

Shared-decision making within the context of recovery-oriented care

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Purpose: This article will consider the role of shared decision-making as one component of recovery-oriented care.

Design/Methodology/Approach: This article is conceptual and reviews literature relevant to recovery-oriented care, person-centered recovery planning, and shared decision-making.

Findings: To the degree to which shared decision-making offers tools for sharing useful information about treatment options with service users and family members or other loved ones, it can be considered a valuable addition to the recovery-oriented armamentarium. It is important to emphasize, though, that recovery-oriented practice has a broader focus on the person's overall life in the community and is not limited to formal treatments or other professionally-delivered interventions. Within the more holistic context of recovery, shared decision-making regarding such interventions is only one tool among many, which needs to be integrated within an overall person-centered recovery planning process. More emphasis is given within recovery-oriented care to activating and equipping persons for exercising self-care and for pursuing a life they have reason to value, and the nature of the relationships required to promote such processes will be identified. In describing the nature of these relationships, it will become evident that decision-making is only one of many processes that need to be shared between persons in recovery and those who accept responsibility for promoting and supporting that person's recovery.

Originality/Value: By viewing shared decision-making within the context of recovery, this article provides a framework that can assist in the implementation of shared decision-making in routine mental health care.

“You know, I’m a human being and I have a past and I have dreams and ... before having the person-centered plan in place, ‘what’s your dream’ was never in my dialogue ... it wasn’t there. What was your dream or what would you hope to do, we wouldn’t talk ... like that” -- Provider trained in person-centered care

A core component of the Recovery Movement that has been reshaping mental health care since the early 1990s has been an emphasis on restoring the rights and responsibilities of full citizenship to persons with serious mental illnesses (Davidson, 2016). Although the nature of this new form of “recovery” appears to vary somewhat across cultures (e.g., Davidson, Chan, & Rowe, 2013), within the context of social democracies, at least, foremost among these rights has been the right to self-determination, while foremost among these responsibilities has been that of taking ownership of one’s own recovery. The notion of taking responsibility for one’s recovery is not limited to “the work of recovery” (Davidson & Strauss, 1992), which refers to the efforts the person makes to build a life of meaning and purpose beyond the limits of the illness. It also includes taking responsibility for directing one’s own care, choosing from among available options those various forms of services and/or supports the person will actively use as “tools” in his or her recovery (Davidson, Tondora, O’Connell et al., 2009). In this way, recovery-oriented care strives to enable the person to occupy the “driver’s seat” (Tondora, Miller, Guy et al., 2009) both in his or her life and in his or her treatment, rehabilitation, and recovery.

Within this context, it might seem obvious that the concept of “shared decision-making” (SDM) would be a welcome addition to the recovery-oriented practitioner’s toolkit. As other contributions to this *Special Issue* make clear, shared decision-making is a useful approach to the planning and delivery of care that situates the process of decision-making squarely within the

context of the relationship between the practitioner and the person, at times expanding this dyad to include the person's loved ones as well. Fostering an open dialogue between these parties, inherent to shared decision making is the recognition of the importance of the person's own experiential knowledge as complementary to the practitioner's technical and scientific expertise. As such, the introduction of shared decision-making is intended to move the locus of control from residing entirely with the practitioner, in a traditionally patriarchal relationship (as most physicians used to be men), to a middle ground between practitioners and those individuals most affected by the health care condition(s) of interest. That is, the aim of shared decision-making is to have the practitioner "share" what has historically been his or her unilateral power over health care decisions with the patient and his or her loved ones, and this for a variety of both ethical and practical and pragmatic reasons.

Ethically, it is a central tenet of democracies that adults should be free of unwarranted coercion, and should have their personal sovereignty honored and respected. Practically and pragmatically, it is the patient and his or her family who have the most in-depth knowledge of the effects, signs, and symptoms of the illness and how it manifests on a daily basis, and it is the patient and his or her family who will have to live with and manage the illness and its effects on the same daily basis. A standard justification for the use of shared decision-making is thus that people are more likely to adhere to treatments and use supports that they have themselves played a role in choosing (e.g., Davidson, Roe, Stern et al., 2012).

When framed in this way, however, it can be argued that shared decision-making does not go far enough in promoting the person's recovery in at least one important way. This way has to do with the range and nature of the decisions that are being made within the context of the health care relationship. Thus far, shared decision-making has been introduced primarily with

respect to treatment decisions; decisions, that is, that relate to medications and other somatic interventions that will be administered to the person by health care professionals. In the case of psychiatry, the focus has mostly been on which medications a person will agree to take, at what doses, on what schedule, and for how long. At times, the focus might be broadened to include what psychosocial interventions the person might participate in, including cognitive behavioral psychotherapies, psychoeducational and skill development approaches, cognitive remediation, or rehabilitation programs like supported housing, education, or employment (e.g., Duncan et al. and Zisman-Ilani et al. in this Special Issue).

But recovery from a serious mental illness is seldom solely the result of medication or participation in treatment and rehabilitation. Recovery as an active process of reclaiming a full and purposeful life requires more from the person, and his or her loved ones, than what Rowe (1999) has aptly described as “program citizenship”—i.e., being a compliant consumer/user of mental health and social welfare services. A life lived within the confines of the mental health system is not yet “a life in the community,” as envisioned by the U.S. President’s New Freedom Commission on Mental Health (Department of Health and Human Services, 2003) and other recovery advocates (e.g., Drake et al., 2010).

But isn’t shared decision-making restricted to health care decisions? Why would you need to apply shared decision-making to life domains that lie outside of the scope of health care? Sure, there is more to recovery than treatment, but doesn’t that “more” lie beyond the scope of psychiatry? Wouldn’t it be introducing more unwarranted authority, imposing more external control, over the person to subject his or her life decisions to shared decision-making when they are simply the person’s own decisions to make?

In some cases, the answer is yes. We certainly have worked with individuals who wish to engage in shared decision-making with professionals regarding *treatment* decisions, but who, beyond that, neither need nor want providers' direct input regarding how best to live their day-to-day lives. In cases in which individuals are seriously disabled by a mental illness, though, the lines between treatment and rehabilitation on the one hand and community living on the other are not nearly so clear or distinct. In these cases, it should be acknowledged that mental health professionals inevitably have considerable authority over what would ordinarily be considered personal or life decisions, whether they want that authority or not—decisions such as where to and with whom to live, whether or not to work or go to school, how and with whom to spend the person's time, etc.

It is in recognizing that authority, and in choosing when and how to exercise it, that we can either advance or undermine the fundamentals of shared decision-making. If, in the case of serious disability, these kinds of personal or life decisions cannot be navigated autonomously by the person him or herself, we cannot simply neglect such decisions as beyond the purview of our "clinical" role. To do so could mean abandoning people at the time they are most in need of our compassionate, respectful guidance. Nor is it helpful, or in the spirit of recovery-oriented care, to step in and make these decisions *for* the individual. Even if such decisions are made from a place of benevolent intent, the fact remains that what professionals believe to be in a person's "best interest" is inherently dictated through their own personal cost-benefit analysis, that may, or may not, align with the person's values and priorities. Where, then, are we to find the middle ground?

Rather than exerting undue influence over essential life decisions or dismissing the dialogue around such decisions as beyond the scope of psychiatric decision-making, recovery-oriented care places these intimate concerns at the very center of the work. A central task of

recovery-oriented practice is to elicit and assist the person in envisioning the kind of life he or she wishes to lead, despite or in the presence of an on-going disability and based on his or her own personal preferences and interests. This is done, not as an appeal to professionals to take responsibility for making these life decisions for the person, but rather in acknowledgement that if these decisions are not elicited and explicitly acknowledged by everyone on the care team, including the person him or herself, they are at risk of being ignored altogether in favor of limiting the person's life to one of "program citizenship"—a much easier and relatively risk-free alternative to the more ambitious "life in the community" to which the person remains entitled.

But thus far shared decision-making has not been applied to these personal life domains. Can it, in fact, be expanded to include them? Is there a role for health care professionals to play in what are otherwise, for other people, such private and personal decisions? And, if so, what kind of relationship is required to provide a context for these decisions to be made in a way that respects and promotes the person's capacity for self-determination? These are the questions we will be answering in the following sections.

Shared-Decision Making within the Historical Context of Mental Illness

As other contributions to this Special Issue describe in more detail, shared decision-making (SDM) refers to a process by which a practitioner and a patient (perhaps with his or her loved ones) come together to make decisions about the treatments or other interventions the patient will undergo or utilize in the face of a given health care concern or concerns. The decision-making is to be informed both by the practitioner's professional/technical knowledge of medicine, best practices, and accrued clinical judgment and by the patient's own preferences and values (Towle & Godolphin, 2012). Coming together in this way requires engaging in a process of joint decision-making that embodies mutual respect and genuine dialogue between health care

professionals and the people they serve (Angell et al., 2015). Just as patients are not expected to have extensive technical medical knowledge (what the practitioner brings to the encounter), practitioners are not expected to already understand the patient's own perspective—it is the patient's role to articulate this perspective as it relates to the decisions to be made.

But what if the patient is unable to do so, even after initial prompting—whether due to the nature of the illness or to the person's previous negative experiences with health care. Rather than assuming that the person is comfortable with the provider's recommendations, practitioners must understand that passive acquiescence often comes not from a place of agreement but from a place of deeply held fear and vulnerability in the face of life-altering illnesses. Practitioners are challenged to actively solicit the patient's input through welcoming invitations whereby the patient is given a genuine sense the practitioner intends to both listen to, and respect, his or her position—even when it may be contrary to the conclusion one would arrive at if looking solely at the technical and medical “facts.”

Once this bi-directional sharing of information has occurred, patients and practitioners then discuss various treatment and rehabilitation options that are available and responsive to the person's needs. This phase ideally involves consideration of the potential risks and benefits of the alternative interventions, along with weighing patient preferences for various desired effects and outcomes. Disagreements and conflicts are addressed in the decision-making phase, during which patients and practitioners strive to come to an agreement on what interventions will be tried, at what doses, over what period of time, and with what expected outcomes. Assuming such a mutually agreeable solution can be found, the chosen treatment and/or rehabilitation strategy is then delivered, with both patients and practitioners watching to see what happens.

While such a rational process may be perfectly well-suited to picking an antibiotic or anti-hypertensive medication from among an array of equally effective drugs with differing side effect profiles, it falls well short—on its own—of producing a mutually agreeable care plan for persons with serious mental illnesses, their loved ones, and their practitioners. The reasons for this are multiple and complex, and include the nature of serious mental illnesses; the history of stigma and discrimination associated with mental illnesses and their impact on individuals' sense of identity, self-confidence, and judgment; and the focus of many psychiatric interventions on normative adult life domains such as housing, education, employment, and social relationships.

When incorporated into mental health care, SDM takes place in a historical context in which mental illnesses were assumed to take over the entirety of the person afflicted and to be at least permanent, if not progressive, in nature. This view—that developed during the era of long-term hospitalization, in which many people lived the majority of their adult lives in institutions—was initially transferred to the community along with the patients and psychiatric staff when hospitals were depopulated, beginning in earnest in the 1970s. While the creation of “hospitals without walls” (Stein & Test, 1978) was unequivocally a step forward, these initial intensive community-based programs perpetuated the paternalistic culture of mental institutions based on the long-standing view that patients were permanently disabled, including having their judgment impaired by the illness. The staff continued to make the decisions about what treatment would be administered, when, at what dose and on what frequency, and what other interventions they might benefit from—although the notion of “benefit” was typically limited to avoiding risk and “maintaining” people in the community (Rowe et al., 2009).

That is, prior to the rise of the Recovery Movement, it was seen as an acceptable outcome for people simply to “survive” with their illnesses rather than to “thrive” in their communities of

choice despite them. The best that could be hoped for was that patients would be kept out of the hospital and other institutional settings such as nursing homes, board and care homes, and jails or prisons. Doing so, i.e., keeping them out of the hospital, was the primary role of the community-based practitioner, while the primary role of the patient was to take prescribed medications and otherwise do as he or she was told by the staff (Davidson, 1997; Estroff, 1981).

For the generations of persons with serious mental illnesses who were treated in such programs, the very idea of shared-decision making, and of expanding the dialogue beyond the management of symptoms, is new and fairly radical. Unfortunately, it appears to be equally new and fairly radical for many of the mental health staff serving them as well. This history leaves the service user sitting with an understandable skepticism regarding a practitioner's intent when he or she starts to ask questions about where I want to live, how I choose to worship, and who I want to love when he or she has never explored these areas before. When I have mostly either done or not done what was "recommended" for me by others (with few other choices), how do I go about figuring out what *I* want or what matters to *me*? And when I have been given a message for years, either implicitly or explicitly, that I am not capable of making such choices on my own, how do I go about developing any sense of confidence in my own abilities to do so?

Similarly, generations of practitioners who had been trained, and practiced, in an era in which not only treatment decisions, but these very personal life choices, were based largely on professional knowledge, were ill-equipped to engage in SDM despite the promise of deinstitutionalization to restore fundamental freedoms to persons with serious mental illnesses. Having transferred the hierarchical power and culture of Goffman's "total institution" (1961) from the hospital to the community, little of substance had changed in the degree to which people had been encouraged to take back control of their own lives prior to the Recovery

Movement. And this, in fact, was the primary impetus and emphasis of the Mental Health Consumer/Survivor Movement of the 1960 and 70s (e.g., Chamberlin, 1978, 1984), which then gave birth to the Recovery Movement in the late 1980s. Rather than having anything to do with the nature of mental illness itself, the priority and absolute value given to self-determination, self-direction, and self-management by the Recovery Movement is in direct response to this legacy of institutionalization that continued—and to varying degrees continues—to permeate community-based care (Davidson, 2016).

Although it is true that it is in the nature of serious mental illnesses to manifest at times in acute episodes in which a person's judgment may in fact be seriously impaired, it also remains true that many people return to much longer periods of relative stability between episodes (should such episodes recur at all) during which their judgment is restored (Wexler et al., 2008). Within the context of recovery-oriented care, it is therefore considered an act of discrimination to deny such a person's right to self-determination beyond the limits imposed by an acute condition (SAMHSA, 2011). Few other people are assumed, or even suspected, not to be competent to make their own decisions on an ongoing basis because they have suffered an acute episode of illness; it appears that this suspicion or assumption is based more on the stigma that continues to linger around mental illness than on the nature of the condition itself (Deegan, 1992).

New generations of patients, including young adults having an initial episode of a serious mental illness, have not been subjected to this history and its deleterious effects on identity and self-confidence. Remnants of this legacy remain, however, posing barriers to the straightforward, effective adoption of SDM. And even in cases in which patients may have eluded these effects and are unaware of this history, more concentrated efforts may be needed to counteract the loss of identity and confidence that result from the effects of the illness itself and from how it is still

viewed in the broader society. In order to maximize the utility of this approach, we therefore suggest that it be carried out within the context of recovery-oriented care, as a central component of person-centered recovery planning (PCRP).

Incorporating Shared Decision-Making into Person-Centered Recovery Planning

The strategies and techniques of PCRP were developed to help “re-moralize” persons with serious mental illnesses who may have become demoralized by the combination of illness and discrimination. They include: 1) being oriented toward promoting recovery rather than only minimizing illness and symptoms; 2) being based on the person’s own unique life goals and aspirations; 3) focusing and building on the person’s capacities, strengths, and interests; 4) articulating the person’s role and the role of both paid practitioners and natural supports in assisting the person to achieve his or her goals; 5) emphasizing the use of natural community settings rather than segregated program settings; and 6) anticipating and allowing for uncertainty, setbacks, and disagreements as inevitable steps on the path to greater self-determination (Tondora, Miller, Slade et al., 2014).

It should be obvious from a brief review of the six criteria above that recovery planning is not the same as traditional treatment or service planning in mental health care. Treatment plans were developed primarily to guide, document, and secure payment for the treatment of illnesses or other medical conditions (e.g., broken bones). The treatment that is being planned is to be provided primarily by health care professionals, and the written plan is developed primarily for their use in serving a number of related functions, such as guiding the care offered, assessing the effectiveness of this care, and justifying and documenting this care for the purposes of reimbursement and accreditation. For some time, regulatory and accrediting bodies have required that patients be included in the development of treatment plans and that they sign these plans,

and other various forms of informed consent documents, to demonstrate their involvement and their concurrence with treatments prescribed or recommended for them. Signing such forms, though, neither requires nor reflects anything other than the patient's agreement with the professional's plan. In traditional treatment planning, signing a form does not make it the patient's own plan; it remains the practitioner's plan for how he or she will 'treat' the patient.

This plan has been extremely useful in guiding the treatments provided to people for acute illnesses and other conditions for generations, and it may well be equally useful in some instances of mental illness as well. Such a plan may very well provide an adequate context for SDM, for example, when a physician or nurse practitioner and patient decide on a medication for an isolated, acute episode of anxiety or depression, or when a behaviorally-oriented therapist "contracts" with a person for exposure and desensitization treatment of a phobia. In either of these cases, the person's own role in the treatment process is basically to do what the practitioner recommends—whether that be to take a pill every morning or to visit the reptile house of a zoo (in the case of a phobia to snakes). This approach has been found to be woefully inadequate, however, in the case of serious and persistent mental illnesses, in which the person must play a more significant role in dealing with, managing, and overcoming what has become a disabling condition. In these cases, simply following the recommendations of professionals falls well short of what is required for the person to exercise self-care and to do the strenuous work of recovery.

This has been true for several reasons. First, the interventions that are currently available are limited in their effectiveness in treating serious mental illnesses. While some treatments may be effective for many people in reducing the more active aspects of these conditions, such as in reducing psychiatric symptoms, they typically do not address the more disabling elements, such as neurocognitive difficulties and the social and interpersonal contexts—including the pervasive

impact of stigma and discrimination—that impede, rather than facilitate, improvement. Should medications be developed that were as effective in treating mental illness as antibiotics are in treating certain infections, then we might not find it as necessary to change the ways in which we plan and deliver care. Such a day, however, seems very far off indeed, should it be achievable.

Second, the vast majority of the challenges people face in recovery occur outside of, and beyond the scope of, traditional health care settings such as hospitals, clinics, or day programs. These challenges occur, and have to be dealt with, within the context of the person's everyday life in the community. Intensive outpatient programs developed over the last 40 years attempt to assist persons with serious mental illnesses in meeting these challenges, by deploying staff to teach and role model life skills in the everyday contexts in which they are needed. Staff from these teams accompany a person to the grocery store, the laundromat, the bank, or the movie theatre so that he or she could learn how to negotiate such settings successfully. The more recent advances of recovery mentoring and peer support attempt to provide similar types of assistance (e.g., Chinman, George, Dougherty et al., 2014; Davidson, Bellamy, Guy et al., 2012). Such activities do not fit neatly within the conventional framework of treatment plans, extending well beyond the scope of treatment to the realms of rehabilitation and community-based support.

It is not simply a matter of incorporating rehabilitative interventions and community supports into a traditional treatment plan, however. In both of these realms, the role of the person with the mental illness is an essential and central consideration; it cannot be either assumed or ignored. While it takes a skilled orthopedist to set a broken bone, it requires the activity of the person him or herself, maybe in combination with an experienced physical therapist or trainer, for the person to regain the full use of his or her arm or leg. This is even more so the case within the context of mental health. In the case of a broken bone, there may be both a treatment plan

(e.g., reposition and stabilize the bone) and a rehabilitative plan (e.g., attend physical therapy three times weekly to perform certain exercises), but in combination, even these plans do not address what the person will need to do in order to rejoin his or her soccer team or pick back up his or her violin. In these instances, trainers or instructors (e.g., experienced violinists) might also be required. The challenges of living an ordinary life with a serious mental illness often require a similar level of support, experience, and expertise—not all of which can be found within the confines of the traditional mental health system. Planning for and guiding a person's recovery efforts pushes us beyond the scope of treatment plans that are used by health care practitioners to a plan that the person can develop and use, in partnership with others, to achieve the kind of life to which he or she aspires. Such a plan is called a recovery plan.

When the goal of mental health care was to reduce mental illness, it made sense to view treatment as necessary and sufficient to promote recovery. Now, however, the goal of mental health has moved beyond the maintenance of clinical stability and focuses squarely on enabling people to lead full and self-determined lives in the community (i.e., to thrive rather than merely to survive) regardless of the presence and severity of a mental illness, and this goal cannot be accomplished for many people through the processes of SDM applied to the provision of treatment and rehabilitation alone. Active treatment with medications and psychotherapy, even when coupled with skills training, may remain essential for some people to have the chance of leading a full life, but they alone are not enough for many. What is required is for the person to assume responsibility for, and take an active role in, learning about, dealing with, and overcoming the range of medical, social, and psychological effects of having a mental illness within the current economic, political, and cultural context—for him or her to be “in recovery” in the face of ongoing challenges for which we do not yet have definitive solutions (Davidson &

Roe, 2007). For such people, recovery does not come after and is not the direct result of care. For individuals with prolonged conditions, sharing the decision-making in developing a treatment or rehabilitative plan that only stipulates what practitioners will do is not sufficient for their goal of living full lives in the community.

Considering the Person's Perspective

Since it is understood that the majority of the effort involved in living one's life in the face of a serious mental illness is the person's own, recovery plans are framed as much as possible from the perspective of the person him or herself. Here, too, it is not enough simply to describe the person's presenting complaint or recovery goals in his or her own language, only then to return to conventional clinical concepts. What is required is to reframe even the efforts and interventions of the mental health practitioners and others involved from this person's perspective as well. A doctor or nurse practitioner may want to prescribe antipsychotic medication for me because I have a psychotic disorder or because I am hearing distressing voices. But why should I take the antipsychotic medication if I do not believe that I have a psychotic disorder, or if those voices are the only form of company that I currently have (not to mention the fact that they protest against my taking the medication)?

Addressing this situation within the context of a recovery plan does not require that I forget or ignore my clinical training; I do not have to lie to my patient or pretend that he or she does not have a psychotic disorder. What I have to do instead is figure out how to apply my medical and clinical expertise most effectively in this particular situation. I have to figure out how to put my clinical skill and professional knowledge to the person's use in pursuit of his or her own everyday life goals. So yes, traditional care planning requires some clinical acumen to match a patient's symptom profile to an appropriate diagnosis and to inform the patient and his

or her family what particular illness the person has and what treatments might be beneficial. But in addition to clinical acumen, it requires both experience and a commitment to empathic partnering to find an effective way of helping the person to understand how this particular condition is getting in his or her way, is making his or her life more difficult, or is undermining his or her own efforts to have the kind of life to which he or she aspires.

From a person's perspective, given the ways in which our culture presently perceives mental illness, I have little motivation to believe you when you tell me that I have a psychotic disorder. I don't match the stereotype of "mental patient" and I am not ready to give up on having a good life. But if you tell me that taking a certain medication might make it easier for me to concentrate in school and to get my grades back up to where they used to be before the voices started to bother me, I might give it a try. You can still use terms like "psychosis" within this context, if you think it is necessary or useful, it is not that the word is wrong or inappropriate. It is just that you cannot simply use this word and expect it to suffice. Many people will need to know what this word means and how it helps them to understand important aspects of their everyday life experience, such as difficulties in concentrating or getting out of bed. Shared decision-making provides a useful tool for facilitating such a dialogue.

Beyond the co-discovery of a meaningful recovery goal around which the plan can be built, the art of recovery planning involves being able to imagine and articulate the steps a person can take in the next 3-6 months, along with a range of professional and natural support, and self-directed actions that can be taken to improve his or her life and move it in the direction of his or her longer term aspirations. The fact that a person has a condition we call schizophrenia may not change over that 3 to 6-month period, but lots else in the person's life can. This is one of the many reasons funders, auditors, and accrediting bodies prefer to see person-centered care plans

in medical records, as these plans clearly articulate meaningful “short-term objectives” that focus on positive, practical changes in behavior that move a person forward in his or her own recovery. To meet auditing criteria, these documentation elements need not only to be measurable, but they also are expected to change dynamically over time rather than reflect repeated cycles of “maintenance-oriented” objectives. If the only goal that is stipulated in a care plan is to treat someone’s schizophrenia, and the only objective that follows from this goal is to see a reduction in psychotic symptoms, then this plan may only be useful for the first few care plan cycles. Once the person derives optimal benefit from antipsychotic medication and/or cognitive behavioral psychotherapy, there is little else that mental health practitioners can do directly to decrease psychotic symptoms which may persist despite our best collective efforts. Despite this fact, many care plans have continued to have decrease symptoms as a goal, and patient compliance with treatment as an objective, with little change in clinical or functional status documented in the medical record and few, if any, changes made in the care plan over periods of months, years, and even decades. Switching the goal from one of symptom reduction to maintenance of ‘clinical stability’ does little to improve this situation from either a clinical or an auditing point of view.

There remains, however, much that the person can do him or herself to gain control over and eventually to lessen either the symptoms, the disruption they cause to his or her life, or both. Experimenting with self-care strategies, and finding those that work for a particular individual, as well as exploring and finding meaningful activities and relationships that begin to squeeze the delusions out of the person’s life, remain possible activities for someone whose symptoms have not responded fully to available treatments. The interventions providers may use to facilitate such experimentation and exploration may not be considered treatment per se, and are almost entirely dependent upon the person’s interest and activity in a way that goes well beyond any

conventional notion of ‘adherence’. Practitioners can plan and bill for conducting evaluations and assessments, and for prescribing and monitoring medications, whether or not the person agrees to participate or to comply. The same cannot be said for the person learning self-care skills or exploring meaningful social, recreational, educational, and/or vocational activities. Here the person plays a leading role, with practitioners acting less directly and in a more consultative and facilitative role. As a result, recovery plans end up being more focused on what the person, and supportive others, can actually hope to do and achieve over the next 3-6 months rather than containing a list of the things that providers would like to see happen, but seldom do.

Since it is largely dependent upon what the person will be interested in and willing to do over the next several months, it becomes crucial for the person to be the primary driver of the formulation and implementation of the recovery plan. This does not limit recovery plans to only those things the person will do, however, as practitioners and others can be extremely valuable partners in encouraging, supporting, and guiding the person’s own efforts. There is even room within recovery plans for providers to attempt to increase a person’s interest in or motivation for certain activities (i.e., through motivational interviewing), but the inclusion of such efforts still requires the person’s consent, even if that is the result of a negotiated compromise.

Take, for example, a person who wants to live independently in his or her own apartment in the community but has been unable to do so because of distressing symptoms that lead him or her to feel threatened by neighbors and to get involved routinely in altercations and contact with the police. Rather than developing an objective related to “reducing paranoia” or “increasing insight” (both of which dismiss the person’s subjective experience of vulnerability and lack meaning in the context of the goal of living independently), a person-centered recovery plan might talk about feeling safe enough to attend at least one social event with one’s neighbors from

the apartment building within the next 30 days month or it might involve contacting the agency peer specialist for support when feeling threatened as a way to decrease the number of calls to the authorities over the next two weeks. Similarly, the range of professional interventions in the plan should be discussed, and documented, in such a way that they include an individualized purpose and intent, i.e., they “connect the dots” to both the valued recovery goal and how one is overcoming barriers to achieve it—something which is essential both in meeting medical necessity auditing criteria and in ensuring the plan stays relevant to the person’s recovery.

To continue with our example, a professional service might include the doctor delivering medication management one time monthly for the purpose decreasing discomfort with neighbors at social gatherings. Likewise, a trusted natural supporter (a friend or a family member) might accompany the person to a building pot-luck dinner and the person him or herself might practice a self-directed and strengths-based coping strategy (e.g., knitting) if this serves as an effective strategy in managing distress. By thinking about the various documentation elements in this way, recovery plans incorporating SDM become useful documents both for the person and for his or her care team, as well as becoming an appealing strategy for reducing costs by reducing the use of unwanted or ineffective services.

Consistent with the person-centered principle noted above, in planning care, providers view uncertainty and setbacks as natural opportunities for reflection and learning. For example, at the end of a stipulated time frame, if a short-term objective is not achieved, this is not necessarily a failure but a chance to regroup as a team to explore what may have gone wrong and, more importantly, what do we do differently moving forward. Did certain services or supports not fall into place as planned? Did the person not follow through on his or her self-directed action, and if not, why not? In this sense, the monitoring of progress made, or not,

toward objectives allows all team members to be held accountable (including the person for his or her self-directed efforts) and presents a critical opportunity to change the plan together if it is not working and/or the person is dissatisfied with his or her progress.

In the past, what made a treatment plan a treatment plan was that it was a plan for what treatments would be provided by whom. What makes a recovery plan a recovery plan is that it is a plan for me, and my care or support team, oriented to helping me to live my life as fully as possible in the way that I want. That does not mean that developing a treatment plan through SDM is irrelevant or no longer needed. Rather, it means that shared decision-making about treatments becomes one component of an overall recovery plan rather than the other way around, i.e., “recovery” activities are not something that get tagged on after a person has successfully completed services and achieved a degree of clinical stability. In fact, the pursuit of meaningful recovery activities such as those described in these examples are valued as the pathway through which people often find the motivation and will to manage their conditions in the first place. In a reverse of the traditional logic, treatment becomes only one tool—even if it is an extremely valuable tool—when placed in the context of my ongoing recovery.

I am first and foremost a person who is living my life and who secondarily has to deal with a mental illness within that context. What may be confusing about the notion of recovery planning is that it challenges *all* professional staff to approach their clinical practice from the perspective of the person with the illness, understanding that he or she is the driver of the process and the key decision maker. But this is what it means to say that recovery is what the person does. Recovery planning is one tool that encourages and supports the person in doing so.

Collaborative Relationships as the Context for PCRP and SDM

Because adopting SDM already requires a shift away from conventional care planning to an approach in which the person becomes an active and deciding agent, proponents of SDM have articulated a list of interactional components required to establish the supportive and non-judgmental context necessary for SDM to be effective. Legare et al. (2013), for example, divided essential competencies into two broad domains, one dealing with *relational competencies* and the other dealing with *risk communication*. Relational competencies are needed to foster the non-judgmental and supportive environment that that fosters open, genuine dialogue. These include: 1) developing a partnership with patients by implicitly or explicitly inviting them to participate in treatment; 2) identifying with the patient his or her preferred role in the decision making process (i.e., we cannot assume that every patient wants to play an active or central role in health care decision-making); 3) eliciting and responding to patients' fears, questions, and expectations; 4) checking frequently for understanding and emergent questions or concerns; 5) acknowledging the transition from describing the reviewing options to selecting a decision; 6) generating a concrete action plan; and 7) arranging for follow up to review chosen strategies and their effects.

Risk communication competencies, on the other hand, refer to educating patients about the various treatments available for their condition along with their potential costs and benefits, including those of the alternative of not having treatment at all. These include: 1) identifying and reviewing relevant medical information with patients using non-directive communication; 2) determining the preferred mechanism(s) through which to provide relevant information to the patient (e.g., using decision support tools); and 3) exploring how this information fits with the patient's own culture, language, expressed values, preferences and personal cost-benefit analysis.

Given the lengthy description above of what else is entailed in PCR, though, we should not be surprised that additional competencies may be required to elicit a person's hopes, dreams,

and aspirations, to instill hope and confidence in the person that he or she could have a better life, and to identify, encourage, and support the person's own on-going role in exercising self-care and in leading a life that he or she has reason to value (perhaps despite the illness and in the face of stigma and discrimination). While practitioners have long appreciated the role of trust and safety in the therapeutic relationship, the establishment of this foundation is most often discussed as a means to delivering treatment. To have the kinds of conversations required by PCRP, such relational components may need to be viewed less as a means to delivering care and more as a means to laying the foundation necessary for patients to engage in a process of recovery in which treatment and other life decisions can be considered as meaningful and as shared between the two parties. We have found, that is, that collaboration may require a shift for all staff from thinking solely about treatment to thinking about supporting people in their overall lives through conversations that require honest and open sharing of information, including feelings and concerns. Such collaborations call for empathy and respect, and their use may facilitate and enhance current SDM models that remain more technical in nature.

We have found, for example, that the reciprocal exchange of information required by SDM is often undermined by a power asymmetry between patients and providers. While people need to feel safe enough in their relationships with providers to disclose personal information, this sense of safety is not always present, resulting in the person not being able to meaningfully exchange information in ways that would facilitate his or her own agency and self-determination. We have found that people often have difficulty openly disagreeing with their providers, at times resulting in more subtle disengagements from decision-making. For instance, some patients described feeling like they “were not heard,” but continued with treatment for the fear of being “non-compliant” or wanting to being seen as a “good patient” in the eyes of providers. Others

reported feeling vulnerable in daring to disagree with a professional on whose help they were dependent. These experiences often resulted in people feeling as they could not trust or be open with their providers. Another person described how she did not only feel uncomfortable discussing her hopes and aspirations with her psychiatrist, but would not even tell him when she was having hallucinations because this would result in unwanted changes to her medication regimen. Others described not coming to appointments or not taking medications when they did not feel they could trust their doctors. While “non-adherence” is interpreted in a variety of ways, for some people, it was better to disengage from treatment than feel as though their capacity to engage in decisions was not respected or feel like a failure because they were not assertive enough to clearly articulate their view.

If people distance themselves from their providers in these subtle ways, we have good reason to remain skeptical about SDM, as patients may continue to engage in “shared” decision-making and simultaneously feel as though they do not have their preferred amount of say in their care. Generally, we have found that when people feel respected, they experience a greater sense of agency, self-determination, and hope. We have found that providers demonstrate such respect (or lack of) in a variety of ways. For example, some people described coming to learn of changes in treatment only when they arrived at the pharmacy to find their doctors had changed their prescriptions. People also felt disrespected in subtler ways, such as doctors directing conversations away from what was most important to the person to discussions about diagnosis or treatment. Similarly, we found that patients described trust in more mutual terms than did providers. When they felt trusted by their providers, the relationship felt safe enough to participate meaningfully. Patients described this trust in a variety of ways. Some patients described feeling respected when providers saw their perceptions and communications not as

signs of mental illness but as meaningful within the context of their lives. Others described feeling as though providers trusted their ability to make decisions, their preferences, and their goals and worked with them to support them with treatment. For many people, however, their relationships with providers went beyond treatment and in these cases they described feeling empowered by the knowledge that they were supported, respected, and trusted by providers.

Conclusion

The introduction of shared decision-making into mental health care represents a welcome and valuable step forward in empowering persons with mental illnesses to find and exercise their voice both in their own care and in their own lives. Given the nature of serious mental illness, the history of stigma, discrimination, and paternalism associated with it, and the challenges it poses to everyday life, however, SDM alone falls well short of the breadth of collaboration required to promote recovery and the restoration of full citizenship, especially among persons with persistent disabilities. For these individuals and their loved ones, we suggest the more ambitious and encompassing approach of person-centered recovery planning which identifies the respective roles of professionals, natural supports, and the person him or herself while encouraging and supporting the person to assume, over time, as much autonomy and responsibility for his or her self-care as he or she desires.

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