

# The Texas Medication Algorithm Project Patient and Family Education Program: A Consumer-Guided Initiative

Marcia G. Toprac, Ph.D.; A. John Rush, M.D.;  
Therese M. Conner, Ph.D.; M. Lynn Crismon, Pharm.D.;  
Mary Dees; Cynthia Hopkins; Vicki Rowe, B.S.; and Steven P. Shon, M.D.

Educating patients with mental illness and their families about the illness and its treatment is essential to successful medication (disease) management. Specifically, education provides patients and families with the background they need to participate in treatment planning and implementation as full "partners" with clinicians. Thus, education increases the probability that appropriate and accurate treatment decisions will be made and that a treatment regimen will be followed. The Texas Medication Algorithm Project (TMAP) has incorporated these concepts into its philosophy of care and accordingly created a Patient and Family Education Program (PFEP) to complement the utilization of medication algorithms for the treatment of schizophrenic, bipolar, and major depressive disorders. This article describes how a team of mental health consumers, advocates, and professionals developed and implemented the PFEP. In keeping with the TMAP philosophy of care, consumers were true partners in the program's development and implementation. They not only created several components of the program and incorporated the consumer perspective, but they also served as program trainers and advocates. Initially, PFEP provides basic and subsequently more in-depth information about the illness and its treatment, including such topics as symptom monitoring and management and self-advocacy with one's treatment team. It includes written, pictorial, videotaped, and other media used in a phased manner by clinicians and consumer educators, in either individual or group formats.

(*J Clin Psychiatry* 2000;61:477-486)

Received Jan. 18, 2000; accepted April 19, 2000. From the Texas Department of Mental Health and Mental Retardation (TDMHMR), Austin (Drs. Toprac and Shon and Ms. Hopkins); Department of Psychiatry, University of Texas Southwestern Medical Center at Dallas, (Dr. Rush); Seton Medical Center, Austin (Dr. Conner); University of Texas at Austin College of Pharmacy (Dr. Crismon); and the Mental Health Association in Texas, Austin (Ms. Dees). During the development of the educational program, Ms. Rowe was affiliated with the National Alliance for the Mentally Ill—Texas.

Supported in part by the Robert Wood Johnson Foundation, the Meadows Foundation, the Lightner-Sams Foundation, the Nanny Hogan

Boyd Charitable Trust, the Texas Department of Mental Health and Mental Retardation, and the U.S. Pharmacopeia and by the following pharmaceutical companies: Abbott, Bristol-Myers Squibb, Eli Lilly, Forest, Glaxo-Wellcome, Janssen, Novartis, Pfizer, Wyeth-Ayerst, and AstraZeneca. In addition, support was also provided by Mental Health Connections, a partnership between Dallas County Mental Health and Mental Retardation and the Department of Psychiatry of the University of Texas Southwestern Medical Center, with funding from the Texas State Legislature and the Dallas County Hospital District.

The authors acknowledge the following individuals for their contributions to the development of the patient and family educational materials: Carolyn Canfield, M.A.; James Lochhead, B.A.; Meredith Kiest-Baughman, B.A.; Norma Bangs; Diane Batchelder, M.P.A.; Cliff Gay, M.B.A.; and Delia Saldaña, Ph.D. A special thanks to Gus Sicard, Ph.D., who translated all materials into Spanish (and helped with dubbing of videotapes) and to Andrew Sedillo, M.D., for assistance with translation and dubbing. We also acknowledge the contributions of the staff of TDMHMR and students of the UT College of Pharmacy who volunteered their time to assist with dubbing videotapes. A very special thanks to the National Depressive and Manic-Depressive Association and to the National Alliance for the Mentally Ill for graciously providing the videotapes. Also, thanks to Karla Starkweather, B.J., and David Savage for manuscript editing and preparation.

Reprint requests to: Marcia G. Toprac, Ph.D., Texas Department of Mental Health and Mental Retardation, P.O. Box 12668, Austin, TX 78711-2668 (e-mail: marcia.toprac@mhm.state.tx.us).

A relatively recent response to the rising costs of health care, particularly for chronic illnesses, is the emergence of the concept of "disease management." Disease management is a comprehensive and integrated approach to delivering health care with the aim of optimizing quality of care and patient outcomes while containing costs. Disease management plans tend to include the identification and use of evidence-based best practices or clinical guidelines, measurement of patient outcomes, interventions to improve coordination among caregivers, as well as strategies to enhance the patient-clinician partnership and patient adherence to prescribed treatments and self-care.<sup>1-4</sup> The disease management approach acknowledges the critical role of the patient in the ultimate effectiveness of any therapeutic intervention. The patient decides whether or not to follow through with treatment and prevention recommendations, which is determined, in part, by his or her relationship with the clinician and understanding of the illness and treatment approach. One common element of disease management plans that evolves out of the recognition of the patient's role in

health care is the inclusion of patient (and family) education programs.

Adherence to prescribed medication regimens is a major factor determining the efficacy of medication treatment for people with psychiatric disorders. The degree of nonadherence is clinically significant; it varies among diagnoses, with a range of 30% to 60% across major psychiatric disorders.<sup>5-7</sup> Not taking prescribed medications, or taking them incorrectly, can result in grave consequences for those with serious mental illnesses. Increased relapse rates and subsequent rehospitalization are strongly linked to nonadherence.<sup>8</sup>

Treatment adherence is a multidimensional phenomenon involving patient, caregiver, and system factors.<sup>9,10</sup> Knowledge, beliefs, and attitudes about one's illness and its treatment are factors that have frequently been associated with the degree of adherence in psychiatric patients. Patients with major psychiatric disorders are often unaware of basic information about their illness and treatment.<sup>11</sup> In a study of clients of a public mental health system,<sup>12</sup> those who understood and acknowledged that they had a mental illness were more likely to adhere to medication treatment than those who did not. In another study,<sup>13</sup> a majority of patients surveyed about their knowledge of medication at hospital discharge were unable to report which medications had been prescribed for them and how, when, and why those medications were to be taken. Research has also shown an association between awareness of the purpose of prescribed medication and adherence with treatment.<sup>14</sup>

Considering these associations between adherence and awareness, knowledge, and understanding, it is not surprising that educational interventions have emerged as a major strategy to increase treatment adherence. Indeed, there is growing evidence supporting the utility of various educational approaches in improving adherence among people with serious mental illnesses.<sup>5,7,15-22</sup>

Education can improve treatment adherence by affecting the "therapeutic alliance," or relationship, between the patient and clinician. Patients may not follow treatment regimens because of lack of trust or hostility toward care providers.<sup>10,23</sup> The role of the patient in self-administration of medication and in treatment, in general, is often minimized. Too often, patients are viewed as passive recipients of treatment of which they know little and have little control.<sup>24</sup> Frank et al.<sup>25</sup> suggest the term *adherence* rather than *compliance* to emphasize the active rather than passive stance by patients in managing their illnesses.

Frank et al.<sup>25</sup> encourage clinicians to engage patients in a therapeutic alliance or partnership in order to increase their participation in treatment. They describe various educational strategies to develop the alliance that simultaneously addresses adherence issues. These strategies include (1) defining the illness and explaining its course, (2) providing clear information about available treatments

and the rationale for their use, (3) inquiring into patients' and families' expectations and fears concerning medication, and (4) using various educational approaches with patients and significant others to address potential side effects. They begin by educating patients about their disorder and its treatment, giving them as much information as they can absorb considering their clinical condition, and then providing additional information as they improve. The cornerstone of this approach is "education of, information for, and active participation by the patient in the treatment process," which they refer to as a philosophy of "alliance, not compliance." This approach, in which improved adherence is an indirect effect of enhancing therapeutic alliance or partnership, is a common element in disease management plans for other chronic illnesses, such as diabetes or asthma.<sup>26,27</sup>

Patient/family education can have other effects on therapeutic outcomes, which are also linked to formation of this partnership or alliance. By providing information about symptoms of the illness, possible treatment side effects, and how to recognize them, patients become more capable of communicating effectively with clinicians. If the patient's awareness of symptoms and potential side effects is improved, and he or she has developed the concepts and vocabulary to describe illness status and treatment progress, then this enhanced ability to communicate should result in more precise, individualized treatment decisions.

## THE TEXAS MEDICATION ALGORITHM PROJECT

The Texas Medication Algorithm Project (TMAP) is a collaborative initiative involving the Texas Department of Mental Health and Mental Retardation (TDMHMR), Texas medical schools and universities, and consumer advocacy organizations that aims at developing medication treatment algorithms for individuals with schizophrenic, bipolar, and major depressive disorders and evaluating their clinical effects and potential costs in the public sector.<sup>28-33</sup> The project began with Phase 1, the development of the algorithms for the 3 disorders. Phase 2 was a feasibility trial. Phase 3, now ongoing, is an evaluation of the clinical effects and cost estimates of algorithm-based treatment compared with treatment as usual. Phase 4 will involve implementation of the algorithms in the Texas public mental health system.

The overall goal of TMAP is to increase the effectiveness of medication treatment, as measured by reduction of symptoms and improvements in functioning, by improving the quality of clinical decision-making and practices. Algorithm-based treatment is expected to result in better clinical outcomes as compared to treatment as usual. This hypothesis is currently being tested in Phase 3 of TMAP.

The interventions implemented and tested in TMAP include many of the elements of a disease management

approach to behavioral health care: (1) “best practices” are identified for the targeted disorders (the algorithms), (2) training and clinical and technical assistance are provided for clinicians to facilitate implementation of the best practices, (3) outcomes of treatment are measured, and (4) interventions are included to help patients become more active participants in their own treatment and to enhance treatment adherence (through patient and family education).

TMAP is committed to the aforementioned “alliance, not compliance” philosophy (i.e., a treatment partnership philosophy). This collaborative partnership has been part of the project development itself. Consumer representatives, as well as individuals representing other stakeholders (e.g., physicians and administrators), have been involved in all phases of the project, from the earliest planning stages.<sup>34</sup> Consumer representation was included on the consensus panels that developed the algorithms, and patient choice is a noted element in all 3 sets of algorithms.

Given the importance of the patient-clinician partnership in enhancing not only treatment adherence but also overall disease management, the need for a strong patient education component was recognized from the start. Patient/family education is considered a key element in implementing and tailoring algorithm treatment to each patient.

#### **DEVELOPMENT OF THE PATIENT AND FAMILY EDUCATION PROGRAM (PFEP)**

Consistent with the project’s partnership philosophy, we decided that consumers (i.e., patients, ex-patients) and their families should determine their own educational needs and select or develop the materials and program to address them. A committee, composed primarily of representatives of the major advocacy groups in Texas (Texas Chapter of the National Alliance for the Mentally Ill [NAMI], Mental Health Association of Texas [MHAT], Texas Chapter of the National Depressive and Manic-Depressive Association [NDMDA], and Texas Mental Health Consumers), was formed to create the patient/family education program for TMAP (Appendix 1).

This committee, the Patient/Advocacy Team (PAT), held over 20 meetings prior to the start-up of TMAP Phase 2 and during the months preceding the launch of Phase 3. Rather than beginning with a review of the published literature on patient education, which came later, the group began its work with discussions identifying the education that is necessary and desirable to build partnerships in managing these disorders from the perspective of patients and family members. Educational needs were delineated, and content areas and desired program characteristics were defined.

PAT members designated primary content areas comprising information about the disorder and its treatment:

1. How is the disorder diagnosed?
2. What are the criterion signs and symptoms of the disorder?
3. What is the course of the illness or disorder?
4. What is known about the etiology of the disorder?
5. What pharmacologic and nonpharmacologic treatment options are available for the disorder?
6. What are the benefits and side effects of treatment for the disorder?

At later stages of the program development process, other needs were identified related to self-management and support:

1. How can patients self-monitor both treatment effects and side effects?
2. What other management tools and supports are helpful?

In addition to content areas, group members described characteristics to be included in the educational materials and program, such as phased delivery from simple to more in-depth information, repetition of key concepts, messages of hope and recovery, and use of multiple learning modalities and formats. The PAT also determined that all materials should be available in both English and Spanish.

The PAT then collected and examined available educational materials that addressed the defined needs. Materials were evaluated with respect to the delineated desired characteristics. PAT members who were mental health professionals stressed that the content of the materials needed to be current and accurate, so these qualities were added to the selection criteria. Materials—pamphlets, fact sheets, and videotapes that met the needs and reasonably matched desired program characteristics—were selected for inclusion. Where gaps or deficiencies in available materials existed, consumers and advocates on the PAT, with assistance and feedback from the committee, created new materials. In some cases, this involved a complicated and extended process of conceptualization, artistic design, and production. Some examples of these consumer/advocate-created materials appear in Appendices 2 and 3 at the end of this article. The committee also took on the arduous task of orchestrating the translation of both existing and newly created materials and dubbing of videotapes into Spanish.

The process described above resulted in a set of materials used in the TMAP Phase 2 feasibility study. At the end of Phase 2, prior to initiating Phase 3, feedback sessions were held with physicians and clinical staff who had been involved in implementing the algorithms and educational component. Although the materials were well received by both clinicians and patients, specific guidance on how to use these materials was needed. The PAT recon-

vened, and created a guidebook for using the materials. The PAT also reexamined educational content needs, added materials that addressed newly identified needs, and replaced outdated materials.<sup>34</sup>

## DESCRIPTION OF THE PFEP

### General Characteristics

The implementation of the PFEP is *phased* such that simple, basic information about the disorder and its treatment is introduced at initial clinic visits. More in-depth information and self-management ideas are presented at later visits, when patients have absorbed the basic information and are less symptomatic. The materials intentionally include *repetition of key concepts* to reinforce certain facts, such as the idea that treatments for mental disorders are just as effective as treatments for chronic general medical disorders, like diabetes mellitus or asthma, and that people with the disorder do get better, i.e., “recovery” (not cure) is possible. The materials and program are *multimodal*, including written, pictorial, and oral presentation and videotaped and interpersonal experiential formats, thus accommodating various learning styles. Both *individual (one-to-one)* and *group formats* are incorporated into the program. The inclusion of group education is a priority, as PAT members felt that the opportunity to learn from the experiences of others with the disorder is invaluable.

All of these features allow the program to be *individualized* to the specific needs of the patient and family. It is not expected that every patient and family will receive every part of the program. Some may never receive the more in-depth materials or attend group meetings. While all elements of the program are potentially available to all patients and families, the patient-clinician partnership will determine what and when particular program elements are used.

Another distinguishing characteristic of the PFEP is that *consumers are involved as educators* of patients. Selected consumers are trained (by members of the PAT) to deliver or cofacilitate particular components of the educational program.

### Introductory Patient Education

The educational focus of the initial visits with the psychiatrist and clinical staff is to explain the diagnosis, emphasizing its biological basis and key symptoms. Treatment options, in terms of efficacy and side effects among the available treatment alternatives, are discussed with patients and families. Once the treatment is selected, physicians (or other clinicians) explain the purpose of the medication, directions for use, expected beneficial effects, and potential significant side effects. Also, patients are provided with information and tools to help monitor symptoms and potential treatment side effects.

The initial visits are a critical time for developing the therapeutic alliance (partnership) between patient and clinician. From an educational perspective, this involves taking the time to understand the patient’s level of knowledge, as well as feelings and attitudes about the illness and its treatment, using this information as a starting point for patient education. Time is allowed for patients to process the new information and ask questions. For those newly diagnosed, clinicians should be sensitive to the ramifications that receiving the diagnosis will have on the individual’s life. For those who have had the diagnosis for some time, clinicians are educated to be sensitive to the possibility that the patient may be frustrated with prior misdiagnoses or unsuccessful medication trials. In all cases, a sense of hope for improvement and recovery is communicated.

While the PFEP acknowledges that most educational activity will likely be the responsibility of nonphysician clinical staff, emphasis is placed on the role of the physician in this initial phase of the educational process. PFEP guidelines strongly recommend that physicians be responsible for discussing the diagnosis and treatment options with their patients. Once the physician has introduced the material to the patient, other clinical staff reinforce, clarify, and amplify information supplied by the physician. Because this period is critical to relationship development and because patients are likely to be very symptomatic at this time, it is suggested that all materials be presented to patients (and families, if involved) on a one-to-one basis rather than in a group format. The TMAP PFEP includes the following materials, designed to be utilized by the physician and other clinical staff during the initial visits.

**Disorder Fact Sheets.** The *Disorder Fact Sheets* were conceptualized and designed by members of the PAT. They are 1-page (2-sided), multicolored fact sheets that present basic information on the disorder (see Appendix 2 for an example of the schizophrenia fact sheet; fact sheets are also available for major depressive disorder and bipolar disorder). The front side contains a lay-language definition of the disorder, a large drawing of the brain, and scans of 2 brains, one affected by the disorder and one not affected. The back of the sheet provides ethnically/age/gender-diverse depictions of people experiencing the key criterion symptoms of the disorder according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.<sup>35</sup> The intended message is that the disorder is a diagnosable illness that has defined symptoms that involve abnormalities in brain functioning. The back of the sheet sends a clear message of hope, printed in large letters: “People do get better.” The fact sheet is printed on glossy, heavy paper to encourage patients/families to save it.

**MedCoach Medication Fact Sheets.** These are 1-page information sheets on each medication, originally pro-



duced by the U.S. Pharmacopeia (USP). The sheets are intended to educate patients on proper use and possible side effects of the medication. While several medication information systems are currently available, we chose MedCoach because the information was available in English and Spanish.

**Medication Benefit Sheets.** This is a set of four 1-page documents that describe the potential positive benefits of a class of psychoactive medications (i.e., antipsychotics, antidepressants, antimanics, and anxiolytics). The positive effects are described pictorially and with brief phrases. These sheets were created by the PAT because available medication educational materials tend to emphasize side effects and precautions and do not adequately describe expected benefits, thereby minimizing incentives to take medications. The PFEP Guidebook<sup>34</sup> suggests that the *Medication Benefit Sheets* be given along with the *MedCoach Medication Fact Sheets* to provide a balanced picture of the potential positive and negative effects of the treatment.

**Symptom and Side Effect Monitoring Sheets and Coping Suggestions.** The PAT developed a set of devices to help patients (and family members, where appropriate) become more aware of the symptoms of the illness and medication side effects, to monitor symptom and side effect intensity, and to communicate this information to their clinicians so that, together, the patient and physician can make better treatment decisions (see Appendix 3 for an example of the *Depression Symptom and Side Effect Monitoring Sheet*; monitoring sheets are also available for bipolar disorder and schizophrenia). On the front side of the monitoring sheet, the patient makes ratings of the intensity of symptoms and side effects. On the back, cartoons depict symptoms of the disorder to help patients recognize which symptoms they have experienced. In addition to the monitoring sheets, tips for coping with symptoms and side effects are included.

Ideally, the patient's family (or significant others) should be involved in the educational process. Patients who are not accompanied by family are encouraged to include them in the treatment process. This idea is reinforced in the first few visits, especially with patients who are very ill and may not retain information. The benefits of involvement of family or significant others are explained (e.g., family education can lead to better understanding and support by family members; family members may be better able to retain treatment information during early stages). However, the program recognizes that patients may have legitimate reasons for not involving the family. The patient retains the right to make the decision about family involvement.

The PFEP does not include a separate set of materials for family members, although some of the materials include sections directed to families. The program emphasizes that family members may be at different stages of

acceptance or have different levels of understanding of the illness than patients. Therefore, the various educational materials and processes may be offered to the family at a different pace and level of depth than to the patient.

### Individual Patient Follow-Up and Ongoing Education

After the first few visits, once the patient's condition is more stable, the clinician provides enough additional information to ensure that the patient (1) understands the disorder and can recognize his or her own symptoms, (2) understands why it is important to follow the treatment plan, and (3) has some tools to cope with and manage the illness. When the patient returns to the clinic, the patient's self-assessment of symptoms and any side effects are discussed (i.e., the *Symptom and Side Effect Monitoring Sheet* is reviewed). The patient's understanding of educational material previously presented is informally assessed, and any misconceptions are clarified. Questions are encouraged. At this point, more detailed, yet still basic, information about the disorder and its treatment can be offered.

Several disorder-specific materials serve the purpose of providing this basic information. They include (1) *Understanding Schizophrenia: A Guide for People With Schizophrenia and Their Families*,<sup>36</sup> (2) *Expert Consensus Treatment Guidelines for Bipolar Disorder: A Guide for Patients and Families*,<sup>37</sup> and (3) *Conquering Depression*.<sup>38</sup> These relatively brief booklets or articles were selected because the information contained is basic, reasonably easy to understand, current, and scientifically accurate. They include diagnostic information, criterion symptoms, basic information regarding disorder pathophysiology, etiology, and course of the disease, and general information about treatment options.

The PFEP Guidebook<sup>34</sup> strongly suggests that clinicians "walk through" the information provided in these pamphlets, section by section, highlighting key points (as opposed to merely asking patients to read them). Patients are encouraged to read the materials at home and to share them with family or others.

As symptoms and functioning further improve, more extensive educational interventions are recommended to more fully involve patients in the management of their condition, to foster therapeutic alliance, to help patients and families find ways to improve their quality of life, and to define the goals of recovery. To accomplish these aims, the PFEP includes the use of more in-depth written materials, videotapes about the illnesses, group educational experiences, and referrals to support groups.

The more in-depth materials selected for the PFEP include (1) *Expert Consensus Guideline for Schizophrenia: A Guide for Patients and Families*,<sup>39</sup> (2) *Living With Manic-Depressive Illness: A Guidebook for Patients, Families, and Friends*,<sup>40</sup> and (3) *Treating Major Depres-*

sion: *A Patient's Guide*.<sup>41</sup> These materials repeat and expand upon disorder and treatment information previously presented. They provide further guidance to patients and families on disease management topics, such as handling emergencies, lifestyle regulation (e.g., eating and sleeping habits, exercise, alcohol/drug avoidance), and involvement in self-help/support groups. Guidelines for use of these materials are similar to those given above.

The PAT considered the inclusion of disorder-specific videotapes to be an essential component of the educational program. Videotapes are an alternative means of communicating basic information about the disorder and its treatment, particularly for those who find reading or oral explanations difficult. The videotapes selected for PFEP have the added benefit of "experiential learning," allowing patients to identify with and learn from the experiences of others with the disorder, since they all include real patients talking about their illness and treatment. These videotapes include (1) *Living With Schizophrenia*,<sup>42</sup> (2) *Dark Glasses and Kaleidoscopes: Living With Manic Depression*,<sup>43</sup> and (3) *What's With You, My Friend? Images of Depression*.<sup>44</sup> They were all developed by consumer advocacy organizations and all strongly relate patient perspectives on the illness and treatment. All 3 videotapes include a number of people who talk about their own experiences with the illness and treatment as they went through various stages of denial/acceptance, coping, and recovery. We recommend that the videotapes be used in a group educational format, but allow for use in individual or family formats. While the videotapes are included in the later phases of the educational process, they may be appropriately used at early stages if this medium is best for particular individuals or families.

### Group Education

A group format can be used to deliver factual information, but more importantly, this format is useful for exchange of experiences, problem solving, and identifying and countering misconceptions or false beliefs about mental illnesses and their treatments. In the group setting, patients with the same illness can offer one another a source of hope and support in dealing with their illnesses.

The PFEP includes 2 types of group experiences, one revolving around the videotapes described above, and another referred to as the *consumer-to-consumer discussion groups*. Both group formats are educationally oriented; specific topics are covered with the goal of increasing patients' knowledge about their illness, about mental illness in general, and about treatment. While these groups are not designed to be therapy or support groups, they encourage a degree of mutual support and self-sufficiency.

**Videotape discussion groups.** Drawing upon the format and content of the NAMI *Living With Schizophrenia* education program, the PAT developed a set of written materials and guidelines to accompany each videotape.<sup>45</sup>

These materials were designed to facilitate discussion among patients (or family members) who watch the videotape together. The discussion materials begin with a reiteration of basic facts about the disorder presented orally by a group facilitator. They also include topics and questions to stimulate discussion at designated break points in the video. For example, after the first part of *Living With Schizophrenia* during which patients talk about their early "dark days" with the illness, the tape is stopped. The facilitator then highlights some of the things people in the video have said about their experiences and asks the group participants to talk about how they felt when they first found out they had schizophrenia.

The videotape groups are designed to be 1-time discussion sessions. The groups have clinician and consumer cofacilitators. Generally, the clinician serves as the "content" expert and the consumer facilitates group discussion.

**Consumer-to-consumer discussion groups.** This group educational experience is based on a set of materials developed by 2 consumer members of the PAT. The *Consumer-to-Consumer Discussion Materials* consist of a set of 42 cartoon drawings (used as overhead transparencies) that depict common issues regarding mental illness and mental health treatment from a patient's perspective (3 examples are included in Appendix 4). The cartoons are meant to stimulate discussion around specific topic areas in a group forum as a means to educate, reassure, and support patients. The topics and issues covered are ones infrequently addressed in typical psychoeducational programs (e.g., unrealistic expectations about medications, how to and how not to talk to your doctor, family reactions to your illness). While a few of the pictures are more relevant to one disorder than another, the materials are not diagnosis specific. The same set of materials is used with all 3 disorders.

The cartoons are grouped topically into 6 group sessions (although they can easily be rearranged or used in fewer or more sessions). They are compiled into a manual (*Peer Facilitator Guide*),<sup>45</sup> which provides the group facilitator with specific guidelines for their use, including objectives for each session, materials needed to conduct each session, questions to stimulate discussion on each cartoon, and narrative regarding messages the cartoon was intended to impart. The 6 sessions revolve around the following broad topic areas: (1) diagnosis and treatment, (2) medication therapy, (3) monitoring symptoms and side effects and keeping track of your medication schedule, (4) reasons why some people do not take their medications, (5) communicating with your doctor, and (6) suicide/life and family issues.

This component of the PFEP was designed to be led by a consumer or "peer" facilitator, preferably someone with the same disorder as the group, who is currently stable and functioning well. While a clinical staff person can be present, it is recommended that clinicians leave the room

for much of the discussion so participants can exchange information and feelings that they may be hesitant to reveal to staff. The clinician, however, is available to the peer facilitator at all times to assist should problems or questions arise.

Consumers selected as peer facilitators for both types of educational groups are given specialized training by PAT members, which covers all parts of the PFEP, with special emphasis on the group components. The training also includes general guidelines for facilitating peer groups. Since the PFEP groups are primarily educationally oriented and time-limited, patients are also provided with referral information for local support and advocacy groups.

## CONCLUSION

Educating patients with mental illness and their families about the illness and its treatment is essential to successful medication and overall disease management. Specifically, it provides patients and families with the needed background to participate in treatment planning and implementation as full "partners" with clinicians. Thus, it increases the probability that appropriate and accurate treatment decisions will be made and that a treatment regimen will be followed. TMAP has incorporated these concepts into its philosophy of care and accordingly created a PFEP to complement the medication algorithms for the treatment of schizophrenia, bipolar disorder, and major depressive disorder.

This article describes the PFEP as developed by a team of consumers, advocates, and professionals, which includes written, pictorial, videotaped, and other media used in a phased manner by clinicians and consumer educators, in either individual or group formats. In keeping with the TMAP philosophy of care, consumers and families were true partners in the program's development and implementation. They not only created several components of the program and ensured incorporation of the consumer perspective, but served as program trainers and advocates. The program focuses on providing patients and families with basic and in-depth information about the illness and its treatment and includes information on such topics as symptom monitoring and management and self-advocacy with one's treatment team.

As with the TMAP medication algorithms, the PFEP is considered an evolving product. The algorithms change periodically as new scientific and clinical evidence regarding treatment for a disorder becomes available; the educational materials and program must change as well, to reflect changes in treatment approaches. The educational materials will also change as new knowledge about diagnosis, pathophysiology, and etiology of the disorders becomes available. Thus, the PFEP will continue to evolve as we gather both informal and research data about

the feasibility of implementation and effectiveness of the various parts of the program. For example, feedback from clinical staff using the materials indicates that simpler basic disorder booklets are needed for some of the patients with schizophrenia and bipolar disorder. Available materials to meet this need are currently being reviewed. When identified (or created if necessary), these materials will be incorporated into the program as alternatives to the basic materials now used. Both clinicians and patients have indicated that some patients are either reluctant or unable to attend group sessions. Consequently, alternative guidelines for using the group materials in a one-to-one format with either clinician (or consumer) educators have been developed.

The TMAP Phase 3 prospective study assesses the entire disease management intervention (algorithms, training, clinical and technical support, systematic documentation of outcomes, and patient/family education) with respect to a wide range of outcome variables. While it will not be possible to determine the independent effects of the PFEP component of the intervention, process and satisfaction data specific to the PFEP will provide a basis for further modification of the program. A controlled study aimed at estimating the independent effects of the PFEP alone is important to a complete evaluation of both the algorithms and the education program. Studies that assess the effects of subcomponents of the TMAP intervention are planned for future phases of the initiative.

## REFERENCES

1. National Pharmaceutical Council. Disease Management: Balancing Cost and Quality. Washington, DC: National Pharmaceutical Council; 1999
2. Katon W, Von Korff M, Lin E, et al. Population-based care of depression: effective disease management strategies to decrease prevalence. *Gen Hosp Psychiatry* 1997;19:169-178
3. Katon W, Von Korff M, Lin E, et al. Collaborative management to achieve depression treatment guidelines. *J Clin Psychiatry* 1997;58(suppl 1):20-23
4. Katon W, Von Korff M, Lin E, et al. Stepped collaborative care for primary care patients with persistent symptoms of depression: a randomized trial. *Arch Gen Psychiatry* 1999;56:1109-1115
5. Kelly GR, Scott JE. Medication compliance and health education among outpatients with chronic mental disorders. *Med Care* 1990;28:1181-1197
6. Bebbington PE. The content and context of compliance. *Int Clin Psychopharmacol* 1995;9(5, suppl):41-50
7. Basco MR, Rush AJ. Compliance with pharmacotherapy in mood disorders. *Psychiatr Ann* 1995;25:269-270, 276, 278-279
8. Condeant-Quinn EA, Emmons MA, McMahon M. Self medication during inpatient psychiatric treatment. *J Psychosoc Nurs Ment Health Serv* 1992;30:32-36
9. Lund VE, Frank DI. Helping the medicine go down. *J Psychosoc Nurs Ment Health Serv* 1991;29:7-9
10. Dubyna J, Quinn C. The self-management of psychiatric medications: a pilot study. *J Psychiatr Ment Health Nurs* 1996;3:297-302
11. Drew GM, Verdi MB, Sacco WP. Training psychiatric patients to discuss medication issues. *Behav Modif* 1991;15:3-7
12. Nageotte C, Sullivan G, Duan N, et al. Medication compliance among the seriously mentally ill in a public mental health system. *Soc Psychiatry Psychiatr Epidemiol* 1997;32:49-56
13. Clary C, Dever A, Schweizer E. Psychiatric inpatients' knowledge of medication at hospital discharge. *Hosp Community Psychiatry* 1992;42:140-144

14. Hulka BS, Cassel JC, Kupper LL, et al. Communication, compliance, and concordance between physician and patient with prescribed medications. *Am J Public Health* 1976;66:847-853
15. Seltzer A, Roncari I, Garfinkel P. Effect of patient education on medication compliance. *Can J Psychiatry* 1980;25:638-645
16. Youssef FA. Compliance with therapeutic regimens: a follow-up study for patients with affective disorders. *J Adv Nurs* 1983;8:513-517
17. Myers ED, Calvert EL. Information, compliance and side-effects: a study of patients on antidepressant medication. *Br J Clin Pharmacol* 1984;17: 21-25
18. Altamura AC, Mauri M. Plasma concentrations, information and therapy adherence during long-term treatment with antidepressants. *Br J Clin Pharmacol* 1985;20:714-716
19. Eckman TA, Liberman RP, Phipps CC, et al. Teaching medication management skills to schizophrenic patients. *J Clin Psychopharmacol* 1990; 10:33-38
20. Van Gent EM, Zwart FM. Psychoeducation of partners of bipolar-manic patients. *J Affect Disord* 1991;21:15-18
21. Razali MS, Yahya H. Compliance with treatment in schizophrenia: a drug intervention program in a developing country. *Acta Psychiatr Scand* 1995; 91:331-335
22. Hornung PW, Kieserg A, Feldmann R, et al. Psychoeducational training for schizophrenic patients: background procedure and empirical findings. *Patient Educ Couns* 1996;29:257-268
23. Sackett DL, Haynes RB. *Compliance With Therapeutic Regimens*. Baltimore, Md: Johns Hopkins University Press; 1976
24. Redman F. New areas of theory development and practice. *J Adv Nurs* 1989;4:70-77
25. Frank E, Kupfer DJ, Siegel LR. Alliance not compliance: a philosophy of outpatient care. *J Clin Psychiatry* 1995;56:11-17
26. Rupp MT, McCallian DJ, Sheth KK. Developing and marketing a community pharmacy-based asthma management program. *J Am Pharm Assoc* 1997;37:694-699
27. Day JL, Rayman G, Hall L, et al. Learning Diabetes: a multi-media learning package for patients, carers and professionals to improve chronic disease management. *Med Inform* 1997;22:91-104
28. Gilbert DA, Altschuler KZ, Rago WV, et al. Texas Medication Algorithm Project: definitions, rationale, and methods to develop medication algorithms. *J Clin Psychiatry* 1998;59:345-351
29. Rush AJ, Rago WV, Crismon ML, et al. Medication treatment of the severely and persistently mentally ill: the Texas Medication Algorithm Project. *J Clin Psychiatry* 1999;60:284-291
30. Shon SP, Toprac MG, Crismon ML, et al. Strategies for implementing psychiatric medication algorithms in the public sector: the Texas Medication Algorithm Project experience. *J Pract Psychiatry Behav Health* 1999;5: 32-36
31. Rush AJ, Crismon ML, Toprac MG, et al. Implementing guidelines and systems of care: experiences with the Texas Medication Algorithm Project (TMAP). *J Pract Psychiatry Behav Health* 1999;5:75-86
32. Shon SP, Crismon ML, Toprac MG, et al. Mental health care from the public perspective: the Texas Medication Algorithm Project. *J Clin Psychiatry* 1999;60(suppl 3):16-20
33. Crismon ML, Trivedi M, Pigott TA, et al, and the Texas Consensus Conference Panel on Medication Treatment of Major Depressive Disorder. Texas Medication Algorithm Project: report of the Texas Consensus Conference Panel on Medication Treatment of Major Depressive Disorder. *J Clin Psychiatry* 1999;60:142-156
34. Toprac MG, Hopkins C, Conner T, et al. TMAP Patient Education Plan Guidebook. Austin, Tex: TDMHMR; 1998. Available at: <http://www.mhmr.state.tx.us/centraloffice/medicaldirector/ptedplan.pdf>. Accessed Dec 10, 1999.
35. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Washington, DC: American Psychiatric Association; 1994
36. National Alliance for Research in Schizophrenia and Depression. *Understanding Schizophrenia: A Guide for People With Schizophrenia and Their Families*. Great Neck, NY: NARSAD Research; 1997
37. Kahn DA, Ross R, Rush AJ, et al. Expert Consensus Treatment Guidelines for Bipolar Disorder: a guide for patients and families. In: *The Expert Consensus Guideline Series: Treatment of Bipolar Disorder*. *J Clin Psychiatry* 1996;57(suppl 12A):81-88
38. National Alliance for Research in Schizophrenia and Depression. *Conquering Depression*. Great Neck, NY: NARSAD Research; 1996
39. Weiden PJ, Scheffler PL, McEvoy JP, et al. Expert Consensus Treatment Guidelines for Schizophrenia: a guide for patients and families. In: *The Expert Consensus Guideline Series: Treatment of Schizophrenia* 1999. *J Clin Psychiatry* 1999;60(suppl 11):73-80
40. National Depressive and Manic-Depressive Association. *Living With Manic-Depressive Illness: A Guidebook for Patients, Families, and Friends*. Chicago, Ill: National Depressive and Manic-Depressive Association; 1997
41. New York State Psychiatric Association. *Treating Major Depression: A Patient's Guide*. New York, NY: New York State Psychiatric Association; 1996
42. National Alliance for the Mentally Ill. *Living With Schizophrenia* [videotape]. Arlington, Va: National Alliance for the Mentally Ill; 1997
43. National Depressive and Manic-Depressive Association. *Dark Glasses and Kaleidoscopes* [videotape]. Chicago, Ill: National Depressive and Manic-Depressive Association; 1997
44. Mental Health Association of Minnesota. *What's With You, My Friend? Images of Depression* [videotape]. Minneapolis, Minn: Mental Health Association of Minnesota (distributed by Media, Inc.); 1990
45. Dees M, Canfield C, Rowe V, et al. TMAP Consumer-to-Consumer Discussion Materials Peer Facilitator Guide. Austin, Tex: TDMHMR; 1998 Available at: <http://www.mhmr.state.tx.us/centraloffice/medicaldirector/consumer.pdf>. Accessed Dec 10, 1999.

---

Editor's note: See pages 485 and 486 for Appendixes.

---



## Appendix 1. Texas Medication Algorithm Project (TMAP) Patient/Advocacy Team<sup>a</sup>

Marcia G. Toprac, Chair  
(Texas Department of Mental Health and Mental Retardation [TDMHMR], Austin)  
Cindy Hopkins, Co-Chair  
(TDMHMR, Austin)  
Therese Conner, Ph.D., Coordinator and Editor  
(TDMHMR, University of Texas at Austin)

### National Alliance for the Mentally Ill—Texas

Vicki Rowe, B.S.  
Norma Bangs  
Meredith Kiest-Baughman, B.A.  
Joe Lovelace, J.D.  
Eldon Baber, M.S.

### Mental Health Association in Texas

Mary Dees  
Carolyn Canfield, M.A.  
Jim Lochhead, B.F.A.  
Christine Devall, M.S.W.  
Stella Mullins, M.S.S.W.

### Texas Depressive and Manic-Depressive Association

Cliff Gay, M.B.A.  
Diane Batchelder, M.P.A.  
Helen Littledale

### Texas Mental Health Consumers

Mike Halligan, M.S.  
TDMHMR (Austin)  
Steven P. Shon, M.D.  
Karla Starkweather, B.J.  
University of Texas Health Science Center at San Antonio,  
and San Antonio State Hospital  
Delia Saldaña, Ph.D.  
Center for Health Care Services (San Antonio)  
Gus Sicard, Ph.D.  
University of Texas at Austin College of Pharmacy  
M. Lynn Crismon, Pharm.D.

<sup>a</sup>Note: These were the team members' affiliations when the team was active.

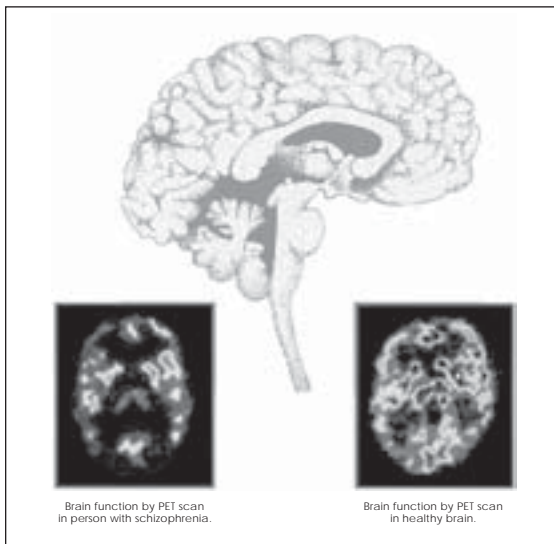
## Appendix 2. Schizophrenia Disorder Fact Sheet (2-sided)\*

Side 1

Side 2

# Schizophrenia

Schizophrenia is a disorder, or group of disorders, that affects the chemical balance of the brain, and in some cases the structure of the brain. Schizophrenia is unrelated to what some people call a "split personality".



# Schizophrenia

## Diagnosis

Schizophrenia involves at least two of the following symptoms, each present for a significant portion of time during a one-month period.<sup>1</sup>

The ♀ of ♦ has gone and  
♂, all the while □ was ♀  
and ♀ didn't see ♂ buy  
— on the way to ♀  
singing X on the third  
level of ♀ turning  
slowly counterclock-  
wise with a ♀ after-  
wards, the ■ was...



Jumping from one subject  
to another and saying things  
that don't make sense

Seeing, hearing or feeling  
things that others do not



False beliefs or thoughts that  
no one believes or understands;  
for example, believing others are  
always talking about you



No interest or feelings  
about anything



Unable to complete  
everyday tasks, such as  
getting dressed

**People do get better!**



1. As defined by Diagnostic and Statistical Manual of Mental Disorders,  
Fourth Edition. Washington DC: American Psychiatric Association, 1994.  
285-286.

\*This material is in the public domain and may be reproduced without permission.

Appendix 3. Major Depressive Disorder Symptom and Side Effect Monitoring Sheet (2-sided)\*

Side 1

Symptom and Side Effect Sheet

Depression

In the last week, the symptoms of my illness were:

Not Present	Mild	Moderate	Severe	Very Severe
(0)	(1)	(2)	(3)	(4)

List the 3 most bothersome symptoms in the last week:

1.

2.

3.

Things I did for me:

The side effects of my medication were:

Not Present	Mild	Moderate	Severe	Very Severe
(0)	(1)	(2)	(3)	(4)

List the 3 most bothersome side effects in the last week:

1.

2.

3.

Things I did for me:

List medications that you are currently taking:

1.

2.

3.


4.

About how long have you been taking each medication?


Weeks/Months/Years

Side 2


Symptoms




Not sleeping or sleeping too much




Restlessness or slowness observable by others




Can't make decisions and can't concentrate




Feeling down all day




Blaming yourself too much and feeling worthless




Fatigue or loss of energy nearly every day



Significant change in weight or appetite

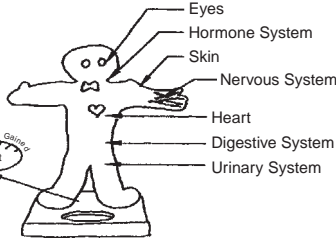


Thinking about death frequently



No longer interested in favorite activities

Medications can cause side effects in many parts of the body. Some may go away in time, others can be treated by your doctor.



Since the last visit I have...

Low



Same

Gain

Weight

Ask your doctor about side effects that need to be reported immediately!

Illegal drugs and alcohol may increase the side effects of medications or keep them from working.



\*This material is in the public domain and may be reproduced without permission.

Appendix 4. Exemplary Consumer-to-Consumer Discussion Materials\*

\*This material is in the public domain and may be reproduced without permission.

486

J Clin Psychiatry 61:7, July 2000