

Consumer Perspectives on Quality of Care in the Treatment of Schizophrenia

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Published online: 15 August 2006
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Abstract Guidelines and best practices represent advances in the promotion of quality care in the treatment of schizophrenia. These efforts have been primarily developed by clinicians and academic researchers, and appropriately focus on psychopharmacological treatments. However, including other perspectives in the guideline development process may expand what is considered to be quality care. This study examines the opinions of forty individuals diagnosed with schizophrenia as to what constitutes quality treatment. Results from a thematic analysis indicate wide agreement on the importance of good psychopharmacology and case management, but respondents also emphasized the importance of a good interpersonal process, and the need for psychosocial rehabilitation supports. Current practice guideline efforts should consider including interpersonal process standards that have been demonstrated to enhance therapeutic relationships and ultimately clinical outcomes, and enhance their emphasis on psychosocial rehabilitation supports.

Keywords Schizophrenia · Quality · Recovery · Interpersonal

Introduction

Efforts to upgrade quality care in the treatment of individuals with schizophrenia have led to the development of practice guidelines to enhance clinical practices. These efforts have been primarily developed by clinicians and academic researchers, who base their recommendations on thorough reviews of the research and clinical literature. Practice guidelines for schizophrenia appropriately emphasize psychopharmacological approaches, and to a more limited extent psychosocial treatments. The most prominent guidelines include: The American Psychiatric Association's Practice Guidelines (2004); The Schizophrenia Patient Outcomes Research Team (PORT) recommendations (Lehman et al., 2004); The Expert Consensus Guidelines Series (McEvoy, Scheifler, & Frances 1999); and the Texas Medication Algorithm Project (TMAP) (Rush, Shon et al., 1999). Milner and Valenstein (2002) provide a good comparison of each, and comment on their various strengths and weaknesses such as length, complexity, and comprehensiveness.

A movement to create a consumer and family-driven mental health system also has implications for enhancing quality of care (President's New Freedom Commission on Mental Health, 2003). This movement would suggest that consumer perspectives be integrated throughout the guideline development process. Practice guidelines are primarily based on current understandings of the research literature, though this evidence base may be limited in terms of its focus on certain interventions (e.g., pharmacology) and certain outcomes (e.g., decreased symptoms). Greater inclusion of consumer perspectives in the research process, such as the development of research questions, methods, and outcomes, may increase the comprehensiveness of supports and expected outcomes considered in

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guideline refinement. Many examples of such collaborations exist, including Woodside and Cikalo (1995) who found that such collaborations enhanced consumer collaborators' self-worth, and helped researchers and clinicians to better understand consumers' needs. Toprac et al. (2000) similarly included consumers as partners in the development of an educational training program for the TMAP practice guidelines, and found this approach developed more in-depth treatment information.

One study found that consumers, family members, and providers have differing opinions about the importance of various services (Fischer, Shumway, & Owen, 2002). Providers and family members generally had greater congruence with each other than either had with consumer perspectives. For example, providers and family members both rated control of side-effects higher than did consumers, while consumers rated independence in housing higher. Other researchers have taken steps to discover what consumers want in treatment. Tooth, Kalyanasundaram, Glover, & Momenzadah (2003) asked what consumers viewed as important constructs in their recovery, finding the most common theme to be "an active sense of self," including a realization of the need for self-help, and a determination to get better and manage their illnesses. Carne (1998) obtained consumer perspectives on the importance of having informed choice about services. An improved quality of life was discussed as having an emphasis on crisis prevention rather than intervention. One focus group study involving a consumer–researcher (Mason et al., 2004) identified consumer priorities in treatment, and what they feel contributes to higher satisfaction with services. They found that consumers felt bonding with providers, provider treatment competence/knowledge, and provider cultural/religious competence were important contributors to increased satisfaction.

This study extends these efforts by eliciting completely open-ended comments from individuals with schizophrenia-spectrum diagnoses about what they believe to be most important in order to receive quality care. We hypothesized that consumers would identify additional areas not emphasized in existing practice guidelines, given previous research indicating that real differences in perspectives exist. Such information is important to consider when refining practice guidelines, in order to increase their relevance to and acceptance by consumers, and ultimately to improve outcomes such as satisfaction with services.

Methods

Procedures

This study was part of a larger study assessing relationships between adherence to schizophrenia PORT

treatment recommendations and outcomes, which was conducted at two large mental health agencies in Philadelphia, Pennsylvania. The larger study began by obtaining from each agency a list of all individuals diagnosed with a schizophrenia-spectrum disorder (DSM 295.XX), who received case management services, and who saw a psychiatrist at the agency. Each individual's chart had to be reviewed, however, to ensure that they fit inclusion criteria for one year. All names were assigned a random number, and the first 60 were selected to have their charts reviewed. Facility #1 ultimately only had 57 eligible individuals, and so all charts were reviewed. There were 88 eligible charts based on computer records. Facility #2 provided a list of several hundred names, but a total of only 104 were reviewed before a total of 61 charts were selected that fit the inclusion criteria. Reasons for not fitting the criteria included changed diagnoses, discontinuation of some services, and missing or incomplete chart data.

After charts were selected and reviewed for the larger study, subsets of 20 eligible individuals from each facility were randomly selected to participate in a research interview, for a total of 40 interviewees. Case managers were asked to obtain permission from the individuals to be contacted by a research assistant about the study. A total of 26 individuals had to be excluded, and were replaced with the next randomly selected names. Reasons for exclusion included: being too unstable (4), having an inadequate comprehension of English (5), being unable to comprehend the nature of the information they would be giving (2), could not be contacted (7), or refused to be interviewed (6). Others, at the time of the interview, were deemed by the interviewer to be unable to comprehend the information they would give (2). The interviews assessed current symptomatology, functioning, quality of life, and other outcomes. An open-ended question was asked at the end of the interview, and is what was used for this study. Each participant was asked, "What do you think are the most important things for (AGENCY NAME) staff to do to give you good care?" The study was approved by the Institutional Review boards of two universities and the City of Philadelphia.

Subjects

To be eligible a consumer must: (1) Have had a current diagnosis of a Schizophrenia-Spectrum Disorder, including any DSM 295 classification; (2) Have been a consumer at the CMHC and currently receiving case management services for at least one year; (3) Have received psychiatric services at the agency for at least one year; (4) Have a fluent understanding of English. Eighteen men and 22 women aged 22–68 with a mean age of 47.8 participated.

One (2.5%) was American Indian/Alaskan Native, three (7.5%) were Asian/Pacific Islander, 23 (57.5%) were Black/Not-Hispanic, 12 (30%) were Caucasian, and one (2.5%) of other descent. Because the agencies each serve geographic catchment areas, they have disproportionate numbers of consumers from each ethnic/racial group, and the numbers in this study closely resemble the actual populations served at the agencies. Fourteen individuals (35%) lived in a board and care facility, two (5%) in congregate housing, one (2.5%) in a halfway house, 20 (50%) in a private residence, one (2.5%) in another location, one (2.5%) in sheltered housing, and one (2.5%) in a temporary (homeless) shelter.

Data Analysis

Data was analyzed using traditional qualitative data analysis techniques (Patton, 1987). Responses for each interviewee were first divided into ‘independent thoughts.’ Respondents gave as few as one and as many as 13 thoughts about what staff do to provide good care. We identified a total of 179 thoughts. Thoughts were identified with descriptive labels such as “work therapy,” “visiting me,” and “kindness.” Thoughts were clustered under previous descriptive labels if they were judged by the three-member research team (one doctoral researcher, one doctoral candidate, and a master’s student) as fitting under a previous label, otherwise they were assigned a new descriptive label. This process was continued until the 179 independent thoughts were divided into 44 categories. Once created, categories were examined to identify meta-categories involving common labels. This was continued until 9 meta-categories were generated. A consensus process among the three-member team was used throughout the process to increase the reliability of coding.

Results

Responses resulted in nine constructs that captured what consumers believed to be important in providing good care. Six had one or more sub-categories, some of which had their own sub-categories. The most frequently mentioned construct was the interpersonal process in which services are delivered, followed by case management activities and psychosocial treatments. Other frequently cited constructs included pharmacologic treatments and support. Constructs mentioned less frequently included recreation/socialization, promote independence, encouragement to meet goals, and family issues. Table 1 lists each one, the number of times it was mentioned, and its theme.

The Interpersonal Process

The ‘interpersonal process’ was mentioned most frequently, with over half of the respondents making a statement fitting this theme. Each comment had a common link in referencing *the way in which services are provided*, rather than mentioning a *specific service*. ‘*Enthusiasm/energy*’ referred to the occupational therapists getting a person “up and dancing.” ‘*Don’t give up/believe in me*’ referred to motivating consumers by expressing a belief or faith in their abilities. An example was, “the occupational therapy student teachers don’t give up on you no matter how depressed you feel.” ‘*Positive feedback*,’ referred to how a person can be motivated, specifically through a positive approach—“I can take her [therapist’s] constructive positive feedback and apply it to my daily situation.” ‘*Concern*’ focused on feeling like the provider cares about them. An example was, “[providers] care about us, what we really need and how we want to get better.”

‘*Professionalism*’ included expectations that the staff treat consumers how any person would want to be treated when seeking professional services. This included a sub-category of ‘customer service,’ such as being taken for an appointment on time, and wanting efficient and responsible care, “I feel that my case manager is very efficient with responsibility for me.” The sub-category of ‘confidentiality’ included, “keep information confidential between doctors.” ‘*Listening*’ was the most frequently mentioned sub-category. Several examples referred specifically to the doctor, and others were general, such as, “they listen, he’s a really good friend.” Telling the ‘*Truth*’ pertained to providers giving honest information. ‘*Dedication*’ referred to how the consumer felt the staff felt about them—“counselors are dedicated to people. From their dedication you can see it reflects on how we maintain our stability.” ‘*Kindness*’ referred to how consumers are or should be treated. “all are kind to me.” ‘*Accept me as I am/understand me as I am*’ referred to a general acceptance, “get woman who accepts me as I am.” Finally, ‘cultural awareness’ included comments about providers needing to “try to understand me as far as who I am. Not my name but my nationality.”

Case Management Activities

‘Case management activities’ was the second most frequently mentioned construct. The most frequently mentioned sub-categories were ‘*Monitoring/maintaining contact*,’ and ‘*Assistance with life activities*,’ which had three further sub-categories. These were: (1) ‘*General*’ comments, such as “TCM [targeted case-manager] helps with my whatever concerns I may have—legal, housing,” (2) ‘*Daily stuff*,’ regarding help with activities of daily

Table 1 Summary of constructs and sub-categories

Constructs and sub-categories	# mentioning sub-category	Theme
Interpersonal process (<i>N</i> = 23, 58%)		The way in which services are delivered
Enthusiasm/energy	1	Getting a person “up and dancing”
Believe in/don’t give up on me	1	“Don’t give up on you, no matter how depressed you feel”
Positive feedback	1	Motivation through a positive approach
Concern	3	Feeling like the provider cares about you
Listening	6	Paying attention to concerns and issues
Truth	1	“I want to thank them for telling me the truth”
Dedication	1	How staff feel towards their work
Kindness	2	“All are kind to me”
Understand me/accept me as I am		General acceptance for a consumer as he/she is
(a) General	2	General acceptance and understanding
(b) Cultural awareness	2	Awareness of cultural needs/differences
Professionalism		Treatment as one would expect of any professional
(a) Customer service	2	Treated nicely as a valued customer
(b) Confidentiality	1	Confidential information is kept confidential
Case management (<i>N</i> = 19, 48%)		Services generally performed by case managers
Court help	1	Help with legal problems
Assistance with life activities	(14 unique)	Activities most people in society take for granted
(a) General	6	General assistance
(b) Daily stuff	5	Help with activities of daily living
(c) Money management	6	“Give me allowance twice a month”
Transportation	5	Assistance with transportation needs
Monitoring/maintaining contact	14	General monitoring of consumers’ conditions
Linking	4	Helping make contacts with other service providers
Psychosocial treatments (<i>N</i> = 14, 35%)		Treatments to address psychological/social deficits of mental illness
Work therapy	4	Help to obtain job skills/work
Groups	3	Groups to discuss issues
Day treatment	1	Daytime program to attend
Psychotherapy/Counseling	6	“Talk to me one-on-one basis”
Psychoeducation	5	Information about mental illness/recovery
Medications (<i>N</i> = 12, 30%)		Pharmacological treatments
Prescribing	8	Prescribing appropriate medications
Adherence	5	Helping maintain adherence to medication regimens
Support (<i>N</i> = 12, 30%)		Helping on an as-needed basis
General	8	General supportive activities
Advice	4	Suggestions of what to do in different circumstances
Recreation/socialization (<i>N</i> = 5, 12%)	5	“Take me out”
Promote independence (<i>N</i> = 3, 8%)	3	Help become more independent of mental health services
Encouragement to meet goals (<i>N</i> = 2, 5%)	2	Goals
Family issues (<i>N</i> = 1, 2%)	1	Assistance with issues involving the consumer’s family

Note The total of column two may be more than the *N* because *N* is the number of consumers who mentioned the construct. Some consumers mentioned more than one sub-category in a construct, and were counted only once when totaling the number of times the construct was mentioned

living: “talk to ICM about my laundry, shopping, he takes care of my problems,” and (3) ‘*Money management*,’ including help managing finances. These included broad comments, and management of specific items, such as “if ICM’s have clients who smoke and live in group homes, [client specified his or her CMHC] should make sure clients have cigarettes—if they take care of money. Don’t like having to give away cigarettes.”

One person mentioned ‘*Court help*,’ meaning that their case manager was accompanying them in court at a future date. ‘*Transportation*’ was distinguished from the construct ‘*Recreation/socialization*’ because it was always to the CMHC or a doctor’s office, and did not reference any

services beyond the transportation. ‘*Adherence*’ referred to reminders of doctor appointments. ‘*Monitoring/maintaining contact*’ was the most common sub-category. These comments did not discuss specific activities, but all referred to general monitoring or contact. Some individuals mentioned specific time-periods as, “visit us at our residence once a month,” or, “get in touch with me at least once a week,” and some were more general as, “make sure I’m living well.” The last sub-category was ‘*Linking*,’ which referred to helping individuals contact other providers or services. This included specific medical issues, as “help with your heart problems, my hospital, health problems [heart],” and other various services.

Psychosocial Treatments

These were all treatments to address psychological and social deficits associated with mental illnesses, so that people can reintegrate into the community. *'Work therapy'* included statements as, “and to get some type of skills to get a job and work. Was in work program but left because got pregnant.” *'Groups'* were mentioned four times. One individual was very general saying just, “groups,” and others mentioned specific groups, such as CA [cocaine anonymous], AA, or self-esteem group. The *'Day program'* came up once. *'Psychotherapy/counseling'* included broad comments and more analytic comments such as, “they need to look at, analyze, why I keep talking about what happened to me as a child. Also they need to help me find why I'm 41 years old and not at that level. I'm still at the teenage level.” *'Psychoeducation'* denoted being taught information pertaining to general or mental health needs, such as, “getting information about your mental illness from psychiatrist.”

Medications

'Medications' reflected themes associated with *'Prescribing'* and help with *'Adherence.'* *'Prescribing'* included making sure the person had prescriptions for appropriate medications, such as, “the doctors give me my medicine every month,” and “give you medication and try to find out more new medication to treat you.” *'Adherence'* referred to ensuring that an individual actually took his or her medications.

Support

This theme refers to as-needed supports. Examples included “be there when needed—scared to go it alone,” and “they were there for me [when I needed it], its comfortable.” This theme also pertained to support provided by any staff at an agency rather than just a case manager. *'Advice'* was a sub-category of comments and suggestions solicited from staff. Examples included, “I want their advice,” and, “give on advice/feedback, good or bad.”

Recreation/Socialization

This theme reflected statements with a purely recreational focus such as assisting the person in going to new places where they could meet new people or partake in activities unrelated to their mental illnesses. Examples include, “give parties, thanksgiving dinners,” and “help me try to go meet some new friends.”

Promote Independence

This theme reflected a desire for help in becoming more independent of agency services. One statement referred to being done with the program altogether with minimal provider involvement, saying “should be a quitting time, says you've been through program, to evaluate what you've done—time for yourself to reflect on what you've done, without them being so involved.” Another individual referred to their living situation and payeeship, saying, “to get low income housing and become my own payee, they're helping me with that.”

Encouragement to Meet Goals

There seemed to be a focus by some consumers on receiving encouragement to accomplish their goals. Many other categories involved some form of encouragement, but seemed to denote a distinct category. Examples here include, “more support, being there for us encouraging us to step forward, set goals and try to accomplish those goals,” and, “encourage me more about my goals, that is, to be drug counselor or minister.”

Family Issues

'Family issues' was only mentioned once by a consumer who wanted help in mending a split in the family, “ICM [intensive case manager] helped me get back with my daughter.”

Discussion

Even more important than medications, case management services or psychosocial treatments, consumers gave the greatest emphasis to the interpersonal process of service delivery. This finding also further expands the previously mentioned research of Mason et al. (2004), which found that consumers placed high importance on ‘bonding with providers,’ ‘provider competence/knowledge,’ and ‘cultural/religious competence.’ Notably, no identified set of practice guidelines addresses the interactions between consumers and providers. Although words like “friendly” and “non-threatening” are used to describe how treatments are to be administered, no recommendations focus on the interaction itself. A number of therapeutic *approaches* address the interactional process, such as Humanism, Existentialism and Feminism, though none of them are specifically suggested among practice recommendations or in the more prominent scientific journals.

Establishing strong consumer–provider relationships may be especially important in the wake of the recent

Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study (Lieberman et al., 2005), in which it was found that 74% of all patients discontinued their initially prescribed antipsychotic medication before 18 months. The therapeutic alliance has been discussed as critical for improving treatment adherence (Blackwell, 1997), and there is growing evidence that good relationships facilitate adherence (Day et al., 2005; Loffler, Kilian, Toumi, & Angermeyer, 2003). Rugins (2005) concluded that the CATIE findings should serve as a “wake-up call” to increase attention to, among other things, the interplay of therapeutic alliances with psychopharmacological effectiveness.

Persons with schizophrenia also have been found to have a slightly greater desire to be involved in treatment decision than persons in primary care (Hamann, Cohen, Leucht, Busch, & Kissling, 2005), and a good working alliance can facilitate this involvement. A recent study (Ware, Tugenberg, & Dickey, 2004) identified eight areas that persons with psychiatric disorders felt were important in facilitating good relationships with their providers, and that are consistent with the findings from this study: getting “extra things,” looking for common ground, feeling known, the importance of talk, feeling like “somebody,” practitioner availability, practitioner flexibility, and opportunities for input into treatment. These findings, combined with the relationship variables mentioned by individuals in this study, provide solid suggestions that might be incorporated into best practices that providers can use to facilitate the development of good therapeutic relationships.

Current treatment recommendations for schizophrenia focus heavily on psychopharmacological approaches. This includes the PORT, in which 14 of 20 recommendations (originally there were 30, but a revised set includes only 20, Lehman et al., 2004) focus on medications. Nearly one third of consumers in this study mentioned medication issues as important in obtaining good care. This suggests that such an emphasis in current guidelines is consistent with what consumers believe represents good care. Consumers also gave equal or greater emphasis to both psychosocial treatments in general, and more specifically to case management services, than to medications. Such practices are also given high priority by the PORT (six recommendations). Nearly half of the interviewees mentioned case management services as among the most important in providing quality care. The PORT has one recommendation to provide Assertive Community Treatment, a comprehensive form of case-management; but this recommendation is only for consumers with very challenging cases (frequent hospitalizations or non-compliance issues). Case management is an expensive service, but one which consumers consider to be important in obtaining good care.

‘Support,’ was also a frequently mentioned theme. This theme is not present in current PORT recommendations. There are specific psychosocial treatments in which support should be given (i.e. therapy), though nothing addresses how consumers feel about the support they are given. This seems to be the case with most practice guidelines that advise what should be done, but do not address how it should be done. Interestingly, ‘family issues’ were only raised once. This could be because consumers were thinking of activities provided at their CMHC or supportive housing facility, and so they did not think of their families. When collecting data for the larger study on PORT compliance, however, there was oftentimes contact between the CMHC staff and consumers’ families. That family was only mentioned once is significant in light of the importance now being given to family therapy, in the PORT and elsewhere, even if family therapy has yet to be widespread in clinical practice. This apparent lack of importance ascribed by consumers suggests that clinicians might need to educate both consumers and their families as to the importance of family involvement in treatment.

Limitations

The respondents in this study were randomly selected from the sampling frames of the two facilities, although generalizability to other facilities cannot be automatically assumed. The finding that consumers have additional ideas about their care beyond what practice guidelines currently suggest does, however, seem to be consistent with the findings discussed from other studies.

There was also a sizable number of individuals originally selected but unable to participate. Their reasons might indicate that they have different views on care. Those who were uncooperative, for example, might have preferred case managers to be less involved. The sample size and demographics of the facilities also ended up excluding certain racial and ethnic groups, which may have differing views about quality care. There were few Hispanic individuals at the two facilities, for example, and none in the sample drawn. Such consumers, who may be more often cared for by their families or communities than by case managers, might give greater emphasis on family members when considering quality care.

A related limitation is that although the question for this study was asked after interviewees were encouraged to contemplate broad thoughts about their care and lives, with additional time or interviews, they may have given different responses.

Another limitation is the value of the numbers, which are not statistically significant. This was a descriptive study with a qualitative analysis, and so additional research would be needed to determine if themes are universal

across consumers. Finally, the fact that participating facilities were selected because of past cooperative efforts with the researchers may also mean these facilities are different from others—it would imply that they are open to criticism and are interested in suggestions for improvement. This might also, however, have created an environment where consumers feel more comfortable being honest, lending validity to the findings in this study.

Implications

The Institute of Medicine in *Crossing the Quality Chasm: Improving the Quality of Health Care for Mental and Substance-Use Conditions* (2005), states that consumers should be included in the design and delivery of services, and that they should be supported in making decisions and choosing treatment preferences. The purpose is to improve the quality of healthcare for these individuals, and supports the objectives of the President's Freedom Commission (2003), which states that consumers should be fully involved in orienting the mental health system towards one in which recovery is a goal. Spaniol, Gagne, & Koehler (1999) discuss how one of the most difficult challenges in recovery involves acceptance of oneself. This means that a person needs to recognize and acknowledge all the various aspects of their self, without devaluing their self-worth. Being involved in decision-making about oneself, and specifically about one's health care and how it is provided, can help foster such a sense of self-worth. This may be especially true for a population of individuals who have historically been stigmatized, shunned from communities, and even locked in institutions.

When consumers were asked for their opinions of what is important in their care, they gave both validation for the research that has been developed thus far, and also insight into a construct that has yet to be very well explored. Many clinicians already intuitively understand the importance of this concept of the interpersonal process of service delivery. They accept and practice what consumers might define as a good interpersonal approach, whether or not they utilize a treatment model that clearly defines this process between consumers and providers. Treatment recommendations for individuals with schizophrenia, however, which have been developed largely without the input of consumers, seem yet to have addressed the importance of this construct. Perhaps this has to do with the gaps between research and clinical practice, or with a difficulty in operationalizing such a construct. This study suggests though, that consumer involvement in the development of treatment guidelines has substantial potential for improving upon what has thus far been established by research as best practices.

Many sets of treatment recommendations, including the PORT, have been shown to be effective guides for providing quality care, and consumers seem to agree with their recommendations. Consumers of mental health services have historically had minimal say in the treatments with which they are provided. Giving more importance to the way in which we interact with consumers may take a dramatic shift in thinking for some people, but it may be a missing factor of how best both to help consumers and to help consumers help themselves.

Acknowledgements This study was funded by a University of Pennsylvania Foundation award given to the second author. The writing was partially supported by a grant for the UPENN Collaborative on Community Integration from the National Institute on Disability and Rehabilitation Research (NIDRR: Salzer, PI - H133B031109). Also special thanks to the three anonymous mental health agencies in Philadelphia for participating in the study and, of course, to the consumer participants. Additional appreciation is extended to the Bryn Mawr social work faculty who offered comments on the first author's dissertation from which this study is taken.

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