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# A Cognitive-Behavioral Approach to the Beginning of the End of Life

## Minding the Body

*Facilitator Guide*

Jason M. Satterfield

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# About Treatments *ThatWork*™

Stunning developments in healthcare have taken place over the last several years, but many of our widely accepted interventions and strategies in mental health and behavioral medicine have been brought into question by research evidence as not only lacking benefit but perhaps inducing harm. Other strategies have been proven effective using the best current standards of evidence, resulting in broad-based recommendations to make these practices more available to the public. Several recent developments are behind this revolution. First, we have arrived at a much deeper understanding of pathology, both psychological and physical, which has led to the development of new, more precisely targeted interventions. Second, our research methodologies have improved substantially, such that we have reduced threats to internal and external validity, making the outcomes more directly applicable to clinical situations. Third, governments around the world and healthcare systems and policymakers have decided that the quality of care should improve, that it should be evidence based, and that it is in the public's interest to ensure that this happens (Barlow, 2004; Institute of Medicine, 2001).

Of course, the major stumbling block for clinicians everywhere is the accessibility of newly developed evidence-based psychological interventions. Workshops and books can go only so far in acquainting responsible and conscientious practitioners with the latest behavioral healthcare practices and their applicability to individual patients. This new series, Treatments *ThatWork*™, is devoted to communicating these exciting new interventions to clinicians on the frontlines of practice.

The manuals and workbooks in this series contain step-by-step detailed procedures for assessing and treating specific problems and diagnoses. But this series also goes beyond the books and manuals by providing an-

cillary materials that will approximate the supervisory process in assisting practitioners in the implementation of these procedures in their practice.

In our emerging healthcare system, the growing consensus is that evidence-based practice offers the most responsible course of action for the mental health professional. All behavioral healthcare clinicians deeply desire to provide the best possible care for their patients. In this series, our aim is to close the dissemination and information gap and make that possible.

This facilitator guide, and the corresponding workbook for clients, is designed to help individuals cope with chronic and/or terminal diseases. Its focus is on care rather than cure. While these patients' diseases may not be cured nor their lives prolonged, their suffering can be reduced while supporting their mental, social, and spiritual health. Quality of life deserves as much mindful attention as quantity of life.

This collaborative, skill-based program addresses the emotional, psychosocial, and spiritual needs of patients. It uses a flexible, modular format that can be adapted to best suit each client. Sessions cover stress, mood, and symptom management. Clients may work on improving social support and communication skills. This program also addresses practical concerns about medical care and explores spiritual issues. It includes goal setting and a broad assortment of cognitive-behavioral techniques. Those working with this population will find this book an indispensable guide to help patients adjust to their conditions and begin to prepare for the end of life.

David H. Barlow, Editor-in-Chief,
Treatments *That Work*™
Boston, Massachusetts

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# Contents

**Module 4: Quality of Life**

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Jason M. Satterfield

# Introductory Information for Facilitators

## Background Information and Purpose of This Program

The unprecedented advances in twentieth-century biomedicine gave rise to a transformation in how medical providers and the public thought about the end of life. Death became an enemy to be conquered, or at least held at bay for as long as possible. As medical trainees were taught to cure illness instead of care for patients, quantity of life trumped quality of life. "High tech" replaced "high touch." One success of the high-tech approach is the irrefutable increase in life expectancy. Individuals in industrialized nations are living longer and they are dying mostly from chronic diseases that cause a gradual but eventually unstoppable decline toward death. This shift in the causes and trajectory of death, coupled with the rapidly increasing numbers of the elderly, has created an expanding need for both chronic-disease management and attention to the non-biomedical needs that arise as the end of life approaches.

With the birth of the modern hospice movement and the initial publication of scholarly works such as Kübler-Ross's *On Death and Dying*, the notion of caring for the whole patient at each stage of life including death began to regain legitimacy. Endings were seen as important as beginnings. As with birth, death required planning and preparation, and presented important and often difficult medical, psychosocial, emotional, and spiritual challenges. To meet the needs of the whole person, a multidisciplinary team with flexible tools and resources was often required.

This treatment program was developed to assist medical providers in meeting the psychosocial, emotional, and spiritual needs of patients with advanced, chronic disease who are still well enough to actively participate in treatment—i.e., a population at the "beginning of the end of

life." Although many excellent resources are available for caregivers, there are few equivalent programs for the dying person. Many of the tools provided in this treatment rely heavily on cognitive-behavioral therapy (CBT), although other diverse theoretical systems such as humanism, existentialism, family systems, pastoral counseling, thanatology, and chronic disease self-management have informed much of the overall framework and approach.

Facilitators should already have some expertise with cognitive-behavioral interventions. Master's level counselors, social workers, and nurse practitioners or others with mental health training may qualify. The basic philosophy of this program supports the hospice model of multidisciplinary end-of-life care but brings mental health and other psychosocial concerns to the foreground. Ideally, multidisciplinary team comanagement of clients will occur. It is recommended that all facilitators of any level have regular consultations and support depending on their level of competence and the level of difficulty the client's situation presents. Fidelity checklists have been included in an appendix for convenience. Each checklist includes an outline of the corresponding session and space for notes. Facilitators may want to use this as part of the supervision process or to rate self-adherence. Facilitators may also find it helpful to record time estimates for each session element. Forms from the book may be photocopied as needed.

## Disorder or Problem Focus

Life is a terminal condition. Although cause, timing, and circumstances may vary greatly, everyone must eventually face this normative stage of life. This program was developed to assist adult clients who have serious, progressive illnesses that will most likely result in their death. In this circumstance, these individuals have the opportunity to prepare for their death and exert some control over the rate and intensity of their decline. It is important to note that this program does not address terminally ill children.

Chronic illnesses that are the leading causes of death include heart disease, stroke, pulmonary disease, cancer, and diabetes. Related contribu-

tors include obesity, high blood pressure, high cholesterol, smoking, and excessive alcohol use (McGinnis & Foege, 1993). High comorbid levels of chronic stress, depression, and anxiety may amplify psychosocial impairment and actually hasten the biomedical progression of disease (Adler & Matthews, 1994).

This program targets a wide range of issues that commonly occur during the course of a serious illness. These issues include stress and coping, depression, anxiety, anger, social support, communication, working with medical providers, symptom management, and spirituality. It is important to remember that most clients will not become clinically depressed nor develop other new psychiatric disorders at the end of life. However, many will face adjustment challenges and may benefit from both the practical and emotional support provided by this program. As an overarching goal, this program aims to maximize the quality of life at the end of life by alleviating unnecessary suffering and facilitating the achievement of whatever the client may deem a "good death."

## Assessment and Diagnosis

Before beginning treatment, it will be essential to perform a thorough assessment and diagnostic workup. Given the range of issues that may arise, multiple assessment tools should be used to capture both possible psychopathology and more general issues in coping and adjustment. It is important to remember that every client will have a serious biomedical condition that may influence their performance on various assessments—e.g., scores for fatigue, insomnia, or weight loss may be due to a medical condition and not psychiatric impairment.

This program is intentionally designed to offer flexibility in focus, intensity, and duration based on assessment results. Data from assessments should be used to inform treatment planning, goal setting, and targets for initial self-monitoring exercises. (For group, couples, and other format variations see the chapter Program Adaptations at the end of this book.) Initial intake results should be shared with the client during the first session. Clients should participate in ongoing self-assessments and treatment modifications as the program progresses. Further discussion

of assessment issues and suggested tools can be found in the next chapter (Assessment).

## Diagnostic Criteria for Adjustment Disorders

In the following outline we list the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revised) (DSM-IV-TR; American Psychiatric Association, 2000) criteria for adjustment disorders. Please note that clients may meet criteria for other disorders including major depression or generalized anxiety. However, most clients at the beginning of the end of life will not have a new psychiatric diagnosis. Any prior history of psychiatric impairment or substance abuse should be assessed in order to gauge possible prognosis and target interventions to prevent relapse.

### Diagostic Criteria for Adjustment Disorders

A. The development of emotional or behavioral symptoms in response to an identifiable stressor(s) occurring within 3 months of the onset of the stressor(s).

B. These symptoms or behaviors are clinically significant as evidenced by either of the following:
   1. Marked distress that is in excess of what would be expected from exposure to the stressor
   2. Significant impairment in social or occupational (academic) functioning

C. The stress-related disturbance does not meet the criteria for another specific Axis I disorder (clinical disorder) and is not merely an exacerbation of a preexisting Axis I or Axis II disorder (personality disorder or mental retardation).

D. The symptoms do not represent bereavement.

E. Once the stressor (or its consequences) has terminated, the symptoms do not persist for more than an additional 6 months.

Specify if:

A. **Acute:** if the disturbance lasts less than 6 months

B. **Chronic:** if the disturbance lasts for 6 months or longer

Adjustment disorder subtypes are selected according to the predominant symptoms:

- With depressed mood
- With anxiety
- With mixed anxiety and depressed mood
- With disturbance of conduct
- With mixed disturbance of emotions and conduct
- Unspecified

## Development and Evidence Base for This Program

This program was initially developed in 1998 as part of a larger multidisciplinary project funded by the Robert Wood Johnson Foundation and directed by Michael Rabow, MD. This project created a Comprehensive Care Team (CCT) at the University of California, San Francisco, to deliver evidence-based health care to clients at the "beginning of the end of life" (Rabow, Dibble, Pantilat, & McPhee, 2004). CCT participants were seriously ill, adult medical patients who were actively pursuing treatment of their disease as outpatients at UCSF. Patients had advanced cancer, congestive heart failure, or chronic obstructive pulmonary disease with prognoses ranging from 1 to 5 years. Fifty patients were enrolled in the intervention condition and forty patients served as controls. Since part of the intervention included physician education and training, randomization occurred on the level of the physician clinic and not by patient.

Intervention patients were offered a large menu of options including palliative care consultations, pain management, social services, spiritual counseling, art experientials, and the Minding the Body psychosocial

treatment program. The overall intent of the CCT was to demonstrate the feasibility and clinical utility of creating specialized consultations and clinical care for this patient population. The CCT did not test the stand-alone efficacy of the Minding the Body program nor that of any of the other CCT constituent elements. Results from this study showed improved outcomes in dyspnea, anxiety, sleep, and spiritual well-being but failed to improve pain, depression, or quality of life (Rabow, Dibble, et al., 2004). Primary care providers' failure to follow consultation recommendations and the relatively low enrollment and attendance to the psychosocial treatment elements may have limited gains in these areas. Informally, patients cited transportation problems, uncontrolled pain, and anxiety about group participation as primary obstacles to the Minding the Body program.

As the CCT psychologist, Dr. Satterfield developed an evidence-based, manualized, group treatment called "Minding the Body." Although participants were not required to meet DSM-IV criteria for clinical depression or anxiety, CBT interventions were used as a basis for teaching mood management and ways of coping. Given the importance of social supports in this population, sessions on communication and conflict resolution were added. Practical information for symptom management and working with medical providers were later included based on participant feedback and the success of a local caregiver training program, Home Care Companions directed by Celi Adams, RN. A final session on spirituality was developed with input from the CCT chaplain, Rev. Rod Seeger. Participant input was used to improve cultural sensitivity and acceptability throughout.

Given the breadth of skills introduced in Minding the Body, the program was framed as a sampler of introductory skills that would assist participants in selecting the most personally relevant skills for further development in more focused programs or in individual counseling. After several group iterations, the format was changed from group to individual counseling to provide more one-on-one support and best tailor the program to the needs of the individual. Individual treatment based on Minding the Body ranged from 4 to 24 sessions and sometimes included telephone and Internet counseling. Both group and individual

formats were facilitated by a doctoral-level psychologist, although elements of the program have since been used by master's level social workers, counselors, psychiatric nurses, and chaplains. Further variations, adaptations, and group logistics are discussed in the chapter Program Adaptations.

A review of all of the seminal studies supporting CBT for mood disorders, stress, and other conditions is beyond the scope of this chapter. However, several key studies and treatment programs provided important foundational elements. The cognitive theory of stress and coping (Lazarus & Folkman, 1984) and the Coping Effectiveness Training (CET) program (Chesney, Chambers, Taylor, Johnson, & Folkman, 2003) were the basis for the stress management and coping skills sections. CET was effective in improving coping and mood in a distressed HIV population (Chesney et al., 2003). The depression and other mood management strategies were heavily influenced by the empirically supported work of Ricardo Muñoz and others at San Francisco General Hospital (Muñoz and Miranda, 1994; Muñoz et al., 1995). Other key influences include the cognitive work of Aaron Beck and colleagues (Beck, Rush, Shaw, & Emery, 1979) and problem-solving therapy by Nezu (1986) and Arean (2001). Empirical support or conceptual foundations for particular exercises are listed in the relevant chapters throughout this text.

Other empirical studies have shown that psychosocial interventions in similar populations are efficacious. For example, relaxation training is effective for clients with cancer, chronic obstructive pulmonary disease (COPD), or congestive heart failure (Burish & Jenking, 1992; Chang et al., 2005; Gift, Moore, & Soeken, 1992). Stress management training improves quality of life and other outcomes in breast cancer survivors or elderly clients with heart failure (Antoni et al., 2006; Luskin, Reitz, Newell, Quinn, & Haskell, 2002). More generally, CBT interventions have been effectively used for COPD, cancer pain, cancer symptom management, and associated functional limitations (Dalton, Keefe, Carlson, & Youngblood, 2004; Doorenbos et al., 2005; Kunik et al., 2001; Sherwood et al., 2005).

The core skills and ideas introduced in this program include the following:

***Meta-Cognitive***

- Self-monitoring
- Goal setting
- Problem solving
- Cognitive restructuring
- Directed/balanced attention
- Savoring

***Interpersonal***

- Communication skills
- Conflict resolution and negotiation
- Building intimacy
- Acceptance
- Forgiveness
- Expressing gratitude

***Behavioral***

- Activity scheduling
- Graded task assignment
- Somatic quieting
- Breathing
- Progressive muscle relaxation
- Guided imagery
- Expressive writing

***End-of-Life or Disease Related***

- Chronic disease self-management
- Working with a medical team
- Symptom management—pain, insomnia, fatigue, nausea
- Addressing legal issues
- Exploring spirituality
- Leaving a legacy
- Facilitating a "good death"

## CBT Models

There are a number of CBT models contained throughout this program. Participants begin by learning the interdependence of cognition, behavior, and emotion and how this triad relates to social relationships, spirituality, and physical and mental health (Sessions 1 and 2). The cognitive model of stress—stressors, appraisals, and ways of coping—is introduced in Sessions 2 and 3 along with a model of effective problem solving. Cognitive models of depression, anxiety, and anger are presented in Sessions 4–6, respectively. Basic cognitive and problem-solving skills are applied to improving relationships, working with medical professionals, and managing symptoms in later sessions.

## A Caveat about This Treatment Program

As with any type of CBT, the facilitator is expected to be an active, flexible partner who presents a transparent treatment plan and rationale. Interventions are evidence based when possible, but important concepts should be illustrated with salient clinical stories or examples that facilitate client identification and integration of the material. It is essential, however, to remember that there is no correct way of approaching the end of life. Although a common goal of reducing suffering and maximizing quality may be shared, what those outcomes might look like will