EVIDENCE-BASED PRACTICES KIT

Knowledge Informing Transformation

The Evidence

Illness Management and Recovery

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
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The Evidence

The Evidence introduces all stakeholders to the research literature and other resources on Illness Management and Recovery (IMR). This booklet includes the following:

- A review of the IMR research literature;
- Selected bibliography for further reading;
- References for the citations presented throughout the KIT; and
- Acknowledgements of KIT developers and contributors.

Illness Management and Recovery

For references, see the booklet *The Evidence*.

This KIT is part of a series of Evidence-Based Practices KITs created by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

This booklet is part of the Illness Management and Recovery KIT that includes a DVD, CD-ROM, and seven booklets:

How to Use the Evidence-Based Practices KITs

Getting Started with Evidence-Based Practices

Building Your Program

Training Frontline Staff

Evaluating Your Program

The Evidence

Using Multimedia to Introduce Your EBP

What's in *The Evidence*

Illness Management and Recovery

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Review of the Research Literature

A number of research articles summarize the effectiveness of Illness Management and Recovery (IMR). This KIT includes a full text copy of one of them:

Mueser, K. T., Corrigan, P. W., Hilton, D. W., Tanzman, B., Schaub, A., Gingerich, S., et al. (2002). Illness management and recovery: A review of the research. *Psychiatric Services, 53*, 1272-1284.

This article describes the critical components of the evidence-based model and its effectiveness. Barriers to implementation and strategies for overcoming them are also discussed, based on experiences in several states.

This article may be viewed or printed from the CD-ROM in your KIT. For a printed copy, see page 3.

Illness Management and Recovery: A Review of the Research

Focusing on Evidence-Based Practices

Kim T. Mueser, Ph.D.
Patrick W. Corrigan, Psy.D.
David W. Hilton, M.A.
Beth Tanzman, M.S.W.
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Marvin I. Herz, M.D.

Illness management is a broad set of strategies designed to help individuals with serious mental illness collaborate with professionals, reduce their susceptibility to the illness, and cope effectively with their symptoms. Recovery occurs when people with mental illness discover, or rediscover, their strengths and abilities for pursuing personal goals and develop a sense of identity that allows them to grow beyond their mental illness. The authors discuss the concept of recovery from psychiatric disorders and then review research on professional-based programs for helping people manage their mental illness. Research on illness management for persons with severe mental illness, including 40 randomized controlled studies, indicates that psychoeducation improves people's knowledge of mental illness; that behavioral tailoring helps people take medication as prescribed; that relapse prevention programs reduce symptom relapses and rehospitalizations; and that coping skills training using cognitive-behavioral techniques reduces the severity and distress of persistent symptoms. The authors discuss the implementation and dissemination of illness management programs from the perspectives of mental health administrators, program directors, people with a psychiatric illness, and family members. (*Psychiatric Services* 53:1272–1284, 2002)

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In recent years, interest in identifying and implementing evidence-based practices for mental health services has been growing (1,2). Criteria used to determine whether a practice is supported by research typically include all of the following: standardized interventions examined in studies that use experimental designs, similar research findings obtained from different investigators, and objective assessment of broadly accepted important outcomes, such as reducing symptoms and improving social and vocational functioning (3,4). On the basis of these criteria, several psychosocial treatments for persons with severe mental illness are supported by evidence, including assertive community treatment (5), supported employment (6), family psychoeducation (7), and integrated treatment for mental illness and concomitant substance abuse (8). The standardization and dissemination of evidence-based practices is expected to improve outcomes for the broader population of people who use mental health services (9).

In this article, we examine the research that supports interventions for helping people collaborate with professionals in managing their mental illness while pursuing their personal recovery goals. We begin by defining illness management. Next, we discuss

the concept of recovery and the role of illness management in aiding the recovery process. We then review research on illness management programs, and we conclude by considering issues involved in the dissemination and implementation of these programs.

Defining illness management

The practice in medicine of professionals teaching persons with medical diseases and their families about the diseases in order to improve adherence to recommended treatments and to manage or relieve persistent symptoms and treatment side effects has a long history (10–12). Education-based approaches are especially common in the treatment of chronic illnesses such as diabetes, heart disease, and cancer. In the mental health field, didactic methods for educating people have been referred to as psychoeducation (13–15). Other methods, especially cognitive-behavioral strategies, have also been used to help people learn how to manage their mental illnesses more effectively.

People with psychiatric disorders can be given information and taught skills by either professionals or peers to help them take better care of themselves. Although the goals of professional-based and peer-based teaching are similar, we distinguish between them for practical reasons. Professional-based intervention is conducted in the context of a therapeutic relationship in which the teacher—or the organization to which the teacher belongs, such as a community mental health center—is responsible for the overall treatment of the individual's psychiatric disorder. In contrast, peer-based intervention is conducted in the context of a relationship in which the teacher—or the organization to which the teacher belongs, such as a peer support center—usually does not have formal responsibility for the overall treatment of the individual's disorder. Given this distinction, the relationship between a professional and the person with a mental illness may be perceived as hierarchical, because the professional assumes responsibility for the person's treatment, whereas the relationship between a peer and the person with a mental illness is less likely to be perceived as hierarchical, because the peer does not assume such responsibility. This distinction is crucial among individuals with psychiatric disorders who have advocated for self-help and peer-based services as alternatives to, or in addition to, traditional professional-based services (16–18).

Another reason for distinguishing interventions delivered by professionals from those provided by peers is that most professionals do not have serious psychiatric disorders—in contrast, by definition, to peers. Thus when teaching others how to manage their mental illness, peers are able to convey the lessons they have learned from personal experience, whereas professionals cannot. This places peers in a unique position of being able to teach "self" management skills to other persons with a mental illness.

To recognize these differences, we propose a distinction between professional-based services and peer-based services aimed at helping people deal with their psychiatric disorders. We define illness management as professional-based interventions designed to help people collaborate with professionals in the treatment of their mental illness, reduce their susceptibility to relapses, and cope more effectively with their symptoms. We suggest that illness self-management be used to refer to peer-facilitated services aimed at helping people cope more effectively with their mental illness and facilitating people's ability to take care of themselves. In this article we focus on the substantial body of controlled research addressing the effectiveness of illness management. Although a variety of illness self-management programs have been developed (19–22), rigorous controlled research evaluating the effects of these programs has not been completed.

Recovery

Illness management programs have traditionally provided information and taught strategies for adhering to treatment recommendations and minimizing symptoms and relapses. However, many programs go beyond this focus on psychopathology and strive to improve self-efficacy and self-esteem and to foster skills that help people pursue their personal goals. Enhanced coping and the ability to formulate and achieve goals are critical aspects of rehabilitation and are in line with the recent emphasis on recovery in the mental health self-help movement. We briefly address the relevance of illness management to recovery here.

According to Anthony (23), "Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness." Recovery refers not only to short-term and long-term relief from symptoms but also to social success and personal accomplishment in areas that the person defines as important (24–26). Recovery has been conceptualized as a process, as an outcome, and as both (27–30). What is critical about recovery is the personal meaning that each individual attaches to the concept. Common themes of recovery are the development of self-confidence, of a self-concept beyond the illness, of enjoyment of the world, and of a sense of well-being, hope, and optimism (31–34).

Critical to people's developing hope for the future and formulating personal recovery goals is helping them gain mastery over their symptoms and relapses. Basic education about mental illness facilitates their ability to regain control over their lives and to establish more collaborative and less hierarchical relationships with professionals (16,35–37). Although relapses and rehospitalizations are important learning opportunities (38–40), prolonged periods of severe symptoms can erode a person's sense of well-being, and avoiding the disruption associated with relapses is a common recovery goal (30,41). Improvement in coping with symptoms and the stresses of daily life is another a common theme of recovery, because such improvement allows people to spend less time on their symptoms and more time pursuing their goals (27,30,42). Thus illness management and recovery are closely related, with illness management focused primarily on minimizing people's symptoms and relapses and recovery focused primarily on helping people develop and pursue their personal goals.

Research on illness management

Although illness management and recovery are intertwined, almost all the available treatment research pertains to illness management. Thus we confined our research review to studies of illness management programs. Because extensive research has been conducted on illness management, we confined our review to randomized clinical trials. We also limited our review to programs that addressed schizophrenia, bipolar disorder, and the general group of severe or serious mental illnesses, excluding studies that focused on major depression or borderline personality disorder. Studies included in this review were identified through a combination of strategies, including literature searches on PsycINFO and MEDLINE, inspection of previous reviews, and identification of studies presented at conferences.

With respect to outcomes, we examined the effects of different interventions on two proximal outcomes and three distal outcomes. The proximal outcomes are knowledge of mental illness and using medication as prescribed. The distal outcomes are relapses and rehospitalizations, symptoms, and social functioning or other aspects of quality of life. Distal outcomes are of inherent interest because they are defined in terms of the nature of the mental illness and associated problems. Proximal outcomes are of interest because they are related to important distal outcomes. Specifically, knowledge of mental illness is critical to the involvement of people with psychiatric disorders as informed decision makers in their own treatment (14,15). Using medication as prescribed is important because medications are effective for preventing symptom relapses and rehospitalizations for persons with severe mental illness (43,44), yet many people do not take medications (45), and nonadherence accounts for a significant proportion of relapses and inpatient treatment costs (46). Although adherence to medication regimens is important in and of itself, illness management approaches involve forming partnerships between clinicians and persons with a mental illness in order to determine the services each person needs, including medication, and respecting patients' rights to make decisions about their own treatment (36).

The literature review was divided into five areas: broad-based psychoeducation programs, medication-focused programs, relapse prevention, coping skills training and comprehensive programs, and cognitive-behavioral treatment of psychotic symptoms.

Broad-based psychoeducation programs

Most broad-based programs, summarized in Table 1, provided information to people about their mental illness, including symptoms, the stress-vulnerability model, and treatment. Among the four controlled studies, all but one (47) provided at least eight sessions of psychoeducation. Follow-up periods ranged from ten days (15) to two years (48). Three of the controlled studies found that psychoeducation improved knowledge about mental illness (15,47,48); one did not (49). In two studies, improved knowledge had no effect on taking medication as prescribed (47,49); one study reported improved adherence (48).

In summary, research on broad-based psychoeducation indicates that it increases participants' knowledge about mental illness but does not affect the other outcomes studied. This finding may not be surprising: similar didactic information given to families of persons with schizophrenia has been found to increase their knowledge but not to affect their behavior (50,51). The reason for this may be that didactic information does not consider beliefs and illness representations already held by recipients (52). Nevertheless, psychoeducation remains important because access to information about mental illness is crucial to people's ability to make informed decisions about their own treatment, and psychoeducation is the foundation for more comprehensive programs (as reviewed below).

Medication-focused programs

Studies that strove to foster collaboration between people with a mental illness and professionals regarding taking medication used psychoeducational or cognitive-behavioral approaches or a combination of the two.

Psychoeducation about medication involves providing information about the benefits and the side effects of medication and teaching strategies for managing side effects, so that people can make informed decisions about taking medication. These programs, summarized in Table 2, tended to be brief, with only two of eight programs (53,54) lasting more than one or two sessions. Three studies conducted posttreatment-only follow-up assessments (55–57), and five studies conducted follow-ups after the end of treatment (53,54,58–60). Most of the studies reported that participants increased their knowledge about medication. However, three studies reported no group differences in taking medication as prescribed (56,59,60); a fourth study reported improvements (53); and a fifth study reported deterioration in taking medication (54). The three studies that found no differences in taking medication as prescribed compared different psychoeducational methods (56,59,60). Only one study that assessed medication adherence included a no-treatment control group (54); this study found that clients who received psychoeducation were more likely than clients who received no psychoeducation to discontinue medication. A somewhat disconcerting finding was reported in the only other study with a no-treatment control group (58). This study found that psychoeducation increased clients' insight into their illness but also increased clients' suicidality; psychoeducation had no influence on other symptoms or on relapse rates. In summary, research on the effects of psychoeducation about medication indicates that it improves knowledge about medication, but little evidence indicates that it improves taking medication as prescribed or affects other areas of functioning.

Cognitive-behavioral programs that focused on medication used one of several techniques: behavioral tailoring, simplifying the medication regimen, motivational interviewing, or social skills training. Behavioral tailoring involves working with people to develop strategies for incorporating medication into their daily routine—for example, placing medica-

Table 1

Randomized controlled trials of broad-based psychoeducation programs

Reference	Patients	Treatment and duration	Outcomes			Comments
			Knowledge	Not taking medication as prescribed	Other	
Goldman and Quinn (15)	N=60, all with schizophrenia	Psychoeducation and standard care; 25 hours a week for three weeks	Psychoeducation better than standard care	—	Psychoeducation better than standard care for negative symptoms; no group differences in distress	Highly comprehensive educational program
Bäuml et al. (48)	N=163, all with schizophrenia	Psychoeducation and standard care; eight sessions over three months	Psychoeducation better than standard care	Psychoeducation better than standard care	Psychoeducation better than standard care in hospitalizations	Separate psychoeducation groups for relatives
MacPherson et al. (47)	N=64, all with schizophrenia	Three sessions of psychoeducation; one session of psychoeducation; standard care; one or three weekly psychoeduction sessions	Three sessions of psychoeducation better than one session of psychoeducation better than standard care	No group differences	Three sessions of psychoeducation better than one session of psychoeducation and better than standard care for insight	Participants were hospitalized Separate psychoeducation groups for relatives
Merinder et al. (49)	N=46, all with schizophrenia	Psychoeducation and standard care; eight sessions	No group differences	No group differences	—	

tion next to one's toothbrush so it is taken before brushing one's teeth (61). Behavioral tailoring may also include simplifying the medication regimen, such as taking medication once or twice a day instead of more often. Motivational interviewing, based on the approach developed for the treatment of substance abuse (62), involves helping people articulate personally meaningful goals and exploring how medication may be useful in achieving those goals. Social skills training involves teaching people skills to improve their interactions with prescribers, such as how to discuss medication side effects (63).

Cognitive-behavioral programs for medication are summarized in Table 3. All four studies of behavioral tailoring found improvements in taking medication as prescribed (61,64–66), as did the one study that evaluated the effect of simplifying the medication regimen (67). One study of motivational interviewing (68) also reported an increase in taking medication as prescribed, as well as fewer symptoms and relapses and improved social functioning. One broad-based cognitive-behavioral program also reported lower rates of rehospitalization (69). The two studies that examined social skills training were limited. One of these studies found that skills training had no effect on knowledge about medication, but medication adherence was not directly assessed (70). The other study showed that psychoeducation and skills training improved knowledge and social skills in medication-related interactions, but it did not assess taking medication as prescribed (71).

Thus controlled research, which has focused mainly on individuals with schizophrenia, provides the strongest support for the effects of cognitive-behavioral methods (chiefly, behavioral tailoring) for increasing their taking of medication as prescribed, whereas psychoeducation alone has limited, if any, impact. The strong effects of behavioral tailoring on taking medication, compared with the weak effects of psychoeducation, suggest that memory problems, which are common in schizophrenia (72), may interfere with taking medication as prescribed and that behavioral tailoring may work by helping people develop their own cues to take medication, thereby compensating for cognitive impairments.

Most of the programs reviewed were response-based, with little effort made to understand the psychology of why people did not take medication as prescribed. This is very different from the theoretical position in health psychology, in which complex models such as the health belief model and the theory of planned action have been developed to understand health-related behavior. Preliminary studies investigating medication self-administration have used the concept of psychological reactance, which is a motivational state that can develop when a person perceives a threat to his or her personal freedom (73). In an analogue study, reactance-prone individuals rated themselves as being less likely to take medication if their freedom of choice was restricted, whereas no effect of freedom of choice was seen in non–reactance-prone participants (74). In a study of

Table 2

Randomized controlled trials of psychoeducation programs focused on medication

Reference	Patients	Treatment and duration	Follow-up	Outcomes			Comments
				Knowledge	Not taking medication as prescribed	Other	
Seltzer et al. (53)	N=100, 66% with schizophrenia	Psychoeducation and standard care; nine sessions	Five months	No group differences	Psychoeducation better than standard care	Psychoeducation better than standard care on fear about medication	Both groups had high levels of knowledge
Munetz and Roth (60)	N=25, 88% with schizophrenia	Formal (written) psychoeducation and informal (oral) psychoeducation; one session	Two months	Informal psychoeducation better than formal psychoeducation	No group differences	No group differences in relapses	Brief intervention. Younger participants retained more information than older ones
Streicker et al. (54)	N=75, "mostly schizophrenia"	Psychoeducation and standard care; ten sessions	35 weeks	Psychoeducation better than standard care	Psychoeducation better than standard care	No group differences in hospitalizations	Peer counseling included in program
Brown et al. (56)	N=30, all with schizophrenia	Oral psychoeducation on medication and oral and written psychoeducation on medication; oral psychoeducation on medication and side effects; and oral and written psychoeducation on medication and side effects; two sessions	Posttreatment assessment only	All groups improved. No group differences	No group differences	All groups reported fewer side effects at posttreatment	Brief intervention
Kleinman et al. (59)	N=40, all with schizophrenia	Psychoeducation with and without a review session; one or two sessions	Six months	Both groups improved. No group differences	No group differences	No group differences in hospitalizations	Brief intervention
Kuipers et al. (57)	N=60, 55% with schizophrenia	Structured psychoeducation and unstructured psychoeducation; one session	Posttreatment assessment only	Both groups improved. No group differences	—	—	Brief intervention
Angunawela and Mullee (55)	N=249, 21% with schizophrenia	Information leaflets and standard care; one session	Four weeks after distribution of leaflets	Information leaflets and standard care	—	—	Brief intervention. People with schizophrenia learned less than people with affective and personality disorders
Owens et al. (58)	N=114, all with schizophrenia	Psychoeducation and standard care; 15-minute video and information booklets	One year	—	—	No group differences in relapse rates. Psychoeducation better than standard care for insight, but psychoeducation not better than standard care for suicidality	Very brief intervention

people with schizophrenia or schizoaffective disorder, individuals with higher psychological reactance who perceived taking medication as a threat to their freedom of choice were less likely to have taken medication as prescribed in the past (75). Motivational interviewing may provide one strategy for improving peo-

Table 3

Randomized controlled trials of cognitive-behavioral programs focused on medication

Reference	Patients	Treatment and duration	Follow-up	Outcomes			Comments
				Knowledge	Not taking medication as prescribed	Other	
Boczkowski et al. (61)	N=36, all with schizophrenia	Psychoeducation; behavioral tailoring and standard care; one session	Three months	—	Behavioral tailoring better than psychoeducation and equal to standard care		Brief treatment
Dekle and Christensen (70)	N=18, 55% with schizophrenia	Psychoeducation and social skills training; general health instruction; and standard care; 12 weekly sessions	Post-treatment assessment only	Psychoeducation and social skills training equal to general health instruction and better than standard care	—		Small sample size
Kelly and Scott (66)	N=414, 64% with schizophrenia	Home psychoeducation and behavioral tailoring; clinic psychoeducation and behavioral tailoring; home and clinic psychoeducation and behavioral tailoring; and standard care; home three sessions, clinic two	Six months	—	Psychoeducation and behavioral tailoring better than standard care	Psychoeducation and behavioral tailoring better than standard care in symptoms and rehospitalizations	Three experimental groups combined into one group for analysis
Eckman et al. (1)	N=41, all with schizophrenia	Psychoeducation and social skills training; supportive group therapy; two weekly sessions for six months	One year	Psychoeducation and social skills training better than supportive group therapy	—	Psychoeducation and social skills training better than supportive group therapy in social skills	Social skills training addressed medication-related issues and symptom management
Razali and Yahya (67)	N=165, all with schizophrenia	Psychoeducation and simplifying regimen; and standard care; one session	One year	—	—	Psychoeducation and simplifying regimen better than standard care in rehospitalizations	Families included when available. Participants selected for nonadherence
Lecompte and Pele (69)	N=64, all with schizophrenia	Cognitive-behavioral therapy versus unstructured conversation	One year	—	Cognitive-behavioral therapy superior in aftercare appointments	Cognitive-behavioral therapy superior in rehospitalizations	
Azrin and Teichner (64)	N=39, 54% with schizophrenia	Psychoeducation; behavioral tailoring; and behavioral tailoring with client and family; one session	Two months	—	Both medication guidelines groups better than psychoeducation	—	Guidelines included psychoeducation, behavioral therapy, and other advice on taking medication. Brief treatment
Kemp et al. (68)	N=74, 58% with schizophrenia	Psychoeducation, motivational interviewing, and nonspecific counseling; four to six sessions	18 months	— —	Psychoeducation and motivational interviewing better than nonspecific counseling	Psychoeducation and motivational interviewing superior in relapses and symptoms	Better social functioning for psychoeducation and motivational interviewing group
Cramer and Rosenheck (65)	N=60, 32% with schizophrenia	Behavioral tailoring and standard care; one session plus monthly checks	Six months		Behavioral tailoring better than standard care	—	Brief treatment

Table 4

Randomized controlled trials of relapse prevention programs

Reference	Patients	Treatment and duration	Follow-up	Outcomes: Relapse or rehospitalization	Outcomes: Other	Comments
Buchkramer et al. (76,77)	N=66, all with schizophrenia	Relapse prevention; social skills training; standard care; ten weekly sessions	Two to five years	Relapse prevention better than social skills training but equal to standard care	—	Relatives' groups provided
Herz et al. (78)	N=82, all with schizophrenia	Relapse prevention and standard care; weekly groups for 18 months	Post-treatment assessment only	Relapse prevention better than standard	—	Relatives' groups provided
Perry et al. (79)	N=69, all with bipolar disorder	Relapse prevention and standard care; seven to 12 sessions	18 months	Relapse prevention better than standard care in manic relapses	Relapse prevention better than standard care in social adjustment and work	Participants selected after manic episode
Lam et al. (80)	N=25, all with bipolar disorder	Relapse prevention and standard care; six months, 12 to 20 sessions	One year	Relapse prevention better than standard care	Relapse prevention better than standard care in social functioning and coping strategies	Fewer antipsychotics prescribed at follow-up for relapse prevention group
Scott et al. (81)	N=42, all with bipolar disorder	Relapse prevention and standard care; six months	Six months, weekly sessions	Relapse prevention better than standard care	Relapse prevention better than standard care in symptoms and functioning	

ple's understanding of medication and addressing their concerns about taking medication, while respecting their decision about whether or not to use medication. However, only one controlled study has evaluated the effects of motivational interviewing on taking medication as prescribed, and this study is in need of replication.

Relapse prevention

Controlled studies of relapse prevention programs are summarized in Table 4. Relapse prevention programs focus on teaching people how to recognize environmental triggers and early warning signs of relapse and taking steps to prevent further symptom exacerbations (76–81). These programs also teach stress management skills. Because a person may not be fully aware that a relapse is happening (82,83), two of the five relapse prevention programs included groups to train relatives to help in the identification of early warning signs of relapse (76,78).

The five studies of relapse prevention programs all showed decreases in relapse or rehospitalization. These findings are consistent with the findings of a large, uncontrolled study of 370 people with severe mental illness in which teaching the early warning signs of relapse was associated with better outcomes, including fewer relapses and rehospitalizations and lower treatment costs (84). This benefit of involving relatives in relapse prevention programs is consistent with research that shows that family intervention is effective in preventing relapses (7).

Coping skills training and comprehensive programs

Controlled studies of coping skills training and comprehensive programs are summarized in Table 5. Coping programs aim to increase people's ability to deal with symptoms or stress or with persistent symptoms (85–90). Comprehensive programs incorporate a broad array of illness management strategies, including psychoeducation, relapse prevention, stress management, coping strategies, and goal setting and problem solving (91–94).

The four studies of coping skills were quite different, both in the methods employed and in the targets of the intervention. Leclerc and colleagues (85) taught an integrative coping skills approach based on Lazarus and Folkman's model of coping (95,96), which emphasizes the importance of cognitive appraisal in perceiving threat. Lecomte and colleagues (86) addressed general coping skills through building up participants' sense of empowerment. Schaub (87) and Schaub and Mueser (88) taught skills for managing stress and persistent symptoms, combined with basic psychoeducation about schizophrenia. Despite the differences in the programs, all the coping skills programs employed cognitive-behavioral techniques and produced uniformly positive results in reducing symptom severity. Thus research evidence shows that coping skills training is effective.

Table 5

Randomized controlled trials of coping skills training and comprehensive programs

Reference	Patients	Treatment and duration	Follow-up	Outcomes		Comments
				Relapse or rehospitalization	Other	
Leclerc et al. (85)	N=99, all with schizophrenia	Coping skills and problem solving and standard care; 24 sessions over 12 weeks	Six months	—	Coping skills and problem solving better than standard care in delusions, hygiene, self-esteem. No group differences in negative symptoms	60% of participants were from long-stay wards
Lecomte et al. (86)	N=95, all with schizophrenia	Self-esteem and empowerment group and standard care; 12 weeks	Six months	—	Self-esteem and empowerment group better than standard care in psychotic symptoms. No group differences in negative symptoms	Self-esteem and empowerment group improved more in coping skills
Schaub (87)	N=20, all with schizophrenia	Coping-oriented therapy and unstructured discussion group; 24 sessions over 2.5 months	Post-treatment assessment only	No group differences	Coping-oriented therapy better than unstructured discussion group in knowledge of illness, social contacts, well-being, self-confidence, hospitalization. Coping-oriented therapy equal to unstructured discussion group in symptoms, leisure time, coping	
Schaub and Mueser (88)	N=156, all with schizophrenia	Coping-oriented therapy and supportive therapy; 16 sessions over three months	One year	—	Coping-oriented therapy better than supportive therapy in symptom severity, negative symptoms, anxiety-depression	Relatives' groups provided. Two-year follow-up under way
Atkinson et al. (91)	N=146, all with schizophrenia	Psychoeducation and problem solving and standard care; 20 weeks	Three months	—		Psychoeducation and problem solving better than standard care in social functioning, social networks, quality of life
Hogarty et al. (92,93)	N=151, all with schizophrenia	Personal therapy and supportive therapy; 94 sessions over three years	Post-treatment assessment only	Participants living with families: personal therapy better than supportive therapy. Participants living independently equal to supportive therapy and better than personal therapy	Personal therapy better than supportive therapy in social adjustment	Half of participants living at home received family therapy
Hornung et al. (94)	N=191, all with schizophrenia	Psychoeducation; psychoeducation and problem solving; psychoeducation and key person counseling; psychoeducation, problem solving, and key person counseling; and standard care; psychoeducation, ten sessions; problem solving, 15 sessions; key person counseling, 20 sessions	Five years	Psychoeducation, problem solving, and key person counseling better than other groups in hospitalizations	—	

The three studies of comprehensive programs—that is, those using a broad range of techniques—are somewhat difficult to compare because they differed in the clinical methods used. Atkinson and coworkers (91) evaluated a program that combined morning educational presentations and afternoon sessions in which problem solving was applied to the educational topics. Hogarty and associates (92,93) evaluated the effects of personal therapy, a broad-based approach incorporating psychoeducation, stress management, and development of adaptive coping skills to promote social reintegration, and compared these effects with the effects of supportive therapy. They found that personal therapy prevented relapses only for people living with families. However, people receiving personal therapy improved in social functioning, whether they were living at home or not. Hornung and colleagues (94) examined the effects of different combinations of psychoeducation, problem-solving training, and key-person counseling (such as counseling family members) and found that people who received all three had fewer relapses over five years. These three studies suggest that comprehensive programs improve the outcome of schizophrenia, but the differences between programs preclude any definitive conclusions about which approaches may be most effective.

Cognitive-behavioral treatment of psychotic symptoms

Over the past 50 years, since the early work of Beck (97), cognitive-behavioral therapy has been used to help clients with psychotic symptoms cope more effectively with the distress associated with symptoms or to reduce symptom severity. Cognitive-behavioral approaches to psychosis include teaching coping skills, such as distraction techniques to reduce preoccupation with symptoms (98), and modifying clients' dysfunctional beliefs about the illness, the self, or the environment (99). In recent years, several manuals have been developed for cognitive-behavioral therapy for psychosis (100–102).

Over the past decade, eight controlled studies of time-limited cognitive-behavioral therapy for psychosis have been conducted—six in England (89,90,103–112), one in Canada (113), and one in Italy (114). Because several comprehensive reviews of this research (115), including two meta-analyses (116,117), have recently been published, we do not review the results of these studies in detail here. The consistent finding across these studies has been that cognitive-behavioral treatment is more effective than supportive counseling or standard care in reducing the severity of psychotic symptoms. Furthermore, studies that assess negative symptoms, such as social withdrawal and anhedonia, also report beneficial effects from cognitive-behavioral therapy on these symptoms.

Summary of research

The results of controlled research indicate that when illness management is conceptualized as a group of specific interventions, it is an evidence-based practice. The core components of illness management and the evidence supporting them can be summarized as follows. With respect to the more proximal outcomes, three studies (15,47, 48) found that psychoeducation was effective at increasing knowledge about mental illness, and a fourth (49) did not. Similarly, all four studies of behavioral tailoring found that it was effective in improving the taking of medication as prescribed (61,64–66). In terms of the more distal outcomes, all five studies of training in relapse prevention found that it reduced relapses and rehospitalizations (76–81), all four studies of teaching coping skills found that it reduced the severity of symptoms (85–88), and all eight studies of cognitive-behavioral treatment of persistent psychotic symptoms reported that it reduced the severity of psychotic symptoms (89,103,107–109,112–114). Although some studies of coping skills training differed in the symptoms they targeted, they all employed time-limited, cognitive-behavioral interventions. Thus psychoeducation, behavioral tailoring for medication, training in relapse prevention, and coping skills training employing cognitive-behavioral techniques are strongly supported components of illness management. Confidence in these findings is bolstered by the fact that the majority of the studies cited above were based on treatment manuals, and all except the studies by Schaub (87) and Schaub and Mueser (88) and the study by Tarrier and colleagues (89,112) were conducted by different groups of investigators.

The three studies of comprehensive illness management (91–94) suggest emerging evidence of the effectiveness of such programs. Improvements were seen in several important areas, such as social adjustment (92,93) and quality of life (91). However, the differences between the components of the programs and their target outcomes preclude the drawing of any definitive conclusions about them.

Although the results of these studies support several components of illness management, the studies' limitations should be acknowledged. First, most research has focused on persons with schizophrenia, which limits the findings' generalizability. Second, few replications of standardized interventions have been published. Third, most research examines the effects of teaching illness management, with less attention paid to recovery. Although coping and symptom relief are important aspects of recovery (27,30,42), little controlled research has examined the effect of interventions on the broader dimensions of recovery, such as developing hope, meaning, and a sense of purpose in one's life.

Implementation and dissemination issues

Strategies for implementing and disseminating evidence-based practices are critical to keeping these practices from languishing on the academic shelf and yielding little effect in routine mental health settings. Some illness management strategies, including psychoeducation, behavioral tailoring to address willingness to take medication as prescribed, relapse prevention skills, and cognitive-behavioral treatment of persistent symptoms, are available in some settings, but no empirically supported programs are in widespread use. Generic strategies for implementing new psychiatric treatment and rehabilitation programs have been described elsewhere (118). We consider implementation and dissemination issues from the perspec-

tives of four stakeholders: mental health system administrators, program directors, people with mental illness, and family members of people with mental illness. As virtually no controlled data are available on specific strategies for disseminating and implementing new programs, the recommendations provided below are based on the experiences of the authors and other reports in the literature.

Mental health system administrators

Several issues are relevant for administrators attempting to implement illness management approaches, including the selection or development of manuals, monitoring adherence to the model, policies and procedures, and funding.

Although the research supports several practices for teaching illness management, the specific components have not previously been conceptualized and standardized as a unitary package or manual, except in the context of comprehensive programs that go well beyond what the evidence supports. The availability of a treatment manual is critical for broad-scale implementation of a practice. The identification of critical practice components for illness management, supported by research, may facilitate the development of such a manual.

Policies supporting illness management as a core capacity in a service system are important for implementing such programs (119). These policies include the development of program standards that identify illness management as a specific service modality and require it as a necessary capacity in contracts with service providers and managed care entities. Compared with other evidence-based practices, illness management services are not expensive, nor do they require major organizational restructuring to implement. In fact, clinicians routinely work to help people with mental illness improve their capacity to manage their illness and achieve their personal goals. The identification and standardization of core ingredients of illness management will allow clinicians to do what they are already trying to do in a more organized, systematic, and effective manner.

Both the clinic and the rehabilitation options in state Medicaid plans can be used to support illness management services if the services are led by traditionally credentialed staff. When partnerships are sought between clinical staff and peer facilitators as leaders in teaching illness management skills, available resources must support curriculum development and implementation must include ways to accomplish this expansion. Although research has not examined the effects of partnerships between professionals and peers in providing illness management skills, the overlap in curriculum between the programs reviewed here and peer-based illness self-management programs (20) suggests that such collaborations should be considered. Many states that have implemented these initiatives have used combinations of federal block grant funds, Community Action Grants from the Center for Mental Health Services, and legislatively appropriated county and state funds.

The continuity of an illness management program is strengthened by the development of a leadership group that meets regularly and is composed of people with mental illness, their family members, mental health service providers, and mental health service administrators. Such a group can review the progress of the program, develop evaluation plans, assist in addressing system barriers, and create policies as needed to support the program. Finally, such a group can facilitate the regular meeting of providers of illness management training to share teaching experiences, provide mutual support, and assist in curriculum refinement.

Mental health program directors

Program directors need to select a curriculum that successfully integrates psychosocial and medical approaches to illness management. If the approach that is adopted involves people with psychiatric disorders as peer educators, a variety of policies and procedures need to be in place. These include supporting the employment of peers, practices that support reasonable accommodations for employees with disabilities, and supervision to help ensure appropriate boundaries between staff, peer-staff, and the people with mental illness who are the focus of treatment.

Another consideration is whom to target for illness management. Many program directors extend the opportunity to anyone who wants to attend, regardless of symptoms or rehabilitation status, on the grounds that desire to participate is the most important criterion for selection.

Program directors may find it helpful to integrate illness management principles throughout their organization. Case managers, therapists, crisis clinicians, and prescribing psychiatrists all have important roles in helping people use skills and in reinforcing management concepts. As with other service initiatives, the effect of illness management education is enhanced when the organization adopts its principles widely. Offering ongoing training rather than one-time courses can enhance the impact of illness management education. In addition, teaching a curriculum in short segments that are often repeated can be successful.

People with mental illness and their family members

The potential effect of illness management initiatives on people with mental illness is significant. Although the benefits of learning how to manage one's illness and make progress toward recovery are compelling, people report that recovery is hard work (26,120). The switch from being a passive recipient of care to an active partner is very challenging. People with psychiatric disorders and their relatives may feel justifiably ambivalent about these approaches (121). For example, a person learning about ways that others cope with symptoms may consider it a personal failure if he or she uses these methods but continues to experience symptoms. Programs that adopt fail-safe principles, such as unconditional support, zero exclusion, and easy reentry, support individuals' own recoveries and prevent people from internalizing a sense of failure.

Family members may be concerned that educational approaches will be used in lieu of established medical and psychosocial treatments. Family members may consider the

idea of recovery unrealistic, or they may be concerned that their relative is not ready to assume a more responsible role in treatment. Whether or not the person lives with relatives, relatives are likely to have a significant, although perhaps a subtly perceived, role in their family member's attitude toward recovery. Thus it is critical that the family understand and be involved in illness management education and that they appreciate its relevance to recovery.

Conclusions

It is now widely recognized that people with mental illness can participate actively in their own treatment and can become the most important agents of change for themselves. Illness management skills, ranging from greater knowledge of psychiatric illness and its treatment to coping skills and relapse prevention strategies, play a critical role in people's recovery from mental illness. Research on illness management has thus far focused on programs developed and run by professionals. This research provides support for illness management programs and guidance on their effective components. Similar research on peer-based illness self-management programs may inform professional-based services and lead to collaborative efforts. ♦

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EVIDENCE-BASED PRACTICES KIT

Knowledge Informing Transformation

The Evidence

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- Introduces readers to the concepts and approaches of evidence-based practices for treating severe mental illnesses.
- Describes the importance of research in intervention science and the evolution of evidence-based practices.
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SAMHSA Center for Mental Health Services

The Substance Abuse and Mental Health Services Agency (SAMHSA) provides a large variety of free (or very inexpensive) publications and videotapes about mental illnesses and effective treatment.

(800) 789-CMHS
Web site: http://www.samhsa.gov/cmhs

Consumer Organization and Networking Technical Assistance Center (CONTAC)

CONTAC provides technical assistance to consumers throughout the U.S.

(800) 598-8847
Web site: http://www.contac.org

Depression and Bipolar Support Alliance (DBSA)

DBSA is a membership organization that provides direct support services to people with mental illnesses and their families, legislation and public policy advocacy, litigation to prevent discrimination, public education, and technical assistance to local affiliates.

Web site: http://www.dbsalliance.org

Mental Illness Education Project (MIEP)

The Mental Illness Education Project seeks to improve understanding of mental illnesses by producing video-based programs for use by consumers, their families, mental health practitioners, administrators, and educators, as well as the general public.

(800) 343-5540
Web site: http://www.miepvideos.org

Mental Health America (MHA)

MHA provides information and referral services for people in the process of recovery.

Web site: http://www.mentalhealthamerica.net

Mental Health Recovery

Mary Ellen Copeland has developed a number of publications and programs for helping people in the recovery process, including the Wellness Recovery Action Plan (WRAP). Her web site offers a free newsletter and articles and a list of publications and workshops that can be purchased.

(802) 254-2092
Web site: http://www.mentalhealthrecovery.com

National Alliance on Mental Illness (NAMI)

NAMI is a support and advocacy organization of consumers, families, and friends of people with mental illnesses. It provides education about severe brain disorders, supports increased funding for research, and advocates for adequate health insurance, housing, rehabilitation, and jobs for people with mental illnesses. Each state has a chapter and many communities have their own chapters. NAMI offers a consumer-led educational program called *Peer-to-Peer*.

Helpline: (800) 950-NAMI
Web site: http://www.nami.org

National Empowerment Center (NEC)

NEC is a provider of mental health information, programs, and materials that focus on recovery. NEC provides referrals to local support groups and helps people set up new groups. Newsletter and audiovisual materials are also available.

Web site: http://www.power2u.org

National Institute for Mental Health (NIMH)

NIMH is engaged in research for better understanding, more effective treatment, and eventually prevention of mental illnesses. Its web site provides educational materials and an excellent list of free publications on mental illnesses, including a comprehensive listing of resources for help.

Web site: http://www.nimh.nih.gov

National Mental Health Consumers' Self-help Clearinghouse

This organization provides information about mental illnesses, technical support for existing or newly starting self-help groups, and a free quarterly newsletter for consumers. It sponsors an annual conference. Spanish language services are available.

Web site: http://www.mhselfhelp.org

Resource Center to Address Discrimination and Stigma Associated with Mental Illness

This center provides resources and information to help people implement and operate programs and campaigns to reduce the stigma of mental illnesses.

(800) 540-0320
Web site: http://www.adscenter.org

U.S. Psychiatric Rehabilitation Association (USPRA)

USPRA is a nonprofit organization committed to promoting, supporting, and strengthening community-based psychosocial rehabilitation services and resources. It also publishes a journal, newsletters, and a resource catalogue.
(410) 789-7054

Web site: http://www.uspra.org

EVIDENCE-BASED PRACTICES KIT

Knowledge Informing Transformation

The Evidence

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