in their treatment at the agencies you use? What kind of opportunities to provide input would you like agencies to offer? Consumers were also asked about familiarity with evidence-based practices from a list of examples read by the interviewer and about effective information exchange experiences. Interviews were conducted via telephone and lasted about 30 min each.

Data analysis

Interviewers took detailed notes during the interviews and entered the notes into Atlas.ti (Atlas.ti 5.0, Scientific Software), a qualitative analysis program that aids in the coding and retrieval of text for analysis. Codes were established to identify specific information-related text and text on other topics. Following primary coding of several interview documents (SB), the secondary coder (JW) performed a validity check on one interview document using the full set of codes, yielding an initial reliability of 79%. Both coders discussed discrepancies that arose during this process, the initial documents were re-coded, and the primary coder independently coded the remaining documents. A subsequent check of inter-coder reliability by the primary and secondary coders of another interview document yielded a 90% accuracy rate.

Results

Consumers described what kinds of mental health information they are seeking, how they are currently obtaining that information, and in what areas additional information is needed; barriers to good information exchange and deficiencies identified in the current system; and recommendations for how the information exchange process can be improved to benefit consumers and encourage recovery. Researchers constructed a theoretical model grounded in consumers' perspectives¹⁶ describing concepts associated with information exchange for individuals with serious mental illness (see Fig. 1), which includes interconnected concepts of (a) timing in illness and recovery, (b) consumers' levels of functioning and impairment, (c) context of information delivery, (d) source of information delivery, and (e) kind of information sought. Each of these factors is described below.

Timing in illness and recovery

Consumers reported that timing was an important issue that affected the kind of information that was needed. Consumers desired information at the appropriate level of understanding to be provided at the right time in their treatment process. For example, one consumer reported, “You go in [the hospital] during a serious break. As soon as you show signs of ability, they release you. Once you’re out the door, it’s up to you to figure out what the next step is.” That consumer suggested information upon admission and upon discharge should differ in content and should be written for different levels of comprehension.

Consumers’ help-seeking during acute states of recovery also affected their relationships with providers. A consumer reported he “has seen patients looked at as statistics, and kept at a distance from their true goal ... Docs rarely see consumers in a state of recovery [...] and they don’t usually talk about the positive aspects of what’s going on.” Another consumer suggested that providers should view recovery as a developmental process and provide appropriate information to “promote recovery” rather than “manage illness.”

Consumers reported that information needs are different based on their progress in recovery. Individuals who have just been diagnosed may need information about the illness and treatment options, as well as education on basic self-care activities. Individuals who are mostly stable but have occasional relapses may need information on legal recourse for job discrimination or education about managing medication side effects.

Consumers’ levels of functioning and impairment

Participants also stated a preference for informational materials that were appropriate to their level of understanding. In many cases, information was either too complicated or too simple. One participant believed that materials were too complicated for some consumers: “Each case needs to be looked at closely ... Clients need to be pretty [healthy] to understand materials.” Others described a lack of information targeted to “higher functioning” people.

Several participants observed that there is no single form or amount of information appropriate for all consumers. While comparing passive (e.g., pamphlets or bulletin boards in a waiting room) and active (e.g., one-on-one interactions with a provider) approaches to providing information, participants indicated that a combination of approaches would work best to accommodate individual preferences.

One respondent observed that his ability to accurately communicate what he knew and what he was experiencing was related to the type of information received from his provider: “If someone goes in to see a doctor with more knowledge and education about medications [... he] could better relate to doctors and they can be treated in a more appropriate manner.” Another participant acknowledged that consumers are not always receptive to information, but suggested that having information available during periods of wellness can help consumers through difficult times. A consumer also suggested that peer support specialists could help providers offer information appropriate to the consumer’s level of functioning.

Context of information delivery

Consumers emphasized that the medical establishment is only one source of information for consumers and that they receive information from medical providers, materials in waiting rooms, or materials provided by health care organizations, peer-to-peer networks, and other venues, like correctional facilities. Consumers stated the context of information delivery influences the kinds of information needed and the quality of information received. Context interacted with the stage of recovery; consumers reported that, earlier in the process of recovery, they were more receptive to information from inpatient hospital and correctional

facilities, which provided a more illness-focused (as opposed to a recovery-focused) perspective. Consumers described experiences in which they could not understand information due to symptoms or other impairment; they also described experiences in which they were not provided with any information because providers assumed they could not understand anything. Consumers reported that certain sources of information were more common in specific treatment settings (e.g., community centers tend to have peer support, whereas hospital inpatient units tend to be staffed by medical providers).

Source of information delivery

Consumers said their plans for recovery included multiple sources of support, and they expressed frustration with and suspicion of medical providers who devalued non-medical interventions (e.g., organized peer support, behavioral therapy, etc.). Consumers reported being less receptive to medical providers who provided information on “illness,” rather than information on “recovery,” leading some to seek peers for positive, recovery-oriented information. Some consumers also stated frustration that medical providers seemed concerned solely with medication and suspected they may be overly influenced by the pharmaceutical industry.

Consumers also reported barriers to obtaining information that they perceived were related to provider stereotyping and stigma. Consumers stated that mental health providers’ low expectations of consumer comprehension may limit the amount of information provided. One consumer reported, “There is still the stigma that consumers won’t understand or will be overwhelmed. If [only] we could get through that barrier, to let people know I’m just like you and I can think and make decisions...”

Consumers conducted their own research to supplement information from providers. One participant reported, “Meds are very confusing. I do research before I agree to take anything.” Another participant indicated self-initiated research was a way to assert her role in treatment: “I do research, [and] I walk in with handouts, because I am part of my [treatment] team.”

Other consumers saw themselves as part of a network of resource-sharing peers; one consumer noted, “I read [informational materials] and then I pass the information along.” Consumers also reported seeking information through classes sponsored by NAMI or other advocacy organizations. A few participants reported service on committees, boards, or councils through which they have the opportunity to obtain information and influence policy or program changes. Consumers were excited about the legitimization of peer support services in promoting recovery, in part because consumers reported being very receptive to information provided by peer support specialists. As one participant said, “I feel that peer support is going to be the new future for mental health. There are people who are proactive with their programs and they feel that peer support is going to be a big part of their programs in the future.”

Kinds of information sought—Participants reported seeking information in two distinct areas: information about their illnesses, medications, and treatment and recovery options, and, to a lesser extent, information about policies and decisions that may affect their access to and quality of care.

Consumers sought information on their diagnoses and possible etiologies of their conditions, medications (e.g., side effects, options), guidance on self-care following discharge from inpatient care, and options to pursue treatment and recovery outside of the medical model.

Consumers sought information on their rights in terms of legal recourse. One participant reported needing information about her legal rights when she was denied medication for psychosis while incarcerated; her doctor there told her, “This is a jail, not a hospital.” Another participant described her state’s bill of rights for people with mental illness, but noted that not all hospitals in the state knew of the bill’s existence. Consumers reported gaps in information for both consumers and providers about patients’ rights in hospitals, outpatient and residential treatment facilities, and correctional settings.

A few consumers reported seeking information about policies and decisions that may affect their access to and quality of care. For example, participants were asked specifically about their familiarity with evidence-based practices. Most consumers knew little or nothing about evidence-based practices. Some respondents were initially unfamiliar with the term “evidence-based practices,” but could recognize practices from the list of examples read by the interviewer. A few consumers had more knowledge about evidence-based practices and could give a brief explanation, or knew how their state or agency was implementing them.

A specific kind of information that was sought but rarely provided through medical avenues was information about non-medical approaches to treatment and recovery, such as peer support and psychotherapy. One participant said she felt her state’s model relied too much on the medical model. She said, “Information is not given about self-determination, that people do recover, that medication is a choice, [that as] life changes, needs for medication may change,” and said she desired this kind of information. Consumers also felt that medical providers did not acknowledge peer-to-peer support as a valuable adjunct to treatment; several respondents, for example, found NAMI and other resources on their own, without referral or mention from their medical provider.

Integration of information for recovery

This section provides some examples from consumers about how these factors worked together to result in unsuccessful, successful, or partially successful information transfer.

Some participants reported getting an adequate amount of information and resources from their providers and other sources. For example, this participant reported satisfaction with the information she received from her mental health providers: “Doctors and staff worked closely with me in the hospital to work toward rapid recovery; they followed up with my treatment once I was in outpatient treatment. I used a Club House [an informal environment with peer and professional support], where I had a case manager to fill out paperwork I needed. I got what I wanted from the mental health care system.” She received information from multiple providers, and the amount and type of information received met her needs.

At times, consumers may prefer to talk with a peer about mental illness and recovery. This consumer reported how a NAMI education program was helpful, but still did not address all of the consumers’ needs for information: “[The consumer education piece] was very effective. It was a six-week consumer group that met once a week. Once they completed it, people didn’t want to leave. They would sit through the whole education group three times and then start asking for more information. There was no other peer-to-peer support at that time. People are hungry for peer-to-peer stuff.” This experience may indicate that the scope of the course was too narrow and that significant milestones in consumer illness and recovery may require different information needs.

Discussion

This study sought to identify experiences of mental health consumers regarding the information desired in treatment and recovery. This study presents a preliminary conceptual

model grounded in participants' responses¹⁶ that describes information exchange valuable to consumers as consisting of accurate and appropriate information, given in a manner appropriate to the consumer's level of functioning and progress in recovery, within an appropriate context, by the right provider.

Other examples of consumer perspectives are congruent with these findings. People with schizophrenia who responded to a "Dear Abby" newspaper column asking for their stories had requests for information similar to those expressed by study participants.²³ They asked that their conditions not be "mystified" and that information be given directly to them rather than to their families. They encouraged other people with schizophrenia to educate themselves about their illness in order to combat stigma and misinformation. These suggestions, and the findings from this study, do not appear to be diagnosis-specific, but rather illustrate consumers' desire to see providers support patient empowerment by providing information.

In seeking information, mental health consumers are similar to the general population seeking health care. Many patients being treated for physical conditions prefer to receive a great deal of information about their illness and treatment options,²⁴⁻²⁶ and being satisfied with the right amount of information received correlates with overall satisfaction with care received.²⁷ As the specter of stigma continues to hang over mental health consumers, however, it may be difficult for providers to see that the choice to accept or decline information falls within the realm of typical human behavior rather than the consequence of a mental illness.⁹

Despite the movement toward using evidence-based practices in mental health treatment,²⁸ these findings suggest consumers may be unaware of them and thus unable to participate in discussions about such practices, their development, and their implementation in treatment settings. When consumers and family members are informed about evidence-based practices, they tend to have concerns about funding EBP to the detriment of other programs, the differing outcome goals of consumers and policymakers, and the differing values of consumers and providers (e.g., approaches that support recovery, and peer-run services).^{29,30} If consumers are not aware of the trend toward evidence-based practices, then it is likely that they are being left out of important policy discussions as to their selection and implementation.

Future research

Future research should conduct broad-based surveys of the kinds of information consumers have found useful or would like to receive. Consumers in this exploratory study acknowledged the wide range of preferences for receiving information that reflects the variety of learning styles in the general population. It will be important to determine differences in information acquisition and preferences for subgroups of people with mental illness, which was beyond the scope of this study. Future research should also be structured to facilitate data collection from a greater number of participants; meeting with subjects in person or working closely with local contacts may increase the yield of participants by fostering greater trust.

The field would benefit from studies that parallel those in biomedical health services that have looked at the relationship between information and satisfaction with services and informed choice.^{24-27,31}

Limitations

The sample size for this study was small (N=12), despite extensive efforts over 12 months to recruit consumers. Contacts may have been reluctant to respond to an unsolicited email from

an unknown entity regarding research on a sensitive subject, and organizational contacts may not have posted or forwarded the recruitment flyer. Recruitment for future studies may benefit from more geographically focused sampling, or sampling at agencies where a professional relationship has been established. Although it would have been useful to obtain information from more consumers and achieve full saturation, the information provided in this exploratory study provides a useful set of themes for further exploration. The sample may over-represent people who are already connected to NAMI or MHA. Participants were not asked to identify their diagnosis, although some did voluntarily disclose this information. Consequently, it is not possible to compare information preferences and treatment experiences among conditions.

Implications for Behavioral Health

The results from this exploratory study reinforce previous findings on the benefits of collaborative consumer–provider relationships and add specific consumer needs for information and consumers’ recommendations for improving information transfer. Accurate and thoughtfully delivered information appropriate to consumers’ circumstances can help decrease the consumer–provider power differential and increase consumer autonomy, potentially improving recovery from mental illness. Improved communication techniques in mental health may also be applicable to other fields.

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Figure 1.
Concepts of successful information exchange for individuals with serious mental illness