

GUEST EDITORIAL

The Promise of Shared Decision Making in Mental Health



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Introduction

Shared decision making is a verb. It connotes a process, supported by specific information technologies, that reengineers how practitioners and people with diagnoses work together (Montori, Gafni, & Charles, 2006). Undoubtedly, the foundational values and principles of shared decision making are familiar to the readers of this journal. Person-centered care, respect for individual autonomy, choice and collaboration are well known and widely embraced in behavioral health and psychiatric rehabilitation (Anthony, 1979; Cohen, Farkas, Cohen, & Unger, 1991; USPRA, 2009). Shared decision making advances these principles through the use of specific information technologies such as decision aids and electronic decision support programs (O'Connor et al., 2009). When carefully designed and strategically inserted into the everyday workflow, these technologies hold the promise of helping busy practitioners put person-centered and recovery-based values into practice. In this paper we discuss the promise of shared decision making for advancing our field.

The Center for Shared Decision Making

Our first glimpse of shared decision making in action was at the Dartmouth

Hitchcock Hospital in Lebanon, New Hampshire (http://www.dhmc.org/shared_decision_making.cfm). The main hallway of the hospital is laid out like a small village with storefront signs indicating various offices. Hospital departments and clinics are located on the upper floors. We entered the storefront called the Center for Shared Decision Making and were greeted by a nurse who introduced us to a wide variety of decision aids. We learned that decision aids were carefully designed tools that supported people who faced tough healthcare choices such as the decision to carefully monitor prostate cancer or to have prostate surgery, which could leave one impotent or incontinent.

At the hospital physicians refer patients to the Center for Shared Decision Making after diagnosis but before deciding on a treatment. There, people interact with decision aids that clearly describe specific medical conditions and relative efficacy of treatment options, including "watchful waiting." But decision aids do more than present patients with risk-adjusted information. Decision aids also include values clarification exercises through which people grapple with questions of how

treatment might affect quality of life, e.g., is surgical removal of the cancer worth the risk of possible impotence or incontinence *for me*? Family and friends are invited to use decision aids that can be brought home via a lending library or used via the Internet. The final task in a decision aid is to complete a decisional leaning scale. Here people indicate the status of their treatment preferences such as surgery, alternate treatment, watchful waiting or still undecided. This report is sent to physicians who review it with patients at the next appointment. Through discussion they arrive at an informed shared decision about next steps.

Having observed shared decision making in action in a hospital setting, we were immediately struck by its applicability to behavioral health. First, shared decision making, decision aids and other decision support technologies are desperately needed, particularly in the arena of psychopharmacology and the routine medication visit where decisions are complex, often involving significant risks and benefits that impact quality of life (Drake & Deegan, 2009). Shared decision making could help level the playing field, giving people with psychiatric disabilities independent access to unbiased, evidence-based information about treatment and recovery. Second, embedding information technologies and support for using them into routine clinical and rehabilitation practice could re-engineer how practitioners and people with psychiatric disabilities collaborate in shared decision making. In particular, these technologies could help amplify the voice of people with psychiatric disabilities, bringing the perspective of the individual to the center of the care team. And finally, decision support technologies could scale with relative ease, and the tools themselves could train and reinforce person-centered practice within the

workflow. Activated, empowered service users who have higher expectations for collaborative care might in turn activate practitioners to engage in more collaborative care.

Shared decision making assumes that two experts (or teams of experts) should collaborate in making complex health care decisions (Charles, Gafni, & Whelan, 1999). The health care provider (often a team of professionals) brings expertise in understanding the health problem, the possible interventions, and the potential benefits and risks of these alternatives. The person with the health problem (often assisted by family or support network members) brings expertise related to personal experience of the illness, values, goals, supports, and preferences. In the shared decision making paradigm, the partners present their respective views and then negotiate a plan that they agree is ethical, consistent with the evidence, congruent with individual preferences, and practical. **Conceptually, shared decision making falls between two extremes of medical decision making: the paternalistic and the autonomous decision models (Joosten, DeFuentes-Merillas, de Weert, Sensky, van der Staak, & de Jong, 2008). In the traditional, paternalistic model, the caregiver assesses what is best for a particular individual, based on scientific evidence and clinical judgment, and makes the decision. In the autonomous decision model, the person with the health problem collects information, weighs the information, and makes the choice unilaterally.**

A Consumer-Survivor Perspective on Shared Decision Making

Shared decision making is consistent with foundational tenets of the consumer-survivor movement and is a welcome addition to recovery-based practice in mental health. Historically, people who have been diagnosed with

psychiatric disorders have advocated for “voice and choice” (Chamberlin, 1990; National Council on Disability, 2000). They have advocated for the opportunity to have a voice in the treatment planning process. **Having a voice allows people to be self-determining and to work through the complex trade-offs associated with choosing the right treatment.** People with psychiatric diagnoses have advocated for choice. **Real choice is predicated on having access to unbiased information about psychiatric treatment and alternatives to treatment.** Having a voice and making an informed choice in treatment may seem like a given. But this has not always been the case.

There is a complex backdrop to the question of how issues of voice and choice became defining themes of the consumer/survivor/ex-patient movement. We do not offer a complete analysis of this history here. Instead, we focus on a single experience described by an asylum inmate over 150 years ago. The following is an archetypal portrait of medical paternalism and, unfortunately, it rings true even in contemporary times:

In 1851 Isaac Hunt published a first person account of his confinement at the state asylum in Maine (Hunt, 1851). In it he described his experience of psychiatric medicine administered by the asylum superintendent:

Dr. Ray [gave me] medicine that caused me to weep like a child—tears of anguish that I could not restrain. Then the reverse would occur; I could not weep—not a tear would flow—I felt as stoic and indifferent as a pirate, believing that I could stand unmoved by any sympathy...The next night the medicine would put me in the most deadly stupor—a leap of unconscious heaviness. Nothing could wake me... (p. 6)

Hunt reported that when he appealed to Dr. Ray to stop administering the medicine, the superintendent replied:

Nothing is given you but what is for your good; you shall go home when you get well. (p. 6)

Clearly Dr. Ray's reply is steeped in **medical paternalism**. An analysis of the phrase Dr. Ray used—"Nothing is given you but what is for your good"—reveals three toxic effects. The reply **silences** Hunt through the assertion of Dr. Ray's medical authority. It **leaves Hunt alone and isolated in his subjective experience of medication-induced torment**. And Dr. Ray's paternalism **reframes Hunt's experience of the medication as being good for him, thereby casting doubt on Hunt's ability to judge for himself** what is in his own best interest. Others are now free to doubt the veracity of Hunt's self-report. But, more important, a seed of doubt has been cast within Hunt's own experience of himself. Can he trust what he perceives? Can he believe what he experiences? Must he rely on others to interpret his experience for him?

In the wake of the superintendent's reply, Hunt was left silenced, alone, discredited and filled with self-doubt. These are iatrogenic wounds. Such wounding reminds us that *treatment* and *how one is treated* are inextricably intertwined. Arthur Frank (1995) underscores this point when he writes:

Seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away. (xi)

In order to heal, one needs to recover the voice that illness, treatment and how we are treated often take away. Therefore, it is not surprising that upon discharge from the asylum, Hunt self-published a book telling the story of his ordeal: *Astounding Disclosures: Three Years in a Madhouse*, by a

Victim. In writing his story, Hunt broke the silence inflicted by medical paternalism. He also broke through isolation by reaching out to others through his story. And finally, as others read and identified with his story, Hunt found validation and learned there was truth in what he experienced. In other words, through telling his story, **Hunt was healing from the iatrogenic wounds inflicted, not just by treatment, but by how he was treated.**

The example of Isaac Hunt helps us to understand why issues of voice are so central to the consumer/survivor/ex-patient experience. The centrality of being wounded in voice remains true even in contemporary times:

Life is hard with a diagnosis of schizophrenia. I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can report my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even ex-client is to be discounted. (Leete, 1989, p. 199)

Shared decision making is an alternative to the wounding practice of medical paternalism, because it honors and values the voices of people with diagnoses. Unlike the encounter between Isaac Hunt and Dr. Ray, shared decision making is predicated on speaking up during the consultation. Instead of isolating people in their experience of suffering and resilience, shared decision making is about *sharing* and collaborating as partners with medical practitioners. And finally, **shared decision making is founded upon understanding there are two experts present in the medical consultation. Rather than discrediting what people say, in shared decision making the individual's opinions, values and preferences are required to make the best treatment decisions.**

In addition to voice, having a choice about treatment has also been a central tenet of the consumer/survivor/ex-patient movement. Choice assumes unfettered access to reliable, unbiased evidence-based information about treatment efficacy, risks, benefits, options and alternatives. Particularly in regards to somatic treatments in psychiatry, consumer-survivors have long campaigned for access to unbiased information about psychiatric medications, psychosurgery, and electroconvulsive therapy (Frank, 1978; Madness Network News, 1976). For instance, on May 30, 1976, ex-patients held a demonstration in Boston and presented 20 demands at the Massachusetts Mental Health Center, one of which was:

Mental patients demand the right to be informed in clear language of the effects of any treatment offered.

Again, the historical backdrop of this demand for informed choice sheds light on the synergy between the consumer/survivor/ex-patient movement and shared decision making. In the pre-Internet age, information about treatment was hard to find. Aside from pharmaceutical company trinkets and advertisements left in waiting areas, clinics did not have a systematic and reliable way of making treatment information available. Although information about psychiatric medicine could be found in the Physician's Desk Reference, it was densely written and hard for laypersons to understand. Scientific journals were kept in university libraries and were difficult to access without credentials. Word of mouth was a valued source of information, but it was not always accurate. In the last analysis, most people relied solely on practitioners to convey information about the benefits and risks of treatment.

By the 1970s that started to change. Beginning in 1972, Madness Network News began to be published every other month and was available, free of charge, to current and former psychiatric inmates. Each issue contained a special column by David L. Richman MD, under the pen name of Dr. Caligari. The column was called "Dr. Caligari's Psychiatric Drugs" and featured detailed, unbiased information about medications and their side effects. By 1976, these columns had been organized into a 22-page booklet. So great was the desire for information about psychiatric medications, that in 1984 "Dr. Caligari's Psychiatric Drugs" was in its third edition and had expanded to 64 pages.

The example of Dr. Caligari's Psychiatric Drugs helps us understand that even in the pre-Internet age, people with psychiatric disabilities had a deep desire for information about psychiatric treatment and found ways to write and disseminate such fugitive literature. From our vantage point today we might say that the issue of informed patient choice is coming full circle. **The demand, made over three decades ago by those early protesters, is echoed today by none other than the National Institute of Health's Quality Chasm Report for Mental Health and Substance Use Conditions (2006):**

The patient as the source of control. Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making. (p. 8)

Issues of voice and choice are close to the hearts of many people with psychiatric disabilities. The practice of shared decision making, with attendant decision support technologies and decision aids, holds the promise of amplifying

voice and informing choice for those with psychiatric diagnoses. **Thus, it is not surprising that researchers have found that people with psychiatric diagnoses express higher than average preference for participating in shared decision making than the general medical population (Adams, Drake, & Wolford, 2007; Hamann, Cohen, Leucht, Busch, & Kissling, 2005).**

Empirical Support for Shared Decision Making

Shared decision making should be a foremost priority for mental health reform. Effective mental health care should be person-centered (Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders, 2006; President's New Freedom Commission on Mental Health, 2003). As is true for all long-term illnesses (Montori, Gafni, & Charles, 2006; Wagner et al., 2001), empowering people to be knowledgeable and active in managing their own mental illnesses is critical (Mueser, Corrigan, et al., 2002) because there are many opportunities to make and revisit the decisions, and the individual must take responsibility on a daily basis (Montori, Gafni, & Charles, 2006). Mental health decisions almost always involve complex trade-offs, and people living with the illness can best evaluate trade-offs in terms of efficacy, goals, and side effects (Charles & DeMaio, 1993; Charles, Gafni, & Whelan, 1997). In mental health, shared decision making should invigorate the relationship needed to optimize long-term outcomes (Deegan & Drake, 2006). For example, learning to use medications involves a dynamic, longitudinal process with decisional conflicts, positive and negative effects, and changes (Deegan, 2007).

In addition to these practical concerns, there are ethical and legal arguments for shared decision making. Autonomy

refers to the right to make decisions regarding one's body and is a fundamental principle of western medical ethics (Schneider, 1998). **Meanwhile, the legal standard for medical care is shifting from informed consent to informed choice among reasonable alternatives (King & Moulton, 2006).**

The majority of people with mental illnesses express a desire to participate in making decisions regarding medications and hospitalizations (Adams, Drake, & Wolford, 2007; Hamann, Cohen, Leucht, Busch, & Kissling, 2005; Noble & Douglas, 2004; O'Neal, Adams, McHugo, Van Citters, Drake, & Bartels, 2008). **Shared decision making is, however, generally neglected in published medication algorithms (Mistler & Drake, 2008) and in daily medication management (Deegan & Drake, 2006). People with severe and persistent mental illnesses believe that they are not actively involved in medication decisions (Adams, Drake, & Wolford, 2007; Deegan, 2007; O'Neal, Adams, McHugo, Van Citters, Drake, & Bartels, 2008). Equally worrisome, many psychiatrists report that shared decision making is inappropriate for decisions regarding medications and hospitalizations due to patients' decisional incapacity (Hamann, Mendel, Cohen, et al., in press; Seale, Chaplin, Lelliott, & Quirk, 2006).**

At the same time, the evidence in support of shared decision making in mental health is expanding rapidly.

Research shows that nearly all psychiatric patients, even the great majority of those with severe disorders such as schizophrenia, are capable of understanding treatment choices and making rational decisions (Carpenter, Gold, Lahti, et al., 2000; Grisso & Applebaum, 1995; Stroup, Appelbaum, Swartz, Patel, et al., 2005). Those with limited education, learning disorders, or other disadvantages require repeti-

tion of information or multi-modal sources of information (McGurk & Mueser, 2006). For individuals who do experience temporary decisional incapacity, such as during psychotic episodes, psychiatric advanced directives are helpful (Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006).

Shared decision making constitutes a core principle of several evidence-based practices and partially accounts for their effectiveness (Becker, Xie, McHugo, Halliday, & Martinez, 2006; Bond, Salyers, Rollins, Rapp, & Zippel, 2004; Corrigan, 2006; Mueser, Corrigan, et al. 2002). For example, supported employment follows the client's decisions about job choice, when to search for a job, how many hours to work, whether or not to disclose illness to the potential employer, supports on the job, manner of follow-up, and so on (Bond, 2004). Emphasis on shared decision making is also central in illness management and recovery (Mueser, Corrigan, et al., 2002), behavioral family therapy (Mueser, Glynn, & Liberman, 1994), integrated dual disorders treatment (Mueser & Drake, in press), and systematic medication management (Miller, Crismon, Rush, et al., 2004). Assertive community treatment, which has been criticized for paternalism, is also becoming more consumer-centered (Salyers & Tsemberis, 2007).

Although research on shared decision making in mental health is clearly behind other areas of medicine, several randomized controlled trials support its effectiveness (Malm, Ivarsson, Allebeck, & Falloon, 2003). These studies show that shared decision making increases the quality of decisions (knowledge, participation, and congruence with values). As in other areas of medicine, there is minimal evidence regarding objective health outcomes. Long-term studies of health outcomes

related to greater knowledge, participation in illness self-management, and better relationships with practitioners need to be evaluated.

Limitations

Despite some progress, the barriers to shared decision making are considerable (Gravel, Legare & Graham, 2006). Clinicians lack familiarity and training, sometimes disagree with the concept, and often have concerns regarding decisional capacity and legal responsibility. People with mental illnesses often lack the information, empowerment, motivation, and self-efficacy needed to participate in shared decision making. Mental health systems often lack the computer infrastructure needed to provide information and access to medical records. These issues need to be clarified by further research and addressed at many levels: basic decision making science, clinician training, structural implementation, electronic infrastructure, patient empowerment, and so forth.

Summary and Conclusion

Shared decision making is congruent with the foundational tenets of the consumer-survivor movement and with the values that inform recovery-based practice in our field. It is first and foremost an ethical imperative.

Implementing shared decision making in routine mental health care could also enhance quality of care, informed decisions, consumer satisfaction, self-management, alliance, and meaningful outcomes. Realizing these potentials will be an enormous challenge that must involve users of the mental health system as central figures. We must address these barriers through research, advocacy, policy, and practice reforms.

This Special Section

The articles in this section of the journal provide just a glimpse of the activity underway to promote shared decision making in mental health. Nevertheless, they are important windows into the new world of possibilities regarding care planning, medication management and the use of information technology. Curtis et al. offer a broad overview of shared decision making, its migration into behavioral health and SAMHSA's effort to develop decision support tools, including a decision aid for treatment of psychosis. Woltmann and Whitley shed light on service user views of their decision making in mental health. Their findings remind us that consumers often view decision making in the broader context of having ongoing relationships with case managers. It can be challenging to speak up or differ from staff. More research is needed to learn how to help people mitigate these difficulties. Deegan describes a web-based software application designed to support shared decision making that was developed by and for people with psychiatric disabilities. Users access the software in peer-run decision support centers in psychiatric medication clinics. She finds that these technologies support shared decision making and activation in routine practice. And finally, Andrews, Drake, Haslett and Munusamy introduce an online tool that allows researchers to rapidly design, deploy and study decision support technologies, thereby paving the way for future exploration of the promise of shared decision making in behavioral health.

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