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Shared Decision Making

To the Editor: In their November Open Forum, Deegan and Drake (1) call for a shared decision-making process in prescribing medication instead of the traditional authoritarian compliance process. They argued that deciding to take medication is a complex decision that needs to be processed with the patient. They even mention that clinicians who make decisions for patients may be acting unethically unless it is an emergency.

Although these authors state that there may be situations such as emergencies in which shared decision making may not fully apply, they seem to ignore situations in which it should generally not apply at all. Specifically, patients from some cultural backgrounds expect the physician to tell them what medication to take. In such cases, should the physician ask them for their opinion, they may view the clinician as incompetent (2). Among patients who are not acculturated to mainstream values in the United States constitute one such group. The same is true of other recent immigrants or refugees who are used to a paternalistic society. In some cultural groups, it is also common for certain people in the family

to make health decisions for others in the family.

Therefore, although Deegan and Drake's strategy may well apply to most mainstream, acculturated Americans (perhaps with the exception of those who have strong dependent personality traits), it will not be applicable cross-culturally. Cultural competence will call for a more adaptable prescribing practice. Individual prescribers can try to adjust their level of paternalism on the basis of their cross-cultural knowledge and an assessment of the degree of acculturation of the individual patient. A question as simple as "Would you like to know more about this medication?" may help.

Medication prescribing is even more complicated than Deegan and Drake indicate if cultural background is taken into account.

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To the Editor: In the November Open Forum Deegan and Drake's argument that medication management in the recovery process should take the form of shared decision making between clients and practitioners is most welcome, as is their emphasis on the need for more research on how this can be achieved. We wish to take issue only with one assertion they make—that psychiatric advance directives allow shared decision making to occur.

As documents that can be completed in the absence of any practitioner involvement, psychiatric advance directives are aimed at promoting patient autonomy rather than an agreement with practitioners regarding future emergency mental health care.

Their mode of preparation therefore conforms much more closely to the consumer choice model (1).

However, consumer choice in this context is limited by several provisions of advance directive legislation. For example, the instructions can be overridden by commitment law or if they are unfeasible or in conflict with community practice standards. The operational and service culture barriers to implementation of psychiatric advance directives further limit the extent to which consumer choice can be exercised through their use (2,3). These barriers include having to get the document witnessed and notarized and finding someone to act as a health care power of attorney, as well as practitioners' ignorance about advance directives resulting from the lack of infrastructure to support their dissemination, and practitioners' resistance to being limited by clients' preferences for certain treatments. Thus, although psychiatric advance directives appear to offer consumer choice, they are detached from any mechanism to deliver it.

In contrast, the joint crisis plan (4,5) fits the model of shared decision making much more closely. It is an advance agreement regarding emergency mental health care that is made between a client and a practitioner, with negotiation facilitated by an independent practitioner. Disagreements about care that cannot be resolved are made explicit in the plan. Although the final choice of content is the client's, the involvement of the client's usual care providers increases the chance that they will be aware of and able to act on the preferences expressed. Again, a fragmentary system of care increases the work needed to disseminate joint crisis plans. In the service setting of the United Kingdom, most community psychiatrists are also responsible for their patients during hospitalization. The use of joint crisis plans in the United Kingdom was associated with a 50% reduction in involuntary hospitalization compared with a control group, as well as a reduction in episodes of violence (4). Economic analysis suggest-

ed a high probability of cost-effectiveness. The results suggest that the joint crisis plan allows practitioners to manage risk in a way that is more closely based on patients' preferences.

We suggest that the joint crisis plan is one example of the interventions that Deegan and Drake call for "to help activate clients to become involved in the shared decision-making process."

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In Reply: In response to the thoughtful letters about our Open Forum—the two above and the letter in the December issue from Peyser and Shadoan (1)—we would like to offer this vignette and commentary.

In a psychiatric medication clinic located in an urban center in the Midwest, a young woman arrived for her appointment accompanied by

her case manager. She was a longtime client of the center and had a diagnosis of a substance use disorder and schizophrenia. Her presentation on this day was disorganized, distressed, and psychotic. At the clinic, she was greeted by a peer specialist, offered food and beverage, and encouraged to use assistive technology to organize the information she wanted to share with her doctor. The young woman sat at a kiosk, put on headphones and, when prompted, entered her responses via a touch screen. The software organized the story that she wanted to tell her doctor, at a time when she could not organize this story herself. When finished, she pressed a print icon, walked to the printer and picked up her one-page report.

The report generated by the software program summarized how this client felt she was doing, how she had been using medications, and what her goals for meeting with her doctor were. It also identified her decisional uncertainty about using medications. She brought the report into her appointment. According to the young woman and her doctor, assistive technology enabled her to effectively communicate her concerns and to participate in shared decision making.

The technology described in the vignette is part of a decision support center in a psychiatric medication clinic. It represents the types of innovations in decision support that are the future of medicine in the 21st century. As the vignette illustrates, when we move beyond medical paternalism and the related notions of compliance and coercion, innovative strategies to collaboratively engage even the most challenging clients in shared decision making often emerge. Sweeping assumptions that large groups of people require benevolent paternalism and are not fit for shared decision making are empirically unsubstantiated (2). Most people, including those with a diagnosis of schizophrenia, want some level of involvement in medical decision making (3). Reliance on unilateral decision making and involuntary interventions can lead to unnecessary curtail-

ment of fundamental civil liberties and little clinical or psychosocial improvement (4). The 2006 follow-up to the Institute of Medicine's Quality Chasm report concluded that the principles of person-centered care can be applied to those with substance use and mental disorders. Shared decision making is a key to realizing the report's recommendation and "ensuring that patient values guide all clinical decisions" (5).

Shared decision making may not be possible in situations of temporary decisional incapacity. In such situations the use of medical guardianships, advanced crisis planning, and psychiatric advance directives may help clinicians remain faithful to clients' values and preferences. However, this does not mean that shared decision making is a privilege for those with milder mental disorders. Shared decision making is an ethical imperative and is a fundamental tenet of evidence-based medicine. People with psychiatric disabilities want to be involved in treatment decisions. Rather than excluding large groups of people on the basis of clinical or cultural characteristics, we seek ways to create assistive technologies and supports so that all people with psychiatric disabilities can participate in shared decision making.

Patricia E. Deegan, Ph.D.

Robert E. Drake, M.D., Ph.D.

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Conditional Release and Reduced Mortality

To the Editor: If the purpose of commentaries is to demonstrate the irrationality of consumer advocates, the one in the November 2006 issue accomplishes this purpose well. In Taking Issue, Bernstein (1) commented on a study by Segal and Burgess (2). These authors examined case register data for several thousand patients in Australia and found that over a 13.5-year period those who had been given conditional release from a psychiatric hospitalization experienced a 14 percent reduction in the probability of noninjury-related death and a 24 percent reduction in injury-related death. Bernstein states that the study's methods were insufficient to establish causal links showing that conditional release exercised a protective effect in terms of subsequent mortality.

Does anyone believe that if an intervention were to increase mortality by similar rates, advocates would dismiss it with the comment that association does not establish causality? No—they would be shouting from the rooftops that so strong an association establishes causality beyond any doubt.

Moreover, what is the basis for the statements that public systems in Australia are “neglectful” of patients and that 15-minute outpatient appointments are inadequate? Judging from this large-scale study, it would seem that they are adequate to the task of these large reductions in mortality. Bernstein dismisses these reductions as “blunt indicators of clinical effectiveness,” when, in truth, they are impossible-to-manipulate proxy measures, unlike some of the presumably more sophisticated measurements that are the dream of spin doctors everywhere.

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In Reply: Certainly no one would find improvements in mortality rates for people with serious mental illness to be a trivial matter. The mechanism whereby mortality rates could improve as a result of limited periods of court monitoring after hospital discharge is not intuitively obvious; however, incidental factors may be at play. For example, the community service system may be more accountable for individuals on conditional release, giving them greater service priority or more consistent services. On the other hand, because individuals included in the study by Segal and Burgess were not randomly assigned to court-monitored and unmonitored release from psychiatric hospitals, it is possible that differential selection practices account for the gap between mortality outcomes. For instance, medically compromised individuals might be regarded as candidates for long-term care settings and not in need of post-discharge court supervision. Or to the extent that, as the authors suggest, court oversight encourages physicians to discharge patients earlier, simply getting out of the hospital quickly may lead to reduced mortality.

But this is all speculative. Notwithstanding the attraction of Segal and Burgess's findings or the impressive size and scope of their database, their associational data are just that. Without minimizing the significance of their study or the improved mortality rates, it must be noted that these data simply do not establish that court-monitored release is the formula for lower death rates—or for anything else.

Extracting a broader lesson from this research and the reaction to my comments, if reductions in mortality rates were an adequate proxy for the goals of the public mental health system, one might argue that the currently configured system (epitomized in my commentary by “15-minute outpatient ‘therapy’ sessions”) bolstered with ramped-up court intervention might be a compelling direction to pursue. On the other hand, as articulated by the President's New Freedom Commission, many stakeholders believe that mental health care should strive for goals well be-

yond low death rates or recidivism rates—indeed, for recovery. Court participation in individual treatment plans is a dubious pathway to such aspirations. As a general matter, routine reliance on court intervention can be seen as diagnostic of a system that is both neglectful and neglected. When used in noncrisis situations such as hospital discharge, requests for court intervention signal reservations about the impact of inpatient care, the capacities of the community system, and the status of the individuals being served. Given the erosion of the public mental health system and the underutilized potential of innovative interventions, various schemes involving the court in treatment can be seen as buttresses to a floundering system. Through this lens, the data presented by Segal and Burgess suggest that in Victoria, Australia, the climate is quite hospitable for judicial participation in individuals' mental health treatment, so much so that court-monitored discharges are regularly sought even for those entering the hospital voluntarily.

All of this raises a much more fundamental issue facing professionals in public mental health: Is their quiet complicity in involving the courts in nonemergency treatment of competent individuals perpetuating devaluation of public mental health care, the individuals it serves, and even the providers themselves?

Robert Bernstein, Ph.D.

Kinship Status in CATIE

To the Editor: In a study reported in the August 2006 issue, Perlick and her colleagues (1) examined baseline data from the CATIE study (Clinical Antipsychotic Trials of Intervention Effectiveness) to determine the correlates of family burden in schizophrenia. The researchers are to be commended for their four-factor solution of more than 40 variables related to family burden and their innovative examination of how the quality of life of adults with schizophrenia and their use of services are related to the burdens experienced by their family.

I offer a few comments about the theory and methodological approach.

The seminal literature on family caregiving in schizophrenia has shown that burden consists of both objective and subjective domains (2), which have been empirically validated as consisting of distinct sets of correlates (3). It seems that the authors' report on the components and correlates of family burden could have been strengthened had they recognized this line of research and the types of burden that exist.

Caregivers were defined as family members or friends who were identified by the adult with schizophrenia as being most directly involved with his or her care. Although demographic characteristics of the caregivers were analyzed as covariates, the authors did not present descriptive data on caregivers' age, gender, race, socioeconomic status, or their relationship to the adult with schizophrenia. This information is important, because the experiences and relationships between adults with severe mental illness and their parents, siblings, other relatives, and friends are unique (4), and the components and correlates of burden examined in this report could be distinctly related to the type of kin relationship. For example, research has found that the burdens experienced by parents and siblings who faced similar types of maladaptive behaviors depended on the amount of instrumental support they provided to their relatives with severe mental illness (5). Thus findings from the study by Perlick and colleagues would have been strengthened if data were analyzed across different types of family caregivers to determine whether certain burdens varied because of the kinship status of the caregivers.

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In Reply: In his thoughtful comments on our report of the experience of caregivers of CATIE participants at study entry, Dr. Smith identifies two ways in which he feels the study could have been improved. First, he suggests that we might have usefully employed the distinction between objective and subjective burden frequently made in studies of family burden. Second, he argues that the findings would have greater utility if we had broken down our analyses by kin relation of the caregiver, rather than using as covariates marital status and whether the caregiver resided with the relative with schizophrenia.

Although we agree with Dr. Smith that the distinction between the objective stresses that caregivers encounter (for example, financial expenditures and time lost from work) and the subjective strains (for example, level of distress) is conceptually an important one, in our experience such distinctions have proved elusive. For example, in two previous studies of caregivers of people with bipolar disorder, we found that the objective and subjective burden scales of a widely used instrument were so highly intercorrelated (.76 to .83) that we combined them to avoid statistical redundancy (1,2). Such high intercorrelations likely reflect measurement error, because most measures evaluate objective burden through caregivers' reports of problem behaviors, use of financial resources, and so on, while operationalizing subjective burden as the degree of distress experienced in relation to each reported problem. Objective burden ratings

based on self-report lack external validation, and subjective ratings based on these "objective" reports are not obtained independently. Devising measures that accurately capture objective dimensions of burden, such as the economic cost to caregivers, will require not only incorporating methods of external validation but adjusting for factors that may bias or mitigate the cost, such as the ordinary provision of supports from one family member to another or the economic contribution from the consumer to the total family income (3).

Indisputably, the experience of caregiving differs for relatives with different kin relationships. However, our preliminary bivariate analyses found that other sociodemographic factors, such as living in the same residence and marital status, covaried with, and explained more variance than, kin differences. For example, although spouses and parents had significantly higher levels of problem behavior burden (factor 1) than siblings, these differences were no longer significant after the analysis adjusted for living situation, because spouses and parents more often reside with the consumer. This pattern of results is consistent with data cited by Dr. Smith that the amount of instrumental support provided—rather than the kin relation per se—explained the experience of burden.

Dr. Smith's comments illustrate the complexities and challenges confronting research on caregiving for individuals with major mental disorders.

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Richard Kaczynski, Ph.D.

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