

PORT Through a Recovery Lens

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This updating of the Patient Outcomes Research Team (PORT) recommendations is a most welcome resource from the perspective of a recovery-oriented clinician investigator. To say that it is most welcome is not to overlook the fact that, as Kreyenbuhl et al¹ write in their contribution, there has been no “dramatic breakthrough psychosocial treatments or medications” in the 600+ studies they reviewed over the previous 5 years. Rather, it is welcome as it is for the most part better to know the facts than not to know them. One of the cornerstone principles of the recovery paradigm, in fact, is that people with serious mental illnesses are best served by being educated about the nature of mental illness and the various somatic and psychosocial treatments and interventions available to them so that they can make fully informed choices. For the purposes of informing decision making by people with mental illnesses and their families, the information and recommendations contained in the PORT reports are invaluable. It is in this sense that it is a most welcome resource.

But what about the fact that there have been no dramatic breakthroughs in the past 5 years? Surely, this is not news to patients and their families. They are only too familiar with the limitations of our current approaches, with the dangerous side effects of existing medications and with the small to modest effect sizes of even those practices that are considered evidence based. It is useful, though, to have these unfortunate realities of current psychiatric care carefully and publicly documented, especially in the face of pharmaceutical marketing claims and zealous practitioners. This updating of the PORT provides a very sober recognition of the fact that, again in the terms of Kreyenbuhl et al,¹ “treatments do not ‘cure’ schizophrenia or fully ameliorate symptoms and problems for the majority of affected individuals.”

Lingering questions both for investigators and for clinicians are how best to make sense of these facts

and what to do about them. Kreyenbuhl et al¹ appear to view the limitations of the PORT recommendations as issuing a challenge to researchers to redouble their current efforts to discover the causes and cures of schizophrenia. At the same time, they acknowledge what they describe as the “frustratingly slow pace of knowledge acquisition in this field.” Does this imply that the best that practitioners can do is to encourage patients and their families to try to be patient in awaiting the eventual fruits of these labors? Or, are there more and different things that practitioners can do to be of help? How else can science assist practitioners in their care of a population of people for whom no cures yet exist?

Answers to these questions can be found, in part, in the contribution of Dixon et al² to this issue and, in part, in other bodies of research not covered in the PORT project. How do we reconcile the PORT data on the limited efficacy of existing treatments, eg, with the longitudinal outcome research that has documented a broad heterogeneity in functioning in people with schizophrenia or with the cross-cultural research that has found recovery rates of at least 45% and up to 65% of *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition) criteria schizophrenia samples in diverse countries—including countries in which evidence-based treatments are even less available than in the United States (eg, Cohen et al³)?

Taken together, these 2 bodies of research suggest that people who cannot be cured can nonetheless experience significant improvements in their psychiatric condition, many of them recovering fully from the disorder over time. One implication of these studies is that treatment studies typically do not follow people long enough to evaluate the impact of a given intervention on the trajectory and longer term outcome of the disorder. Another, more interesting, implication, though, is that it may be easier, or at least less difficult, for people to figure out how to live with schizophrenia than to be rid of it altogether. While the medical and psychiatric fields have had limited success in reducing or containing the illness, many people with the illness have themselves found ways to live with it and some to eventually recover from it. It has been these efforts and relative successes in finding ways to live productive and meaningful lives in the face of mental illness that have stimulated and driven the so-called “recovery movement.” For some people in this movement, the

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notion of “recovery” has come to be defined as the process of learning how to live with and despite an enduring psychotic disorder—rather than as an outcome defined by the clinical criteria of symptom remission and restored functioning⁴. For these people, entering into and pursuing this process represents a more feasible and gratifying prospect than simply waiting for causes to be discovered or new treatments to be developed.

It is worth noting, in support of this perspective, that those interventions reviewed by Dixon et al² that had the most robust effect sizes were those that supported people in occupying normative adult roles while continuing to suffer from mental illness. Arguably, the most effective breakthroughs in psychiatric practice for people with schizophrenia since the introduction of chlorpromazine have not been in the development of new and better medications (for which we still must wait) but in development of the psychiatric rehabilitation practices of supported housing and supported employment. Hopefully, by the next update of the PORT in 2013, Dixon et al² will be able to add other supported activities, such as supported education, supported socialization, and peer support, to that growing list. All these interventions have in common the presumption that while schizophrenia cannot be actively cured by others, there remain many things practitioners can do to assist people living with the disorder to live the best lives that they can in the face of it. In addition, what outcome research, as well as research on cognitive-behavioral psychotherapy, seems to suggest in this regard is that the more a person learns how to live with schizophrenia, the less severe the illness becomes (eg, Chadwick et al⁵ and Bellack⁶).

While some readers may find this last comment to be a statement of the obvious, other readers will find this comment to be, at best, unproven and, at worst, fallacious and misleading to patients and their families. To those readers, I would suggest the example provided by other chronic illnesses, such as diabetes or cardiac disease. We know, for instance, that the better control a person has of type 1 diabetes, the less virulent the illness and the better the outcome. Similarly, the more a person with cardiac disease eats heart-healthy foods and gets regular exercise, the less severe the condition and the better the outcome. What the outcome literature suggests is that the same most likely is true of schizophrenia. The better able a person becomes to control the illness, the less destructive the condition and the better the outcome.

Those readers who consider this to be merely a statement of the obvious need to pause to consider its implications for practice. The PORT recommendations tell us

which medications to try at what dosages at what points in the course of illness and with what expected outcomes. They also suggest several psychosocial interventions that can improve functioning and quality of life. What they do not do and what would be extremely useful for practitioners, families, and (especially for) patients themselves is to include data on what people can do to live with the disorder as effectively and in as meaningful and gratifying way as possible. The current recommendations of taking prescribed medication and avoiding or minimizing stress do not lead by themselves to full participation in community life (ie, the vision of the 2003 President’s New Freedom Commission on Mental Health⁷). These recommendations would be similarly of little use to patients with diabetes or cardiac disease, although they are equally relevant to these conditions. What can a person living with schizophrenia, even a person who is fortunate enough to have access to evidence-based treatments and who derives maximum benefit from them, do to manage the residual symptoms and compensate for the residual deficits brought on by the illness? It is possible that research could be done to address this question as well as the questions of causes and cures and that answering this question would make significant contributions to the field while we all eagerly await the breakthroughs that have yet to come.

References

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