Updated Schizophrenia PORT Treatment Recommendations: A Commentary

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This commentary on the updated Patient Outcomes Research Team recommendation from a policy perspective notes that the quality of research recommendations is improved but that there has been only limited impact and utility for providers.

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The punch line to an old, bad, and bawdy joke goes “you’ll have to do it over and over again until you get it right.” Somehow, reviewing the third iteration of the Schizophrenia Patient Outcomes Research Team (PORT) recommendations in this volume brings this thought to mind. From a research perspective, the current findings are more thoughtfully documented and the recommendations more nuanced than in the earlier versions. However, viewed from the perspective of people living with schizophrenia and their families or even from a policy point of view, one wonders how much has changed.

As I remarked in previous commentaries,1,2 the PORT research summaries and the use of systematic evaluations to produce treatment recommendations are impeccably done and useful syntheses of knowledge. However, it is remarkable—and increasingly unacceptable—how little research has contributed to improvements in the general well-being of people with schizophrenia. I know of no current systematic assessment of the status of these individuals. The assessment by Frank and Glied3 of long-term changes in the overall well-being of Americans with mental illness finds some improvements but attributes this primarily to inclusion of those with a mental illness in mainstream benefits (eg, Medicare, Medicaid, Social Security). Their review finds little contribution from improvements in the quality of care. Examining the last decade, casual observation suggests that not much has changed. There is no credible reason to expect that the conditions cited by Torrey4 and Hall5 in their reviews of the last PORT report have changed much: Most people with schizophrenia get no or virtually no care, little of the care is delivered consistent with the best evidence, and people with schizophrenia are overrepresented in most of life’s worst circumstances: incarcerated, homeless, disabled, or dying early.

It is not reasonable to suggest that the research enterprise is responsible for this sad state of affairs. Indeed, for a long time, state mental health officials to complain about this problem is surely a variant of the pot calling the kettle sooty. But what is increasingly frustrating to someone laboring in the trenches is the disassociation of the research enterprise from the problems of care.

I have commented on some of these problems before; perhaps, this is simply more trying to get it right. The customary complaint about this problem is framed in research terms; how do we improve “translation” of results into practice? As Kreyenbuhl et al note in this volume, “passive dissemination of clinical guidelines alone, such as publication in a peer-reviewed journal … is generally insufficient for effecting successful implementation.”6 Viewed from the practitioners’ perspective, most efforts to date to use recommendations to improve care are strangely reminiscent of the challenges related to patients’ adherence to treatment recommendations. “Let me get this straight … you haven’t really explained it to me so that I understand it, but if I get it right the treatment may not help much, it’ll take a long time to work, I’ll have to adjust my life significantly, and it’ll make me feel terrible?”

My review of the 2004 PORT report, along with Hester’s commentary,7 sounded an optimistic note about the possible benefits of sustained efforts to promote “evidence-based practices” or EBPs. Indeed, in 1999, David Satcher’s first Surgeon General’s Report on Mental Health8 was just being published. The release of the 2004 recommendations followed the report of The President’s New Freedom Commission on Mental Health,9 which also emphasized the inability of the current system to deliver the (evidence-based) services that could best support recovery, and urged that we both “accelerate research to promote recovery and resilience …” and “advance evidence-based practices using dissemination and demonstration projects.”

Half a decade later, one cannot point to much of substance that is being done at the national level to address either recommendation. Many states continue modest
efforts to foster use of the “tool kits” on EBP implementation that grew directly from the Schizophrenia PORT recommendations, but these efforts are underpowered when the now better understood requirements of program level change are considered.10

What gives me the greatest pause in considering the meaning and implications of these trends is the continued sense that science and services are alienated and locked in a kind of parallel play. The challenges in the world of mental health services can be illustrated simply by considering the level of national action to address the Surgeon General’s report and the President’s Commission report. No doubt lists of activities are maintained by various agencies, but any inventory of relevant trends (eg, rates of treatment, changes in disability enrollment or employment, incarceration) would yield at best a grade of “incomplete.” If one focuses more narrowly on measures of the promotion and use of EBPs, there is still not that much substantial to report.

The PORT approach summarized in this volume by Buchanan et al, Dixon et al, and Kreyenbuhl et al,6,11,12 for all its care and thoughtfulness in reviewing the evolving science, typifies the self-referential limits of current scientific methods. When the criteria for evaluating practices or interventions are a minimum of 3 randomized controlled trials (RCTs), easily evaluable practices—especially pharmacological treatments—dominate. Discrete psychosocial interventions are somewhat more complex to evaluate; despite their prominence in care systems, the treatment recommendations are not as well developed as those for medication treatment. Relying on what has been proven in RCTs is useful to illuminate what has been proven, but in terms of improving care it is something like looking for the dropped car keys under the streetlight instead of by the car.

What do we know (eg, clinically, from well-developed theory, from first-person accounts) about living with schizophrenia and about good and bad outcomes? The following factors are very well established although largely not illuminated by RCTs.

1. Delays in entering care are normative, yet untreated psychosis and its consequences are harmful. Early detection and entry into treatment are exceptionally important.

2. As the PORT medication treatment recommendations note, response to treatment and experience with side effects are variable, personal, and complex. Therefore, having a consistent relationship with a trusted treating clinician (Torrey termed this “continuity of caregiver”) is crucial.

3. As I noted in an earlier commentary1 and as much of the “recovery literature” has noted, positive hopeful expectations from caregivers have a potent effect. Some work suggests that this factor is more significant than the impact of clinical technique in psychotherapy, eg, and that hope is especially important for people with substantial impairment.

4. Evidence about better outcomes for people with schizophrenia in some locations in less developed countries—as well as common sense and clinical wisdom—suggests that maximizing normative early adult development (education, work, social roles), as well as sustaining the human relationships that these roles produce, is very powerful and perhaps more significant to outcomes than are dimensions of treatment.

5. Stable housing is crucial to life stability in general and is doubly important to people with disabilities.

As valuable as it is to have better distilled treatment recommendations such as those in this edition of the Schizophrenia PORT, I suggest that the incremental benefit to future revisions is far less than the benefit that would be achieved by better attention to these general factors that make large contributors to recovery and well-being. The recently announced Recovery After Initial Schizophrenia Episode (RAISE) research study funded by the National Institute of Mental Health will test some of these questions. Perhaps, the RAISE effort can demonstrate the value of large “practical clinical trials” in uncovering more complex and nuanced success factors in treatment than simpler RCTs. Whether the current trajectory of research programs can add knowledge that tangibly improves the life circumstances of people with schizophrenia remains to be seen.

References


