

Considerations for Research on Consumer Empowerment and Psychosocial Interventions

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Consumer empowerment is a political movement that, among many goals, seeks to diminish the stigma and discrimination experienced by people with severe and persistent psychiatric disorders. This paper reviews research strategies that address the methodological problems of studying consumer empowerment. Key issues include defining the subject of investigation, describing consumer-developed treatments using discovery-oriented research strategies, and sorting out the diverse roles of consumers in contemporary psychosocial programs. Consumer empowerment introduces a political paradigm into the understanding of severe mental illness, a paradigm that can be difficult to integrate with the goals of empirical research. (*Psychiatric Services* 48:347-352, 1997)

Because of societal misconceptions about mental illness, persons with serious mental illness face discrimination similar to that experienced by other minority groups (1-4). For example, the general public may discriminate against persons with schizophrenia because of a belief that they are dangerous or are unable to take care of themselves. Such discrimination is not unlike that experienced by members of ethnic groups because of their skin color or persons with physical disabilities because they wear a prosthesis or are in a wheelchair. Discrimination against individuals with severe mental illness may result from their unusual (or what some may term "abnormal") behavior in the community. Moreover, persons who have been labeled as mentally ill experience stigma and discrimination even in the absence of aberrant behavior (5,6).

Stigma and discrimination associat-

ed with severe mental illness may produce significant social and economic disadvantages (7-9). Otherwise competent adults may be prevented from acquiring adequate housing and independent employment and from experiencing satisfying relationships (10,11). This kind of discrimination has led individuals with severe mental illness to organize into potent consumer groups (12). These groups have significantly influenced the mental health agenda at both the local and the national levels (13-15).

In particular, consumer empowerment has had an impact on the development and implementation of psychosocial interventions. Because proponents of consumer empowerment wish to effect rapid and sweeping change, their impact on services has occurred without the kind of slow, empirical review that guides development of many psychosocial interven-

tions. To advance the careful study of consumer empowerment, this paper will review methodological problems posed by researching the roles consumers assume in psychosocial interventions. We then propose some tentative strategies for resolving these problems.

The subject of study

Defining who should be included in a study is an essential first step in behavioral research. It is frequently accomplished by delineating inclusion and exclusion criteria for a specific group, such as consumers of mental health services. For example, a study on psychosocial treatments for schizophrenia might include individuals who have a history of delusions, hallucinations, disorganized speech, grossly disorganized behavior, or negative symptoms; individuals with a history of pervasive developmental disorders or substance abuse may be excluded from such studies (16).

Who are consumers? Unlike diagnostic categories set forth in *DSM-IV*, no set of definitive terms or criteria is generally accepted as defining or describing mental health consumers (17). The concept of exclusionary criteria seems contradictory to the inclusionary spirit of the empowerment movement. Utilization of mental health services is often a criterion: consumers are those who use psychiatric, psychotherapeutic, or social work services. However, the heterogeneity associated with such open membership presents difficulties for researchers, who desire narrow and relatively exclusive groups.

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Table 1

Positive and negative beliefs and experiences endorsed by African Americans and by mental health consumers as characteristic of their groups

Type of belief or experience	African Americans	Mental health consumers
Positive	Strong work and achievement ethic Highly supportive extended family Strong religious orientation Greater acceptance of gender equity Sensitivity to interpersonal matters	
Negative	Less acceptance by majority group Fewer cultural role models in high-ranking government and business positions Negative stereotypes, including beliefs about dangerousness and lack of ambition and intelligence	The need for treatment conveys a sense of powerlessness Difficulties in "qualifying" for housing Lack of work opportunities Social isolation Exploited for entitlements Treatment resistance due to previous bad experiences is reframed as "noncompliance"

Research strategies from cultural psychology

Researchers in cultural psychology who study ethnic groups have struggled with methodological strategies that distinguish members of various groups. Some insights from this area are relevant for developing research methods to examine consumer empowerment.

One of the assumptions underlying any kind of classification is that populations are heterogeneous and that some sense can be made out of this heterogeneity by dividing the population into meaningful subgroups (18). For example, the American population can be divided into ethnic subgroups that include African Americans, European Americans, Asian Americans, Latinos, and Native Americans. To make this division, researchers need relatively exclusive criteria that are supported by objective data. Objective criteria that have been used to distinguish cultural subgroups include genealogy, the number of years a person has lived in a particular area, and endorsement by the individual of various cultural practices (19,20).

Using similar methods, the population could be divided into consumers and nonconsumers of mental health care. The objective criterion most often used to differentiate a consumer from a nonconsumer is a history of

mental health care (21). According to the narrowest definition, consumers of mental health care are individuals who have had repeated hospitalizations and a long course of neuroleptic medication to ameliorate severe psychiatric symptoms. Broader classifications might include individuals who need relatively short hospital stays and brief medication regimens to address transient mental illnesses (22). But at what point would an individual who has had some experience with mental health providers not be regarded as a consumer? Are visits to a psychiatrist for psychotropic medication sufficient? Are individuals who have participated in some kind of psychotherapy consumers? A large segment of the population will eventually seek mental health treatment of some kind. Thus defining consumers based on any experience with a mental health professional would include the majority of Americans.

Self-identification. Cultural psychologists have realized that the assumption about classification systems and mutually exclusive groups is problematic, at least when using objective data to verify the assumption (23). For example, many people have objective attributes and lineage that qualify them for both European-American and African-American ethnic groups. Assigning people to groups based on objective data can

obscure the importance of ethnic self-identification. That individuals identify themselves as African American is more critical than their possession of objective attributes and ancestral lines believed to be consistent with that group. If researchers on mental health consumers were to borrow this definition, consumers would be individuals who identify themselves as part of a consumer group.

Self-identification methods assume that cultural groups share common values and beliefs so that individual members can reliably decide whether these characteristics describe themselves (24). For consumers, the descriptors can be divided into positive values and beliefs that represent a cultural heritage and negative attitudes and beliefs that may result from experiences with majority cultures. For example, Table 1 lists several positive and negative attributes that have commonly been used to describe the African-American experience. Such lists can be developed by focus groups of individuals from the specific culture who are charged with defining the fundamental characteristics of that culture and the stereotypes associated with their negative experiences (25). These characteristics and experiences are then cross-validated with a second group of people of the same ethnic background to make sure that erroneous stereotypes are not perpetuated.

Consumer self-identification. To our knowledge, no studies have used focus and cross-validation groups to generate a list of positive beliefs and negative experiences characteristic of mental health consumers. However, literature surveys have yielded some frequently discussed experiences with which consumers identify (21, 26-30); they are also listed in Table 1. Consumers' experiences seem to be dominated by negative interactions with the majority culture. Indeed, negative experiences alone seem to lead to self-identification as a consumer.

Consumers per se do not have the well-developed culture that distinguishes minority groups, nor do they share a heritage marked by a unique lore, aesthetic, or life view. Rather, unfavorable experiences with the ma-

jority culture appear to have led to the consumer empowerment movement. Thus the analogy between consumers and ethnic minorities may be limited.

Strategies from AIDS research

Perhaps persons with physical illnesses such as AIDS are a better comparison group for examining the stigma of mental illness (31–33). AIDS researchers argue that three factors lead to stigma: an outward presentation of the illness, such as a lesion from Kaposi's sarcoma; a societally perceived "character flaw," such as homosexuality; and a societally perceived "tribal flaw," such as being associated with a disapproved group like gay men (33,34). These factors may also describe persons with severe mental illness: an outward presentation of the illness, such as the positive symptoms of delusions and hallucinations; a "character flaw," such as societally perceived moral weakness as the cause of illness; and a "tribal flaw," such as being a former mental patient. Measurement of these factors may shed more light on the question of who is a mental health consumer.

Unlike most individuals in ethnic cultures, the goal of most persons with severe mental illness is to overcome the illness and its associated stigma—to become a nonconsumer. This assertion suggests that the definition of a consumer will vary with the course of the illness. Do consumers of mental health services stop being consumers when the disease significantly remits? The investigator must determine whether individuals in remission should be included in a study of consumer empowerment.

Individual or system?

The subject of traditional psychosocial research is usually the individual. Questions are asked about how the individual manifests various interpersonal deficits that interfere with community living and about how psychosocial interventions remediate these deficits so the individual can live independently. However, some proponents of consumer empowerment believe that focusing investigations at the level of the individual is actually another manifestation of dis-

crimination against people with schizophrenia. They claim that such an approach distinguishes consumers of mental health care as "misfits" who must be understood so that they can live more effectively with the majority (21,35). Research efforts like these may unintentionally promote stigma and misconceptions about schizophrenia.

A better understanding of the effects of stigma can be achieved only by examining the systems in which prejudice and discrimination occur (36). Such an approach involves studying the interactions of society

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and individuals. Researchers must examine not only individuals with schizophrenia but also groups, organizations, service systems, and communities in which psychosocial interventions occur (21). At the most fundamental level, the situational relevance of clinical interventions should be assessed in terms of the social environment and the economic period in which the intervention occurs.

For example, the contemporary impact of vocational rehabilitation can be understood only when the current

job market in particular communities is documented. Clinical research conducted in somewhat artificial settings, such as carefully controlled academic research programs or inpatient rehabilitation settings, is likely to produce outcomes that do not accurately reflect the various social systems that individuals living in the community encounter.

The role of consumers in psychosocial programs

For more than 25 years, clinical investigators have examined whether professionally developed and operated programs accurately represent the concerns of consumers for whom the programs were designed (37,38). These investigators have questioned whether psychoeducational programs, in particular, are limited because they reflect the goals of the white middle-class professionals who develop them rather than the culture of consumers who are supposed to benefit from them. Thus research strategies were developed to survey consumer groups about their perspectives on "consumer-relevant" treatment.

For example, Goldsmith and McFall (38) developed an effective skills training program based on outpatients' reports about their interpersonal problems and the ways they resolved them. The program was then taught to a separate group of participants, who showed significant gains in self-esteem and interpersonal competence compared with a control group.

The study by Goldsmith and McFall involved professionally led intervention programs. Two other empirically tested programs—the psychosocial clubhouse and Fairweather's Lodge—were primarily developed and operated by consumers. Psychosocial clubhouses, like Fountain House in New York City and Thresholds in Chicago, developed out of consumer dissatisfaction with professionally led treatment programs.

Clubhouses are primarily group-oriented programs in which members decide to participate in various work units that determine the short-term goals for the day—for example, cleaning the meeting room, planning the

Christmas party, or determining the agenda for a substance abuse treatment group. Bond (39) summarized research associated with Thresholds showing that the program significantly reduced hospitalization, helped members find jobs, increased their independence, and was cost-effective. Two controlled studies at Fountain House showed a significant decrease in rehospitalization among participants during the time clubhouse services were available (40). However, the range of variables included in research on clubhouses has been somewhat limited. Additional studies are needed to examine other domains, including quality of life and social support.

Another model of a consumer-developed and -operated program was provided by Fairweather and colleagues (41). They believed that the symptoms and deficits of institutionalized persons would greatly diminish if they were empowered to care for themselves in a lodge setting. In such a setting, consumers benefit from the consensus-building process needed to design and maintain effective residential and vocational programs. Moreover, their sense of self-efficacy (the belief that one's actions are usually successful) and self-esteem is enhanced by living and working with peers.

Results of a 36-month follow-up were promising; participants in the program showed a significantly lower rate of hospitalization and significantly greater rates of employment than participants in a control program. However, employment was limited to jobs within the lodge, and the generalizability of employment findings has not been further tested. Moreover, research failed to distinguish psychosocial adjustment or quality of life across groups.

Researchers have also studied the role of consumer as provider (42,43). Solomon and Draine (44) completed one of the few studies that directly compared a consumer-operated program and a professionally operated program. Ninety-one participants were randomly assigned to case management services provided by consumers or nonconsumers. Solomon and Draine argued that hiring con-

sumers as case managers serves both the system's need for experienced case managers and the consumer's need for employment.

Results showed consumers were as effective as nonconsumers in maintaining the stability of participants (45,46). However, the findings are problematic because they rest on the null hypothesis. The investigators could not be certain that the lack of difference in outcome represented true equivalence between consumers and nonconsumers. The lack of difference may represent some limitation in the research design or lack of sensitivity in dependent measures.



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*Research issues in
consumer-developed programs*

Preliminary research suggests that treatment programs designed and operated by consumers may yield significant improvements in consumer outcomes in some situations. Thus future research must describe the components of consumer-developed programs that account for significant improvements. The identified effects of consumer programs can then be directly compared with those of professionally driven interventions. Findings from such comparison studies

would help determine whether program components that are important in effecting change are unique to consumer programs or whether they are also present in professionally led services.

One of the implicit assumptions of consumer-developed interventions is that consumers will produce interventions that are qualitatively distinct from those of professionals. The distinctive features arise out of consumers' unique knowledge acquired through experience with mental illness and mental health services (47). This assumption must be examined by comparing the active components of consumer-developed and professionally led programs. An examination of this assumption might combine discovery-oriented research on psychotherapy with more traditional hypothesis testing (48-50). Discovery-oriented research on psychotherapy adopts an ethnographic approach to analyze the content of a therapy; the content analysis yields a theory about the impact of the components of a specific therapy. Hypotheses generated from the theory are then tested using the more rigorous methods of hypothetico-deductive research (51).

Mahrer (49) has outlined several steps in conducting discovery-oriented research on psychotherapy. First, targets for the discovery-oriented enterprise must be distinguished from the background or context of therapeutic interactions. What ingredients in psychotherapy account for positive results? In more traditional research on psychotherapy, these targets are embedded in discrete therapeutic contexts like the 50-minute hour. Targets of discovery-oriented research on consumer-developed programs should include instances of empowerment, self-efficacy, and interpersonal interactions that foster these values (35). Unfortunately, the contexts in which consumer-developed programs occur are broader and less clearly defined than the 50-minute hour.

Participants in rehabilitation programs typically engage in several relationships (with other consumers participating in the program, with consumer-providers, and with consultants who provide help with ad-

ministrative duties) in various situations (skills training classes, support groups, community meetings, or psychopharmacology clinics) in a sometimes irregular schedule for several hours each week. To obtain a comprehensive picture, researchers must target instances that combine each of the relationships, situations, and time periods.

Qualitative analyses like these are potentially biased by the investigator's a priori conceptualizations. For example, researchers who are insight oriented are likely to perceive consumer-therapist interactions as representing developmental insights even when such interpretations are absent. Mahrer (49) believes the results of discovery-oriented research are more reliable when they have been determined by consensus among independent judges. One assumption of the empowerment movement is that experience with psychiatric disability provides consumers with unique insights about severe mental illness and ways to treat it. Therefore, consumers should be included as independent judges so that discovery includes their unique perspective.

The consumer's role as participant and provider

Consumers who assume both participant and service delivery roles blur the doctor-patient dichotomy that defines more traditional research. Treatment programs led by nonconsumers neatly differentiate participant and clinician: clinicians provide services, and participants receive them. Process measures neatly describe individuals in these roles; they examine the quantity and quality of interventions provided by the professional as well as the quantity and quality of consumer participation. Measures assess the impact of professional intervention and consumer participation on a variety of outcome variables. As a result, causal models of professionally led programs are relatively simple and unidirectional.

The interaction of roles is far more complex in consumer-developed and -operated programs. Consumers may act as administrators, supervisors, therapists, or evaluators in a program. Consumers may assume these roles as

graduates of the programs or while they are participants (52). Developers of some consumer programs think it is better to exclude professionals from the milieu (53,54). Others might permit professionals to join collaboratively with the consumers. Unidirectional models of causation are not sufficient to describe the latter relationships. Rather, models that include feedback loops and circular causality may yield more appropriate descriptions of the effects of various consumer roles on participant outcome.

Empirical research for a political paradigm

The research strategies described in this paper rest on the assumptions of an empirical psychology. Researchers in psychiatry and psychology assume that empirical epistemologies, with their rigorous methodologies, are the best way of evaluating theories of human behavior (55). However, other epistemological paradigms have been used to explain human behavior (56). Consumer empowerment is a political paradigm that developed out of societal discrimination based on misconceptions about consumers.

This paper has discussed what an empirical epistemology can bring to this political paradigm. Conversely, participatory action research is a political prescription for empirical research. Participatory action research calls for a significant change in the roles of consumers and professionals. Consumers actively investigate research hypotheses themselves and enlist trained researchers as consultants to their projects (57). The goal of participatory action research is to advance research endeavors that support the fundamental assertions of consumer empowerment (58,59).

Proponents of this type of research believe that active participation of consumers will ensure that scientists examine both the technical and the human sides of mental illness (59). Research questions, and ways to answer these questions, will change significantly when consumers undertake studies. Questions governing participatory action research include "Whom does the content of a specific research project empower?" and "Whose voice does it amplify?" (36).

The impact of participatory action research is most dramatic when the research agenda of empirical investigators and the political agenda of consumer empowerment clash. Proponents of consumer empowerment believe that misguided research has led to misconceptions about mental illness. Therefore, the direction of future research should be altered so that these misconceptions are not continued (57). Some governmental bodies that fund research, such as the National Institute of Mental Health or the National Institute on Disability and Rehabilitation Research, are beginning to recognize participatory action research as a priority. Researchers should be mindful of political goals like these when developing and implementing research proposals. ♦

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