State B were more likely than those in State A to be prescribed a vocational intervention and less likely to be prescribed a family intervention or psychotherapy. The appropriate use of psychosocial interventions may be more vulnerable to local idiosyncrasies than are pharmacological treatments.

- The treatment of patients in rural areas was more consistent with the maintenance CPZ dose, adjunctive depression medications, psychotherapy, family, and ACT/ACM recommendations than was treatment of urban patients.

The findings of this survey need to be replicated in other samples and settings using variations on our methodology to evaluate their generalizability and robustness. We consider this study an early step in the development of quality-of-care research and standards in schizophrenia. As such, it moves the field forward. At the very least, it should stimulate more quality-of-care research in schizophrenia and also provoke concern about the quality of care currently afforded persons with schizophrenia in the United States.

References


Commentary by: John M. Kane

Abstract

At a time when the knowledge base available to inform clinical practice is expanding rapidly and there is increasing pressure on clinicians for productivity and cost efficiency, it becomes increasingly difficult for practitioners to critically assimilate data from clinical trials, expert opinion, and personal experience. Such efforts as those undertaken by the Schizophrenia Patient Outcomes Research Team (PORT) are extremely helpful for clinicians from all disciplines involved in the care of patients with schizophrenia. Their report provides a thorough and thoughtful summary of what is known and with what degree of confidence, which helps guide both contemporary practice and future research. In addition, the PORT Client Survey provides a snapshot of clinical practice that highlights the need for more successful knowledge transfer and the development of systems that can better support optimum care.

The Schizophrenia Patient Outcomes Research Team (PORT) is to be complimented on a prodigious effort of evaluating and summarizing a vast body of literature and opinion. Such efforts are of enormous value to everyone.
with an interest in the treatment of schizophrenia, including clinicians, patients, families, health care administrators, payers, and governmental agencies. In a field that sometimes moves slowly and at other times more rapidly, we are now experiencing a flurry of activity, particularly in antipsychotic drug development. At such times it is easy to lose sight of what is known and not known about existing treatments and treatment strategies against which new treatments must be compared. The health care professions have within their ranks both proponents of extreme conservatism in shifting to new agents or approaches and advocates of uncritical acceptance of "new and better" claims.

The PORT Treatment Recommendations regarding the use of antipsychotic drugs are an important resource in this regard and the background against which clinical decisions, comparative trials, and knowledge transfer should proceed. The initial results regarding patterns of usual care based on the Schizophrenia PORT Client Survey further underscore the challenge of knowledge transfer and help identify treatment issues that need particular emphasis. My comments focus specifically on the psychopharmacology aspects of the Treatment Recommendations and the survey findings.

One of the major challenges facing psychiatrists prescribing antipsychotic medications is whether or not to use conventional antipsychotics that are relatively inexpensive (and some of which are available in long-acting injectable forms) or to use the new or second-generation antipsychotic medications. The PORT recommendations are quite explicit in stating that clozapine should not be used as a treatment for the very first episode, but it is the drug recommended for patients with treatment-refractory, positive symptoms and for patients who have repeatedly displayed violent behavior and persistent psychotic symptoms.

The conformance criteria for these recommendations include failure on at least two different chemical classes of antipsychotic drugs. One question that will need to be addressed in the near future is whether there really is value in trying a second conventional drug. Few data are available, but one study (Kinon et al. 1993) suggests that switching between conventional drugs brings about little further improvement, while another study (Shalev et al. 1993) did find some gains. Additionally, if failure on two different classes is a recommended prerequisite, should a new-generation drug be included in this requirement?

Unfortunately, data on clozapine use in treatment-refractory patients could not be gleaned from this type of client survey, but it would be of considerable interest to know to what extent the recommendations regarding clozapine are reflected in clinical practice. My own impression is that clozapine continues to be underutilized in those patients likely to benefit from it.

Regarding Recommendation 1, as additional data accumulate on the newer drugs, clinicians will need guidance on which specific antipsychotic drug to choose. Weighing and balancing the factors of patient acceptability, prior individual drug response, side-effect profile, long-term treatment planning, and cost will prove to be a challenge without much more data to inform these decisions. It is difficult for the busy clinician to sort through clinical trial data, marketing claims, and impressions from personal experience without the help of the kind of process from which the PORT recommendations were derived.

Another challenge facing clinicians is determining what threshold to use to decide whether a patient is a poor or partial responder to drug treatment. The criteria generally applied for clozapine include substantial positive symptoms. How should we treat the patient who is able to be managed in the community but still has troubling, though not severe, symptoms? Should clinicians try alternative treatments and, if so, which ones? What are the potential risks or benefits of switching antipsychotic drugs?

In the PORT Client Survey, the data regarding Recommendation 2 indicate that 22.5 percent of the inpatient sample were receiving doses above 1,000 chlorpromazine (CPZ) equivalents. It is possible that this group might include a higher proportion of poor or partial responders than the other members of the inpatient sample and that clinicians were pushing the dose for this reason. However, this factor would not explain why minority patients were more likely to be on a high dose, since there is no evidence that minority patients per se are less likely to respond to adequate doses. It would also be interesting to determine whether the patients receiving doses above the recommended range were more likely to be receiving "high-potency" antipsychotics, since in many settings current assumptions regarding dose equivalency are often overlooked.

Patients experiencing their first episode of schizophrenia seem to benefit from doses that may be even lower than the low end of the range suggested in Recommendation 2: 300–500 mg CPZ equivalents. Although this could not be assessed in patterns of usual care, it is my impression that first-episode patients in most clinical settings receive higher than necessary doses and also are quite vulnerable to extrapyramidal side effects. If higher than recommended doses are used in this subgroup, prophylactic anti-Parkinson medication should be offered, as these patients could also be considered at substantial risk for drug aversion.

Recommendation 8 suggests that antipsychotic maintenance treatment last at least 1 year, but the value of
maintenance therapy beyond the first year has not been studied extensively. In my opinion, there are sufficient data to recommend maintenance treatment for longer periods of time for patients who have had multiple episodes. The American Psychiatric Association Practice Guideline for the Treatment of Patients With Schizophrenia (American Psychiatric Association 1997) suggests that “for patients who have experienced multiple episodes, maintenance antipsychotic medication treatment should be continued in most cases for at least 5 years and possibly indefinitely.” Although many of the placebo-controlled maintenance trials lasted only 1 year (Kane and Lieberman 1987), some recent studies comparing continuous and intermittent treatment have lasted 2 years and serve to demonstrate an increased risk of relapse during both years among patients not receiving continuous treatment (Jolley et al. 1990; Pietzcker et al. 1993; Schooler et al. 1997).

Even among patients who have been in good remission for longer than 2 years, the risk of relapse when discontinuing antipsychotic drugs is over 50 percent within the next 12–24 months (Hogarty et al. 1976; Dencker et al. 1980; Cheung 1981). Given the possibility that the new-generation drugs may confer a lower risk of tardive dyskinesia, the benefit-risk ratio of continued maintenance treatment might become even more favorable.

Recommendation 12 suggests that depot therapy may be used as a first-option maintenance treatment. Given the fact that noncompliance is common, unpredictable, and not always detected readily or rapidly, should depot drugs be used as a first-option maintenance treatment? At least among patients receiving depot drugs, it is immediately obvious when noncompliance occurs, and strategies to deal with this situation can be implemented quickly while there is still likely to be active medication present in the individual’s system.

Recommendation 17 points out the importance of recognizing associated symptoms and comorbid conditions. It is likely that this area will receive increasing attention, yet at the moment the data base involving adjunctive treatment is primarily from trials that are brief in duration and include chronic patients who are poor or partial responders to antipsychotics. In my opinion the statement that benzodiazepines should be avoided in patients currently receiving clozapine is too strong, as it has not been established clearly that there is an interaction between benzodiazepines and clozapine. However, caution is warranted in the concurrent use of benzodiazepines.

The fact that the rates at which treatment conformed to the recommendations were generally below 50 percent indicates that the field has much to accomplish in knowledge transfer and treatment systems development and support. Even though in general the conformance rates with psychopharmacological recommendations were higher than for psychosocial treatments, the fact that 10.8 percent of inpatients were not prescribed an antipsychotic in their discharge treatment plan is particularly surprising. The fact that only 29 percent of outpatients were receiving maintenance doses within the 300–600 CPZ range is also of concern. The underutilization of depot drugs even among patients who had already experienced significant noncompliance is very troubling given the potentially devastating consequences of psychotic relapse and the fact that some episodes are readily preventable.

These are only some examples of an array of findings that are useful in developing further quality of care research, and the reader cannot but conclude how important an area this is and what a valuable contribution the PORT project has made.

References


Commentary by: William A. Hargreaves

Abstract

This article contrasts the Schizophrenia Patient Outcomes Research Team (PORT) recommendations with the American Psychiatric Association schizophrenia guideline and the Cochrane Collaboration reviews. The PORT Treatment Recommendations stand out as a call to action to improve schizophrenia treatment quality. However, only 7 recommendations are on psychological interventions and 2 concern service systems, even though all 30 are well grounded in current research knowledge. Work in the past decade, especially in mental health services research, seems to support a number of further recommendations on topics that the PORT investigators did not choose for review. A new study of family interventions also calls into question certain aspects of previous family intervention research. On balance, the 30 PORT Recommendations and the evidence of widespread poor conformance to those recommendations in two States provide a focus for vigorous efforts to improve the quality of care for schizophrenia.

The research-based treatment recommendations from the Schizophrenia Patient Outcomes Research Team (PORT) are intermediate in their scope and style between the American Psychiatric Association schizophrenia treatment guideline (American Psychiatric Association 1997) and the Cochrane Collaboration meta-analyses of research on schizophrenia treatment (Bero and Rennie 1995).

The PORT Recommendations are conclusions well supported by research and are envisioned as bases for action to improve treatment delivery. To further this action agenda, the authors engaged a panel of distinguished reviewers to shape the final language of the recommendations and undertook a preliminary investigation of current practice related to the recommendations. The American Psychiatric Association schizophrenia guideline have a more integrative and educational orientation, producing a consensual, middle-of-the-road mini-textbook on schizophrenia treatment. They include any treatment issue seen as important, even when there was little relevant research evidence. At the other extreme are the Cochrane reviews, produced by an international volunteer effort beginning in 1994. As of June 1996, the schizophrenia module of the Cochrane Collaboration had assembled a data base of 453 reports of controlled trials relevant to schizophrenia from 1951 to 1995 and had completed reviews of seven topics with others in progress (Adams et al. 1996). These reviews support “evidence-based medicine” but at a level of detail that is too technical and narrow to serve as recommendations for action or to provide a balanced view of the current state of the art of schizophrenia treatment.

The relative emphasis of the PORT Treatment Recommendations is itself revealing. Of the 30 treatment recommendations, 21 address pharmacotherapy or electroconvulsive therapy. To what extent is this research emphasis a balanced response to current knowledge about schizophrenia treatment? How much of this emphasis on somatic treatment is because it is easier and cheaper to study somatic interventions than psychological ones? How much is due to the large research investment that private firms must make in order to market profitable pharmaceutical products? I wonder whether a more vigorous investment in research on psychological treatments and on the delivery of services might improve the quality of life of persons who suffer from schizophrenia.

Seven recommendations address psychological treatments, and two address service delivery organization. On psychological treatments, the PORT investigators say “no” to psychodynamic psychotherapies but “yes” to well-structured support and training. They say “yes” to family education and support for all families involved...
with their ill family member and "no" to blaming families for schizophrenia. They say "yes" to a specific range of vocational rehabilitation interventions and recommend that vocational services be offered to all who want to work, as well as those who do not want to work but probably could. Finally, they say every treatment system should have assertive community treatment capacity, but only for patients at high risk for repeated hospitalizations or who have been difficult to retain in less assertive treatment.

The recommendations are based on a sound reading of current research knowledge. Nevertheless, I have two comments about the psychological and service system recommendations.

With regard to family interventions, a new five-site cooperative study (Schooler et al. 1997) raises questions about the interpretation of previous family intervention findings. Schooler and colleagues compared two family interventions, one similar to those in several previous controlled trials and a second, much simpler intervention. The two family interventions not only did not differ significantly in their effects but their outcomes were also almost identical. These outcomes were similar to those of the family interventions previously studied. The findings raise the question of whether a much simpler intervention is equally effective, but since all sites of the Schooler et al. (1997) study practiced an intensive and assertive clinic model (Hargreaves et al. 1991), an intensive family intervention may have been unnecessary. More research is needed on simple family interventions.

The inclusion of service system recommendations is notable, since until recently the treatment research community paid little attention to the long history of research on assertive community treatment. Given the recent decade of vigorous activity in mental health services research, it is surprising that no other findings were seen to justify a service system recommendation. For example, there have been at least five randomized trials of less intensive forms of case management, with negative findings from the four that were studies of brokerage case management. Several subsidiary PORT Recommendations regarding psychopharmacological treatment are based on fewer than five studies. Another area of services research has documented poor access to high-quality treatment for persons with schizophrenia in many types of treatment systems. I wonder whether the PORT reviewers were excessively cautious in selecting service system topics for review and making recommendations from existing research on system organization.

The investigation of treatment recommendation conformance in two States provides strong support for the importance of action on the PORT Treatment Recommendations. Despite the limitations noted by the authors in the conformance study, the findings are convincing. The poor quality of practice is alarming, especially with regard to psychosocial interventions.

The examination of treatment conformance also highlights how much we need to learn about (1) the quality of treatment for schizophrenia, (2) the degree to which poor quality affects outcome and cost, and (3) how to provide universal access to high-quality care for every person with schizophrenia. The 30 PORT recommendations will provide a useful organizing focus and motivator for this research agenda.

References


Commentary by: Thomas W. Hester

Abstract

The State of Georgia has benefited from its participation in the Schizophrenia Patient Outcomes Research Team (PORT) project. Technical assistance by PORT increased awareness among stakeholders of the urgent need for services to meet national standards, and the survey results provided a baseline to measure the impact of improvement efforts. Georgia developed strategies to implement the Schizophrenia PORT Treatment Recommendations, including information dissemination and required conformance reporting by providers. One of the national actions to promote adoption of the PORT Treatment Recommendations is a major conference for all State mental health medical directors. To enhance the future impact of the PORT Treatment Recommendations, it is suggested that investigators and clinicians (1) continually update the recommendations based on current research, (2) initiate research on popular treatment interventions that are not evidence based, (3) use expert consensus to broaden the range of interventions included in the recommendations, and (4) develop an administrative tool kit to facilitate the successful implementation of the recommendations.

Historical Background

Georgia's participation in PORT coincided with the reform of its more than 20-year-old public health system for the care of people with mental illness, mental retardation, and substance abuse. Decreased State psychiatric hospital use and increased funding for community services were major reform achievements. From fiscal year 1995 to fiscal year 1997 (July 1, 1994–June 30, 1997), Georgia’s State hospitals underwent drastic changes: the elimination of 562 psychiatric beds, the reduction of 187,589 days of care, and the movement of over $30 million to the community from hospital budgets. In addition to downsizing, three hospitals initiated programs for assertive community treatment.

The comprehensive reform legislation mandated the creation of local community service boards as independent public service agencies and regional boards as planning and funding authorities. This redesign of governance structure is a national benchmark for consumer empowerment because a majority of community service board and regional board members or their family members are required to be consumers. It is a challenge for these citizen boards to determine objectively whether the clinical services they purchase or provide meet current best practice standards.

Georgia’s Direct PORT Participation

The PORT Client Survey results revealed that Georgia’s and the other participating State’s baseline adherence to 12 of the PORT Treatment Recommendations averaged less than 50 percent. Two areas of low conformance were disconcerting: First, minority patients with schizophrenia were more likely than Caucasian patients to receive higher doses of antipsychotic medications and less likely to receive antidepressants when there was evidence of depression. Thus, minority patients were potentially at increased risk for serious side effects and less likely to receive clinically indicated antidepressants. Second, the significant variance between psychosocial interventions included in hospital treatment plans and those actually delivered in the community indicates the lack of services continuity that is often associated with poor treatment outcomes. Georgia’s conformance rates with the Schizophrenia PORT Treatment Recommendations provided a clear call to action and a baseline to measure the results of corrective actions.

In addition to the survey results, Georgia received direct technical assistance. The PORT project provided a series of training conferences to providers, consumers, and purchasers on the recommendations for treatment of schizophrenia. Georgia’s key stakeholders became aware of the urgent need to improve services for persons with schizophrenia to meet the national benchmarks of clinical best practices based on definitive research and careful literature reviews.
Georgia’s Further Steps to Expand PORT Gains

Building on the base provided by the PORT project, Georgia developed further strategies to implement the Schizophrenia PORT Treatment Recommendations, including information dissemination and administratively mandated monitoring to stimulate conformance across a complex statewide clinical system. Initial information dissemination on the PORT Treatment Recommendations included plenary presentations by Anthony Lehman, M.D., principal investigator of the Schizophrenia PORT project, and Leonard Stein, M.D., co-developer of the Program for Assertive Community Treatment, at a 1995 statewide conference in Georgia designed for the continuing education of public mental health professionals. In 1996, this conference was expanded to involve consumers, family members, and administrators. At this conference, the director of clinical activities of the largest State hospital led a workshop on monitoring conformance with the PORT Treatment Recommendations as determined through inpatient chart reviews.

In addition, in 1995 and 1996, eight cross-regional medical management meetings were held in which the clinical directors of the State-operated psychiatric facilities and the medical directors of the associated community service boards engaged in discussions on the key clinical issues of continuity of care between hospitals and community programs, utilization review, level of care criteria, and clinical improvements based on best practice guidelines. At each of these meetings, participants discussed the Schizophrenia PORT Treatment Recommendations. The summary report of the meetings called for the adoption of the Schizophrenia PORT Treatment Recommendations by all public psychiatric hospitals and community settings in a major effort to improve the quality and continuity of care of clients throughout the State.

At the same time, many hospital staffs facing reductions in force were not prepared to work in community-based programs. In response, the State-operated hospital system initiated a major staff education project in 1997. Three-day training events at each of the eight hospitals focused on three modalities emphasized by the Schizophrenia PORT Treatment Recommendations: pharmacotherapies, family interventions, and assertive community treatment/intensive case management.

Georgia’s use of administrative mandates to implement the PORT Treatment Recommendations included formal requirements in purchase-of-service agreements initiated by regional boards. In 1997, State hospitals were contractually obligated to develop a method for implementing and monitoring conformance with the Schizophrenia PORT Treatment Recommendations. The statewide hospital medical executive committee created a computer-assisted physician chart review process. Initial results at four hospitals demonstrate an 82 percent average conformance rate on 18 acute inpatient care indicators. In 1998, all hospitals will be required to submit quarterly conformance reports using indicators from the Treatment of Acute Symptom Episodes section of the PORT guidelines. Regional boards have also been encouraged to require similar performance reporting from community public and private providers. If the same conformance requirements are adhered to by both hospital and community providers, genuine clinical continuity of care grounded on evidence-based best practice should be achievable for all persons with schizophrenia.

National Actions to Implement PORT

The Schizophrenia PORT project, as well as the recent publication of the American Psychiatric Association’s Practice Guideline for the Treatment of Patients With Schizophrenia (American Psychiatric Association 1997) and the Expert Consensus Guideline Series: Treatment of Schizophrenia (Frances et al. 1996), has sparked national interest in the care of persons with schizophrenia. The National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council has evaluated the rationale for using practice guidelines, implementation strategies, monitoring mechanisms, and legal/risk management issues. Even more significantly, the NASMHPD Medical Directors Council and the NASMHPD Research Institute are co-sponsoring a major national conference for State medical directors, the 1997 Best Practices Symposium: Focus on Schizophrenia. Its theme is “transforming knowledge and research into practice in the public mental health sector.” Sessions include a plenary presentation comparing the current sets of schizophrenia Treatment Recommendations, a panel discussion on the experience of several States in implementing schizophrenia treatment guidelines, and a plenary report on monitoring the outcomes of schizophrenia treatment guidelines conformance.

Future Considerations

The Schizophrenia PORT Treatment Recommendations have generated great interest among both clinicians and consumers. They have the potential to improve clinical services significantly, if some important steps are taken. First, it is vital to update the Schizophrenia PORT Treatment Recommendations regularly using current research
findings to prevent institutionalizing out-of-date practices. Second, future research regarding schizophrenia should evaluate the efficacy of clinical interventions that are believed to be state of the art, although sufficient research to confirm their impact on outcomes may not meet the stringent inclusion criteria of the Schizophrenia PORT Treatment Recommendations. Examples of such interventions include supported employment, illness-specific patient education, and consumer-operated club houses. Third, until research is completed to establish conclusively the effectiveness of tested schizophrenia treatment interventions, the research-based recommendations of PORT should be expanded to include recommendations based on expert consensus in order to provide guidance on a full range of services. Fourth, an administrative toolkit should be developed to facilitate the adoption of the Schizophrenia PORT Treatment Recommendations. Key tools might include educational materials (summaries, slides), monitoring methods (performance indicators, chart review forms), and legal items (sample provider contract language, risk management issues).

In conclusion, the public mental health system of Georgia has derived many benefits from its participation in the Schizophrenia PORT project and is working to achieve even more. It is critical that the Schizophrenia PORT Treatment Recommendations be implemented throughout the Nation to further educate clinicians, consumers, and families about current data-based best practices and thereby improve the lives of persons suffering with schizophrenia.

References


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Commentary by: Michael F. Hogan

Abstract

The Schizophrenia Patient Outcomes Research Team (PORT) documents great progress in research on treating schizophrenia. However, it also reveals significant problems, gaps, and limits, both in research and in the relationship between research and practice. It is gratifying that the PORT can make solid recommendations in such areas as pharmacotherapy. However, the conservative and incremental nature of services research—and a failure to use theory and findings from other areas of inquiry adequately—has limited progress in our understanding and in improving services. Furthermore, it is time to reexamine assumptions and practices regarding the diffusion of research results, since the evidence suggests it is ineffective. New collaborative efforts that bridge research and practice are needed.

The Schizophrenia Patient Outcomes Research Team (PORT) findings reported in this journal (Lehman et al. 1998a and 1998b, this issue) contribute significantly to our understanding of schizophrenia and its treatment. The PORT has carefully assessed the research evidence for schizophrenia treatment approaches and produced cogent, evidence-based recommendations. The team also—in a limited but careful fashion—assessed the extent to which usual care patterns are consistent with the best evidence. Their findings about the poor use of validated treatments are depressing, but scarcely a surprise to patients or families. The finding that usual practice conforms to the best scientific evidence less than 50 percent of the time tells us how far we have to go.
Schizophrenia is a complex and still poorly understood disorder, and its stigma still attaches to patients and even to providers and researchers. The decision to initiate the PORT reflects positively on the development of a science base and also on increased recognition of the devastating public health consequences of schizophrenia. The completion of the project is a milestone.

An Incomplete Success
The Schizophrenia PORT reflects the conventions, limits, and biases of medical science. Thus, although the project carefully reviews current data, like most current services research it does not consider potentially relevant findings in other fields and cannot adequately consider exciting new concepts (e.g., very early intervention) or other perspectives that have not been studied adequately (e.g., the phenomenon or perspective of recovery). As a result, the project offers few truly new insights and provides only limited advice to those struggling to improve patterns of care. This commentary attempts to balance the very real achievements of the PORT with these limitations. To be fair, these limits are less criticisms of the PORT itself than reflections on the current state of services research.

The Problem of Starting With “Schizophrenia”
One major theoretical and practical limitation of the study is, ironically, its very focus on the diagnosis of schizophrenia. Current diagnostic conventions require that symptoms be present for a considerable time to meet diagnostic standards for schizophrenia (American Psychiatric Association 1994), and there can be little doubt that schizophrenia and its symptoms develop over a long period of time. The most parsimonious view of the etiology of schizophrenia is perhaps that early brain development is affected in ways that do not become terribly significant until the later developmental stages of late adolescence or early adulthood (e.g., Weinberger 1987). Therefore, significant symptoms and therefore diagnosis and treatment occur decades after the initial brain impact and years after the earliest subtle behavioral effects of the developing disorder can be noted. It is entirely reasonable to expect that the standard of care in the not-too-distant future will consist of the earliest possible treatment of prepsychotic symptoms, well before a diagnosis of schizophrenia is possible (see Falloon et al. 1996; McGorry et al. 1996; Yung et al. 1996). Indeed, avoiding through early treatment the kind of acute episode that is now the starting point for the PORT Treatment Recommendations is likely to be the future approach. Therefore, it is lamentable that the current science must proceed in such a conservative fashion to emphasize validation of “late” treatment. This is because the evidence about the damaging effects of psychosis itself is substantial, we know that years typically pass between the earliest signs that something is wrong and the onset of treatment (Larsen et al. 1996), and the early evidence in favor of early intervention is quite positive.

Limits of Current Services Research
Describing and assessing the strengths and limits of science—as it is generally practiced—are certainly beyond the scope of this commentary. Yet, the greatest strengths and limits of the PORT project flow directly from current practices of medical research and its emphasis on “controlled,” hypothesis-driven studies.

A clear strength of this approach is the ability to sift wheat from chaff—when sufficient evidence is available—and this strength is very evident with respect to the PORT’s review of pharmacotherapy. Partly because medication trials are simpler to evaluate than psychosocial treatments, more such studies are done. Thus, the team was able to synthesize evidence from many reports to produce a cogent and useful set of pharmacotherapy recommendations—and to discover that even these interventions are applied poorly in usual care compared with the best evidence.

On the other hand, the search for verifiable data and “doable” studies can obscure other sources of knowledge and inspiration. For example, mental health services and research often neglect the contributions of theory and of learning from other fields in a focused search to (narrowly) expand knowledge that is particular to mental health.

This limitation is particularly problematic in schizophrenia practice and research—precisely because schizophrenia is so complex. In fact, given the distinct possibility that schizophrenia is a spectrum of disorders, the search for treatments that are specific to this condition is likely unwise. Given the heterogeneity of schizophrenia, developments in other fields should be better considered and integrated into practice and treatment research. But current research emphasizes narrow advances.

There are numerous examples of potentially transferable knowledge that has been by and large ignored in schizophrenia research and therefore falls outside the scope of the PORT’s review. For example, it is clear that positive interpersonal relationships that provide support
and engender hope are a significant factor in human learning and recovery. We have powerful evidence for this impact from multiple sources: the psychotherapy efficacy literature, the self-reports of individuals recovered from mental illness, Edgerton’s (1967) studies of postinstitutional adjustment, and the “Pygmalion in the Classroom” research in special education (Rosenthal and Jacobson 1968). Yet, remarkably, this crucial factor has apparently not been studied specifically in schizophrenia, and therefore it finds no mention in the PORT results.

A similar body of wisdom is emerging regarding the process and dynamics of healing or recovery from the point of view of the person with the disorder. There is a growing literature on the process of recovery that dates at least to the work of Breier and Strauss (1983) and has been expressed best in first-person accounts (e.g., Deegan 1992). Additionally, there is a growing interest in self-efficacy across many fields; for example the concept of resiliency in children as described by Werner and Smith (1989). However, the conventional “professional” frames for treatment and research emphasize the role of external agents, not of human adaptability. Surely there is now enough evidence to consider the role that people play in their own recovery—at least as a variable worth addressing in treatment and research.

A final example of underused knowledge from other fields has to do with the fit between treatment needs and settings. Applied behavioral analysis pioneer Ogden Lindsley (1974) reported that a study of behavior change programs found that placing an individual in an environment likely to support a desired behavior was on average 10 times more effective than changing treatments within an environment. Similarly, the evidence on generalization of learning suggests that, especially for more disabled people, learning is internalized and maintained better when it takes place in the setting where the skills must be used. These factors provide a strong rationale for assertive community treatment (by now, well studied but underused) and supported employment, for which only a moderate level of research evidence can be assigned based on a few “recent controlled studies.” These areas are typical of those where the data are more poorly developed than the relevant knowledge.

Despite these limits, the PORT team is to be commended for pushing the limits of conventional science to include relevant clinical findings. The team labored mightily within their funding constraints to find and include the best available treatment information. The use of categories of evidence emphasizing “fair research-based evidence, with substantial expert opinion” and “expert opinion . . . with significant clinical experience” attests to this inclusive approach.

Research and Practice

A final significant limitation of the study also reflects on the conventional wisdom regarding research and practice. In general, the research community behaves as if knowledge moves from lab bench to bedside. When it comes to testing new drugs, this model is certainly relevant. However, it demonstrably fails when it comes to the design, content, structure, and “replication” of other innovations. Practice patterns and service design are affected by financing, policy, laws, and cultural norms, but providing research data does not appear to affect practitioner behavior significantly (see Prewett 1981). Argyris (1993) has studied this problem with respect to managerial behavior, and his findings are relevant to mental health. He points out that the type of information produced by controlled studies is unhelpful and possibly inapplicable in real-world problem solving because workable solutions must be context relevant. Disciplined and theory-referenced “experimentation” in real-world settings are more likely to yield positive results than is the sharing of research information.

The Schizophrenia PORT has accomplished a great deal for schizophrenia research by demonstrating that a body of knowledge does exist, that it is possible to delineate valid versus inappropriate treatments, and that much current care does not match these standards. It is now time for a new approach that brings the disciplines of research to the adaptation and problem solving that go on in real-world settings. This new approach will involve ongoing partnerships among clinicians, policymakers, consumers and their families, and researchers. It will emulate the “learning organization” models that are developing in many other fields (Senge 1990). It is long overdue in mental health.

References


Commentary by: Laurie M. Flynn

Abstract

The Patient Outcomes Research Team (PORT) Client Survey documents the abysmally poor care that the majority of patients receive. Simply stated, most mental health care providers "just don't get it"! Everyone should be appalled by the PORT survey findings. Usual care for persons with schizophrenia is clearly unacceptable. The PORT survey findings indicate that too many patients are overmedicated and far too few receive effective treatment for side effects and problems with depression or anxiety. Little wonder that medication compliance is a tremendous problem with this population. Much of the noncompliance and associated disability could be reduced dramatically if clinicians adhered to the PORT medication recommendations. Psychosocial interventions, which are valued so highly by consumers, are not a high priority for providers. Even family education and support are widely neglected, though over 75 percent of the patients surveyed reported contact with their families. Real work, including paid employment, is good therapy, yet over 80 percent of persons with schizophrenia are chronically unemployed. The best strategy to improve outcomes for people with schizophrenia may be to disseminate the PORT findings directly to consumers and their families. It is urgent that we begin this work in response to the PORT Client Survey results.

The results of the landmark 5-year schizophrenia Patient Outcomes Research Team (PORT) project will be no surprise to many families and consumers coping with this disorder. Drs. Lehman, Steinwachs, and their colleagues have done a masterful job of reviewing and analyzing the evidence for significant advances in treatment. Yet, tragically, the PORT Client Survey documents the abysmally poor care that the majority of patients receive. The truly
enormous gap between what can and should be done for people with schizophrenia and what is actually happening in practice is the most important message of the PORT study. Simply stated, most mental health care providers "just don't get it!" Consumers and their families have long been vocal about their needs. The first step in closing the gap is for clinicians to listen.

As a parent and an advocate, I am regularly astonished by the difference between how families and treatment providers view schizophrenia. While recognizing that schizophrenia is a complex and often chronic condition, consumers and their families are excited by recent advances in research. We are frustrated and angry at the slow pace of change in everyday patterns of care. If so much progress is being made, why are the outcomes still so poor for our loved ones? Everyone should be appalled by the PORT findings. Usual care for persons with schizophrenia is clearly unacceptable.

National Alliance for the Mentally Ill (NAMI) members have rejoiced in efforts made during the past decade to better understand and manage schizophrenia. Much of the progress has been fueled by our aggressive advocacy for increases in the National Institute of Mental Health research budget. The National Plan for Schizophrenia Research set an ambitious agenda. The National Plan for Research on Services for Persons With Severe Mental Illnesses focused critical attention on longstanding problems in treatment. During this decade—the Decade of the Brain—remarkable new drugs have been introduced by several major pharmaceutical companies, with more to come. Yet, although cost surely plays a big role in access to novel antipsychotics, NAMI members report real resistance from clinicians to trying something new, even when the patient is not doing well. Instead they are told not to expect too much! Worse, the PORT findings indicate that too many patients are overmedicated and far too few receive effective treatment for side effects and problems with depression or anxiety. It is little wonder that medication compliance is a tremendous problem with this population.

Consumers are especially distressed that their complaints of overmedication and difficulty with extrapyramidal symptoms are ignored so frequently. I have come to believe that the persistence of outmoded prescribing practices is a major contributor to the well-documented problem of relapse. Many patients give up hope of feeling better on their medication regimen and simply drop out of treatment. Much of the noncompliance and associated disability could be reduced dramatically if clinicians adhered to the PORT medication recommendations.

Psychosocial interventions, which are valued so highly by consumers, are not a high priority for providers. Even family education and support are widely neglected, though over 75 percent of the patients surveyed reported contact with their families. Given the huge burden of caregiving accepted by the majority of families, this lack of interest and attention is inexcusable. Similarly, connection to vocational rehabilitation services is reported by fewer than 25 percent of the consumers surveyed by the PORT. Do we really believe that a "career" as a mental patient is an acceptable outcome for individuals who usually become ill in their late teens or early twenties? Real work, including paid employment, is good therapy, yet over 80 percent of persons with schizophrenia are chronically unemployed.

It takes a long time to translate research findings into usual medical practice, my friends in the research community tell me. But how can we explain the failure of our mental health system to provide assertive case management to very disabled individuals with schizophrenia? Over 25 years of rigorous research on the Programs for Community Treatment (PACT) model has clearly demonstrated its superior efficacy and cost-effectiveness for those who otherwise would need ongoing inpatient care. The PORT findings strongly support assertive community treatment for persons who are high users of services. Yet, despite the overwhelming evidence of the value of PACT programs, only a tiny percentage of persons with severe schizophrenia are offered them. Because we are disturbed by the lack of access to assertive case management programs, NAMI has begun an initiative to promote incorporation of PACT in both public and private managed care systems.

The best strategy to improve outcomes for people with schizophrenia may be to disseminate the PORT findings directly to consumers and their families. Clearly, we are the most motivated to seek implementation of research-based recommendations on best practices. In a rapidly changing health care system, we are central to defining acceptable quality of life and true satisfaction with services and outcomes. The PORT findings state clearly that current treatment falls far short of what works best for people with schizophrenia. The standard of care in ordinary practice settings must be substantially improved. It is urgent that we begin this work in response to the PORT.

For NAMI members, translating research results into actual practice is more than an academic exercise. As we face the challenges of managed care, the future of our families is at stake. The vigorous advocacy of allies in the treating professions is crucial. We can make a lot of noise, but can we be heard? Why is it so hard for providers to challenge and change damaging patterns of care? Sadly, I think many professionals simply do not believe in recovery.

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People with schizophrenia suffer from a terrible disorder with a terrible stigma. Too many of the professionals who treat people with schizophrenia accept and share stigmatizing attitudes. They just do not see that people with schizophrenia can achieve more than mere symptom reduction. In a study for NAMI conducted by Wahl (1997) earlier this year, consumers overwhelmingly said they most often encountered stigma during encounters with treatment providers. Today, recovery is more than a goal—it is a reality. We cannot cure schizophrenia yet. But with research-based treatment as recommended by the PORT findings, we can give those who suffer a real chance for a real life.

Reference


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An Invitation to Readers

Providing a forum for a lively exchange of ideas ranks high among the Schizophrenia Bulletin’s objectives. In the section At Issue, readers are asked to comment on specific controversial subjects that merit wide discussion. But remarks need not be confined to the issues we have identified. At Issue is open to any schizophrenia-related topic that needs airing. It is a place for readers to discuss articles that appear in the Bulletin or elsewhere in the professional literature, to report informally on experiences in the clinic, laboratory, or community, and to share ideas—including those that might seem to be radical notions. We welcome all comments.—The Editors.

Send your remarks to:

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