

INFORMED CONSENT: Strategies to improve the experience of Massachusetts mental health consumers

Since its beginning in 1999, CQI has had contracts with both the Massachusetts Behavioral Health Partnership (MBHP) and the Mass. Department of Mental Health to conduct interviews with consumers about their experiences with a variety of mental health programs/services.

Background

Mental health clinicians have an ethical and legal duty to obtain a client's informed consent before providing treatment to him/her. As stated in DMH policy 96-3r:

"The Authorized Prescribing Clinician owes to the client the duty to disclose, in a reasonable manner, all significant medical information that the [s/he] possesses or reasonably should possess that is material to an informed decision by the client as to whether or not to undergo a proposed treatment."

"Medical information" that the clinician must disclose includes: 1) a description of the condition being treated, 2) an explanation of the benefits, risks, and side effects of the proposed treatment, and 3) an explanation of alternatives to the proposed treatment (ie, informed consent information). It is also critical for the clinician and client to discuss this

information to ensure that the client has sufficient understanding to make an *informed* decision relative to his/her treatment options. Studies demonstrate that such discussions in the context of a collaborative approach to decision making (ie, shared decision making) elicit patient preferences, significantly improving treatment decisional quality, medication adherence, and quality of life outcomes (Schauer, Everett, del Vecchio, & Anderson, 2007; Adams & Drake, 2006). The impact of shared decision making is magnified when the decisions are about psychiatric medications, all of which have the potential to produce serious side effects, but differ in the types of side effects produced (Deegan, 2007).

Since 1996, when the consumer advocacy organization M-POWER¹ and the Massachusetts Department of Mental Health (DMH) agreed to the above-noted informed consent policy, consumers and others have raised concerns that this policy has not been implemented effectively within the Massachusetts public mental health system. This Issue Brief reports on CQI's findings regarding consumer satisfaction with information survey respondents received about their psychiatric condition and prescribed medications in a variety of settings in Massachusetts. We also offer recommendations to policy makers to improve communication between clinicians and clients, and also to develop interventions to encourage shared decision making in the clinical context.

Data

CQI, with stakeholder input, has developed

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Collecting consumer survey data from 2000-2005, CQI learned that while a solid majority of outpatient clients were satisfied with informed consent information received, just over half of hospitalized patients were so satisfied. In some cases providers were reluctant to provide that information. The groups most dissatisfied were people who were homeless and those held against their will.

Since many of our respondents were not engaged in a collaborative medication planning approach with their clinicians, we recommend that the public mental health system promote evidence-based and promising practices that promote shared decision making. For providers, this would be training in the Illness Management and Recovery approach. Client activation supports include patient decision aids, curriculum-based training, and peer support.

consumer satisfaction surveys for various service settings where psychiatric medications are prescribed, including acute care hospitals, state hospitals and outpatient clinics. Through our contract with the MassHealth² carve-out, the Massachusetts Behavioral Health Partnership (MBHP), CQI interviewed 2,100 MassHealth recipients between 2000 and 2005 about their experiences with acute care hospitals and outpatient clinics³. And through our contract with the Massachusetts Department of Mental Health (DMH), CQI interviewed over 345 patients at nine state run hospitals in 2002. We also asked respondents to qualitatively describe the reasons for their responses.

Besides satisfaction data, CQI surveys collect a variety of demographic information, which allows us to determine if satisfaction varies by different demographic variables. One of these demographics is “patient status” at the hospital. We divide patient status into three categories: 1) “truly voluntary,” 2) “committed,” and 3) “voluntary but does not want to be there.” The latter category refers to patients who have signed into the hospital under a voluntary status, but did so because either they faced a commitment hearing or they had no other treatment options.

Key Findings

Findings related to informed consent from CQI’s surveys of mental health consumers in Massachusetts are summarized below.

1) Outpatient clients were more satisfied with informed consent information than were hospitalized clients

Figure 1 shows the percentage of respondents who were satisfied with the information they received about the nature of their psychiatric condition, and Figure 2 shows satisfaction rates with regard to information received about the benefits, risks, and side effects of their medications. The graphs list the percentage of respondents satisfied for three levels of service.

Several reasons are likely to account for hospitalized people being more dissatisfied. First, these service levels may place different emphases on providing information to clients about the nature of their condition and the potential side effects and risks of medication. For example, hospitalized patients may be seen as “sicker,” and thus less able to handle information or more likely to refuse treatment if fully informed about side effects.

Second, a higher percentage of people in hospitals would prefer not to be in treatment at that kind of setting, and due to the legalities of confinement, are not able to simply opt out of treatment if they are dissatisfied. Outpatient clients who are dissatisfied with an aspect of care can simply stop attending.

Third, acute care settings face challenges in that patients have relatively short stays and may be going through multiple medication changes.

Figure 1

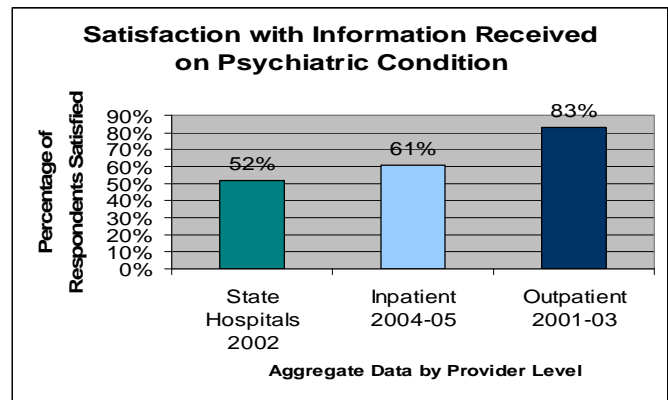
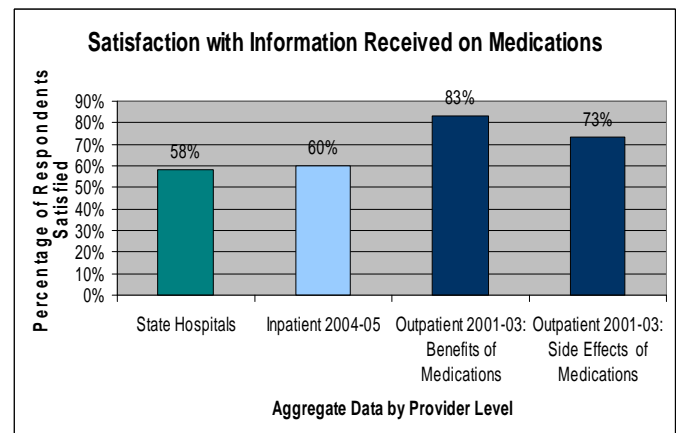


Figure 2



2) A significant number of respondents felt they were receiving insufficient information about their psychiatric condition and medications.

Respondents reported dissatisfaction because: 1) no information at all was provided, 2) information was provided verbally but without any written materials, and/or 3) they had to ask in order to receive the information. Some respondents reported that providers made written materials available, but spent little time discussing the medications or psychiatric conditions with patients.

As a result, improving information to clients on their psychiatric condition and medications was a common recommendation in CQI's reports to inpatient and outpatient providers. CQI gave half of all hospitals surveyed a recommendation to improve the information they were providing to patients about their psychiatric condition and medications.

There were in fact some cases in which hospitals employed multiple methods of information dissemination. For example, some hospital patients said that they benefited from nurse led medication discussion groups.

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3) Some providers are reluctant to disclose informed consent information to patients.

CQI learned from both respondents and providers that certain staff were reluctant to fully disclose information to clients about their psychiatric condition and/or medications. Some staff felt that some to most of the clients they saw are unable to understand this information. Others were afraid that discussing this information with clients would make them less likely to take medications.

4) Demographic differences in satisfaction with informed consent information

Involuntary hospitalized patients are more dissatisfied. At the hospitals, patients whose status was either "committed" or "voluntary but did not want to be there" were significantly more dissatisfied with informed consent information than were those whose status was "truly voluntary."⁴ In addition, those who were committed tended to be more satisfied with the information than those who were "voluntary but did not want to be there" (consistent with the satisfaction levels for other aspects of care).

Homeless clients of outpatient clinics are relatively more dissatisfied with informed consent information. At outpatient clinics, people without stable housing were less likely to be satisfied with information on their psychiatric condition and medications. For information on psychiatric condition, there was a 26% difference in satisfaction rates between those with stable housing (84% satisfied) versus those without stable housing (58% satisfied). For information on medications, those with stable housing were also more satisfied (82%) versus those without stable housing (62%).

Summary of demographic influences on satisfaction with informed consent. It is difficult to say what exactly is causing the above differences in satisfaction. There may be other undetermined factors mediating these demographic variables and the low satisfaction with informed consent information. It does appear however that the demographic groups that are most vulnerable and have the most limited choices are significantly less satisfied with the informed consent information they receive.

Recommendations

CQI offered many hospitals and outpatient clinics specific recommendations to help them improve the quality of informed consent information. These included: a) distributing to patients up-to-date and understandable medication information sheets, b) making available regular medication education groups led by a psychiatrist, nurse, occupational therapist, and/or a peer, and c) educating significant others about the illness and medications where the client provides permission. (For (c), SAMHSA⁵ has developed a helpful toolkit, at http://download.ncadi.samhsa.gov/ken/pdf/toolkits/family/02.FamPsy_Users.pdf.)

CQI recommends that DMH, MBHP and key stakeholders collaborate to promote and establish the use of evidence-based and promising practices that support shared decision-making.

Despite their intrinsic value, we have found that these recommendations have had only a limited effect on provider practice, and even when implemented, tend to have minimal impact on client participation in treatment planning. In fact, transformation to a person-centered treatment approach that supports shared decision making requires a multi-tiered strategy (Schauer, Everett, del Vecchio & Anderson, 2007). Thus, CQI recommends that DMH, MBHP and key stakeholders collaborate to promote and establish the use of evidence-based and promising practices that support shared decision-making⁶ (New Freedom Commission, 2003). This includes technical assistance and support for both providers and clients (and families), as described below:

A. Provider Trainings and Technical Assistance on Illness Management and Recovery (IMR)

Illness Management and Recovery (IMR) is a SAMHSA designated evidence based practice designed to increase patient involvement in treatment planning, improve illness self-management, and promote wellness⁷. The IMR program achieves these outcomes by combining four practice strategies: 1) *Psychoeducation*: informed consent information to consumers and family/community support persons, 2) *Cognitive-Behavioral Methods for Using Medication Effectively*, including motivational interviewing, 3) *Relapse Prevention*, which teaches clients to recognize their relapse triggers, and 4) *Coping Skills Training*, which teaches techniques to manage stress and reduce the distress of persistent symptoms (Mueser, Corrigan, Hilton, Tanzman, Schaub, Gingerich et al, 2002).

Motivational interviewing (MI) is an especially useful technique for providers to engage in discussions with their clients about medications (Possidente, Bucci & McClain, 2005). MI involves “helping people articulate personally meaningful goals and exploring how medication may be useful in achieving those goals.” (Mueser, Corrigan, Hilton, Tanzman, Schaub, Gingerich et al, 2002) MBHP has sponsored MI training for addiction services clinicians, and we recommend that this training be expanded to psychiatrists.

B. Client activation infrastructure for shared decision making in clinical treatment planning

Studies demonstrate that there are a variety of interventions that can develop and enhance client activation in the clinical relationship. “Activation” here refers to a client’s capacity to develop the knowledge, skills and beliefs permitting them to participate effectively in clinical decision making (Alegria, Polo, Gao, Santana, Rothstein, Jimenez et al, 2007). Activation interventions have their greatest effect when the “correct” treatment decision is not clear to the clinician, often the case with psychiatric medications; thus, the client’s judgment of associated benefits versus harms should be the difference maker on what treatment is chosen (O’Connor, Légaré & Stacey, 2003).

Activation interventions that are only didactic in nature are generally not effective. Instead, interventions that are interactive and supportive not only have great potential to activate patients, but also to empower them to manage and take control of their illness. As noted below, activation interventions can be part of a treatment approach or they can be more community-based, perhaps within a consumer-driven resource center such as the DMH-funded Recovery Learning Communities. While activation interventions for a variety of health conditions have been in existence for over a decade, they are

just beginning to emerge for psychiatric care, as described below:

Interventions that are interactive and supportive not only have great potential to activate patients, but also to empower them to manage and take control of their illness.

Patient Decision Aids (PDAs) are designed to help people make specific and deliberative treatment choices by educating them about a specific medical condition, the treatment options, the probabilities of treatment benefits and harms, and methods to clarify their values. PDAs are usually materials, presentations or interactive experiences, including computer programs, audio-guided workbooks, audio tapes, and/or personal coaching or mentoring (O’Connor & Stacey, 2005). A powerful example is Pat Deegan’s *CommonGround*, which transforms a psychiatric clinic’s waiting area into a decision support center, ideally staffed by peers. *CommonGround* includes a user-friendly software program for people with low literacy because it utilizes touchscreens and headphones⁸. (*CommonGround* could also be placed at a consumer-driven resource center.)

Curriculum-based Activation Training- the Right Question Project- Mental Health (RQP-MH)

With the RQP health education curriculum, trainers teach low income mental health clients to formulate, prioritize, and ask questions of their health care providers. The goal is to develop skills that promote more active participation in the clinical context and to encourage greater client self-efficacy with regard to their health care overall; early research results are promising (Alegria, Gao, Santana, Rothstein, Jimenez et al, 2007). The protocol was developed by The Right Question Project, Inc., with the Cambridge Health Alliance Center for Multicultural Mental Health Research as its research partner⁹.

Peer support not only improves the well-being of people with mental illness, but also improves a person’s capacity to engage in shared clinical decision making (Deegan, 2007). One important example is the “peer specialist,” who is hired as part of a treatment team to utilize his/her experience of mental health recovery to assist consumers in articulating and reaching their personal goals for recovery. In

Massachusetts, peer specialists are part of PACT¹⁰ teams, and can act as educators and activation coaches for clients who are having trouble interacting with other staff about medication issues. Peer advocates at Recovery Learning Communities, who are not part of a treatment team, can also serve in this coaching role.

Wellness Recovery Action Plan (WRAP) WRAP is an approach, by which a peer leads consumers through a structured series of workshops that help the consumer clarify their personal values, illness triggers, and wellness promoting activities (Cook, 2005). The result is a written plan of preferred activities and treatments for both crisis situation and regular activities to maintain wellness. WRAP is a great option for people who benefit from written communications.

Notes

1. Massachusetts People/Patients Organized for Wellness, Empowerment and Rights.
2. MassHealth is the Massachusetts Medicaid Program.
3. After completing a series of interviews at a particular provider site, CQI writes a data report that includes recommendations, and meets with provider and MBHP staff to develop an action plan.
4. There was almost a 20% difference in satisfaction rates between those who were truly voluntary and those who were voluntary but did not want to be there.
5. The Substance Abuse and Mental Health Services Administration (SAMHSA) is a federal oversight body.
6. An approach supported directly by Recommendation 2.1 of the President's New Freedom Commission Report.
7. Illness Management & Recovery program materials website: <http://www.mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/default.asp>.
8. http://www.patdeegan.com/common_ground_training.htm, retrieved on 12/15/07
9. <http://www.rightquestion.org/main/node/109>, retrieved on 12/15/07.
10. Program for Assertive Community Treatment.

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