

**LIFE THREATENING ILLNESS
SUPPORTIVE-AFFECTIVE GROUP EXPERIENCE:**

THE LTI-SAGE PROGRAM



Saint Louis University School of Medicine

**St. Louis, MO
2001**

The LTI-SAGE Program

**Using Spiritual-Emotional-Relational Groups to
Help Patients with Life-Threatening Illnesses
Live Until They Die**

Douglas K. Miller, MD

Paul N. Duckro, PhD

Susan D. Videen, MDiv, PhD

John T. Chibnall, PhD

**Saint Louis University School of Medicine
Departments of Internal Medicine, Community & Family Medicine,
Pastoral Care, and Psychiatry**

**St. Louis, MO
2001**

**Funded by:
Supportive Care of the Dying: A Coalition for Compassionate Care
and
Project on Death in America**

TABLE OF CONTENTS

Chapter 1 – Overview	1
General History and Purpose	1
The Supportive-Affective Group Program.....	3
Summary of project methods	3
Specific aims of the project.....	4
Chapter 2 – Theory and Background	5
Introduction	5
Spirituality.....	5
Emotions/Feelings.....	6
Relationships	7
The prevailing medical model.....	8
Importance of Groups in Treatment.....	8
Our approach to groups.....	10
The Role and Needs of the Caregiver	10
Our approach to caregivers	11
Special Needs of African American Patients and their Families	11
Impact of Groups.....	12
Implementation of Change in Medical Practice.....	12
Chapter 3 – Clientele	13
Whom to Include.....	13
What to Separate, What to Combine.....	14
Medical conditions.....	14
Ethnic background	15
Spiritual and religious preference	16
Comments on Recruitment and Retention	16
Chapter 4 – Group Process	18
Group Interaction	18
The Nature of Our Groups	19
The Dynamics	20

The Facilitator	22
Training	22
Standardization of the role	23
Dangerous territory	24
Flexibility: Curriculum, Number of Groups, Frequency of Meeting.....	25
Further Thoughts on Process.....	26
Contact Between Groups.....	27
Journals	27
Chapter 5 – Group Curriculum.....	29
Group #1: Getting Started	29
Group #2: Asserting Your Needs.....	33
Group #3: Feelings.....	36
Group #4: Working with and Helping your Body	39
Group #5: Living Well with Being Ill.....	43
Group #6: Intimate Relationships	46
Group #7: Spiritual Needs.....	49
Group #8: Asking for Help	51
Group #9: Health Care Planning and Decision Making.....	55
Group #10: My Legacy	57
Group #11: Hope and Gratitude.....	60
Group #12: The Final Session.....	63
Chapter 6 – Crises.....	65
Death or Setbacks of Group Members	65
Using Crises to Promote Group Growth	65
Some Warnings About Handling Crises	65
Chapter 7 – Problem Solving and Feedback	67
Hazards to Good Group Process	67
Hazards to Group Success.....	69
Getting Feedback	69
Chapter 8 – Branching Out to Physicians	70
Physician Group #1	71

Physician Group #2	72
Physician Group #3	73
Physician Group #4	73
Chapter 9 – Empirical Evidence	75
Chapter 10 – Final Thoughts	77
Appendix 1 – Journal Questions.....	78
Appendix 2 – Group Session Handouts.....	81
Appendix 3 – Group Evaluation/Feedback Form.....	83
Appendix 4 – Handout–Physician Group #2	85
Acknowledgements.....	88
Endnotes.....	89

CHAPTER 1

Overview

General History and Purpose

The purpose of our work is to address the spiritual, emotional, and relational needs of people with life-threatening medical conditions and their loved ones within the context of everyday medical care. Only a new paradigm and new structures will bring extensive and enduring change to the delivery of end-of-life care by physicians and other health professionals. Healthcare initiatives, though aimed at the creation of healthier communities, often do not address, indeed avoid addressing, one of the most basic aspects of life—that is, dying and death. The care of patients with life-threatening conditions has been inadequate in this country and previous studies have shown that communication between physicians and patients is virtually absent or, if it does occur, chaotic and superficial. Patients are kept on life-sustaining devices well past the time when *meaningful* life can be sustained and they would have readily chosen to die. Death has come to signify for many patients only unrelenting and unmitigated pain.

This is not to say that physicians and other health professionals have not tried to address the problem. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was designed in 1995 to improve end-of-life decision-making and reduce the frequency of mechanically supported, painful, and prolonged processes of dying.¹ Physicians in the intervention group received estimates of the likelihood of six-month survival for patients every day for up to six months, information on CPR outcomes, and reports of functional disability. A specially trained nurse had multiple contacts with the patient, his or her family, the physician, and hospital staff to elicit preferences, improve understanding of outcomes, encourage attention to pain control, and facilitate advance care planning and patient-physician communication. Despite these measures, there was no improvement in patient care. Efforts aimed at enhancing patient-physician communication did not change established practice.

At the root of the problem lies our definition of “health.” Is it merely the absence of disease? Alternatively, does it have a more positive identity of its own? The World Health Organization defines health as “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.”² Health includes loving and intimate relationships, a sense of meaning that makes life worthwhile, a panoply of feelings, faith in the essential goodness of creation, a strong self-concept with a concomitant belief in something greater than oneself. Unquestionably, there is more to healing than the correction of aberrant physical processes. Some would reject such a broad definition of health. Certainly, it makes the job of the health professional more demanding. However, the narrower focus has led to the present state of patient dissatisfaction with healthcare and to charges that healthcare favors technology over humanity.

There is an important distinction to be made between disease and illness. Health professionals may not be able to do anything more about a disease, but they can still treat an illness. Illness is the patient's subjective experience of his or her disease and its physical symptoms. It involves spiritual, emotional, and relational needs. It may be manifest in a heightened sense of anxiety and uncertainty; in a fear of dependency, disfigurement, or death; in a need to construct (or reconstruct) a worldview, a set of meanings that make sense in the face of personal limitations and mortality. We are not interested in health as an absolute value, but health in the service of higher values. We do not deny the vulnerability and limitations of the patient with a life-threatening condition, but we do assert that the patient can use whatever health he or she has to carry on with parts of life that, in the face of death, take on ultimate value. Acceptance of his or her limitations, in the healthy realization that death cannot finally be conquered, does not mean that the patient ceases to search for meaning in the time that is left. Long after the physician has depleted his or her medical armamentarium, the patient can still do much with guidance and inspiration. The physician can open opportunities for self-exploration by offering to a patient both pastoral and psychological care within the community of a support group.

Health professionals have increasingly accepted responsibility for the care of patients with life-threatening conditions. Six Catholic healthcare organizations joined in 1995 to form Supportive Care of the Dying: A Coalition for Compassionate Care. It funded the research into end-of-life care from which this manual grew. *Living and Healing During Life-Threatening Illness*, a report of the coalition's research and findings, describes the mission:

The coalition is dedicated to promoting cultural change that will encourage society to provide supportive care, compassionate relief of suffering, and pain and symptom management for people with life-threatening illness. A contemporary response by the Catholic healthcare ministry to the special needs of people facing death, the coalition is motivated by the Church's belief that human life is a fundamental value and that both healthcare systems and communities should help people live and die well.³

The coalition has three priorities:

- To research the information, service and support needs of people with life-threatening illnesses, their families, and their communities;
- To develop models of comprehensive, community-based, supportive care for dying people; and
- To create both a professional mentorship program that teaches holistic supportive care skills and behaviors and a community education program that works for reformed end-of-life care.

The Supportive-Affective Group Program

The aim of our specific project has been to design and implement a group program for patients, their primary caregivers, and health professionals that focuses on three primary areas: spirit, emotions, and relationships. Necessary modifications were made in this effort to meet the special needs and experiences of patient subgroups, including those related to race, disease category, and healthcare delivery site. Special attention was paid to the unique needs of African American patients and their caregivers. We believe that our Supportive-Affective Group Program, when properly adapted, will prove useful for patients with life-threatening medical conditions over a wide range of clinical problems and with varying prognoses, religious preferences, and cognitive capacities.

Summary of project methods. In addition to the principal investigators (a geriatrician and a research psychologist), the project to develop the group program included a research coordinator who was also a chaplain with experience in group process and facilitation. Early on, the principal investigators contacted physicians in the areas of cardiology, pulmonology, HIV/AIDS, geriatric internal medicine, and oncology to elicit support. These physicians provided lists of patients who fit the project's recruitment criteria: Adult patients; African American or non-African American; experiencing a life-threatening medical condition attributable to heart or lung disorders, HIV/AIDS, cancer, or geriatric frailty (i.e., multiple sources of compromise correlated with advanced age); expected by the attending physician to live at least six months but very likely not more than 24 months. From these lists, the research coordinator recruited patient-caregiver dyads who agreed to participate in the study. Each of these was initially interviewed by the chaplain using a structured, open-ended interview process exploring spiritual, emotional, and relational needs. Patients and caregivers were asked to journal on specific questions related to these issues as preparation for the group meetings.

Prior to this process, the project team—with the oversight of an Operations Committee of physicians, ethicists, pastoral care professionals, and hospital administrators—began to formulate and explicate the group process to be used and the topics to be covered in the groups. Existing methods were reviewed and different group therapy models were examined. From this work came the method and curriculum that was used in our groups. The clinical psychologist on the team—a clinician experienced in both group and individual therapy, with an emphasis on the spiritual aspects of mental health—was the primary architect of this effort.

Two pilot groups were formed first, one African American and one Caucasian, and began to meet several months before the intervention groups. The African American group continued to meet throughout the one-year study period, functioning in an advisory capacity. Subsequently, participants were recruited for the actual groups. All participants were given a battery of baseline outcome measurements and then randomized into either the intervention group or the “self-reliant” (control) group. The intervention group consisted of two mixed disease groups, one Caucasian and one African American; two geriatric groups, one Caucasian and one African American; and an HIV/AIDS group made up of both African American and Caucasian participants. The HIV group was mixed

racially because of difficulties in recruiting enough patients at the hospital where this work was done to create a Caucasian-only group. Caucasian geriatric and mixed disease groups were facilitated by a Caucasian chaplain. African American geriatric and mixed disease groups were facilitated by an African American chaplain or clinical psychologist. The HIV group was facilitated by an African American chaplain with support from a Caucasian chaplain.

Participants met monthly in groups of 5 to 6 patients, some with caregivers. Each group meeting started with a brief socialization period, continued with discussion of the focus topic of the session, and moved into issues raised by the participants themselves that related to spirituality, emotions, and relationships. The meetings lasted 75 minutes and ended with a brief summary of the current session and an overview of the content of the next month's meeting, along with journal questions to be considered in the interim. By their very nature and with guidance from the facilitators, these sessions provided not only information but also considerable group support for people working through difficult issues. Between sessions, the research coordinator made at least one telephone call to each patient and caregiver in order to "keep in touch" and to discuss any spiritual, emotional, or relational issues of importance to that individual. She also visited patients who were admitted to the hospital. The "self-reliant group" did not meet in groups and received by mail only the handouts that were passed out at the actual groups. Both intervention and "self-reliant" groups were again asked to complete the outcome measures at 12 months, following completion of the program.

Specific aims of the project. It was our expectation that patients with life-threatening medical conditions and their caregivers who participated in this program would experience a greater sense of spiritual fulfillment, less depression, more satisfaction with close personal relationships, and less death distress (i.e., anxiety and depression specifically related to thoughts of death) than patients and caregivers in the self-reliant group. Further, we expected the group participants and caregivers to be more likely than the self-reliant group to address issues of advance directives and to discuss the spiritual, emotional, and relational aspects of end-of-life care with their physicians. Our aim was always to improve well-being and decrease healthcare utilization. In the short term, we hope that attending physicians will recognize the value of a program like ours. In the longer term, we look forward to many more physicians receiving training based on our experience with these groups and incorporating parts of its paradigm into their daily practice. After participation in the program, we are confident that physicians will be increasingly willing to refer patients to support group services, discuss end-of-life issues, and set goals for end-of-life care. With an understanding of patients' spiritual, emotional, and relational needs, physicians can trust their ability to evaluate and meet these needs.

CHAPTER 2

Theory and Background

Introduction

Quality of life has been defined as physical, psychological, social (or relational), and spiritual well-being.^{4,5} Our group program aims to address principally the latter three aspects of quality of life and well-being.

Ellison identifies four basic human needs: material necessities (the need for having), intimacy and a sense of belonging (the need for relating), satisfaction with oneself (the need for being, including one's emotional being as defined by feelings), and life purpose and meaning (the need for transcendence or "spirituality"). Thus, well-being involves spiritual as well as social-psychological components.⁶

Spirituality. This concept has been defined as the energy or drive within each person that struggles for meaning and purpose in life.⁷ Spirituality is rooted in the experiential and intuitive, not the conceptual domain, and serves an integrative function for the individual, bringing disparate parts of the personality together.⁸ It is distinct from adherence to a particular religious tradition.

The search for meaning is a universal human experience. Human beings are driven to seek new understandings about the meaning of their lives when they become ill.⁹ Illness often causes a crisis of meaning for the patient. Healing is a process of reconstructing one's life meaning and adjusting one's lifestyle to incorporate the new demands of illness.^{10,11} Lipowsky identifies eight potential ways for patients to see meaning in their illness: as challenge, enemy, punishment, weakness, relief, strategy, irreparable loss or damage, or value.¹²

For many people religion is a powerful way of stimulating a healing faith that restores them to wholeness.¹³ Religion can provide the dying patient with a theoretical framework for making sense of illness and death; practical resources for coping with sickness, suffering, and death; and hope in the face of inevitable death.¹⁴

A transcendent belief system can be a source of hope for the patient because it endows human life with meaning beyond the individual.¹⁵ Hope has been ignored or seen as a "mixed blessing" because of its potential to decrease the individual's contact with reality. Actually, it is necessary to healthy coping, enabling the patient to avoid despair and to bypass ongoing, unpleasant or stressful situations.¹⁶ Hope strengthens the individual to deal with the difficulties and stresses that accompany tragedy, failure, boredom, loneliness, and suffering, all of which are experienced by ill people.¹⁷

Patients with advanced cancer who find comfort in their religious or spiritual beliefs have been shown to be more satisfied with their lives and happier than those who do not.¹⁸

Patients with high spiritual well-being have, for example, shown less anxiety in dealing with the trauma of a cancer diagnosis.¹⁹ Studies have shown that religious beliefs and practices can extend an individual's coping resources and are associated with improvement of healthcare outcomes.²⁰

Emotions/Feelings. In 1969, Elizabeth Kubler-Ross wrote the classic ordering of responses to illness and death: denial, anger, bargaining, depression, and acceptance.²¹ Several articles relevant to our study have addressed more specifically the unique feelings of patients with life-threatening illness: the sense of impaired vocational, domestic, and sexual functioning; fear of losing social esteem; loneliness, isolation, and withdrawal; vulnerability and loss of control; sense of meaninglessness; fear of recurrence, abandonment, and death; and guilt.^{22,23,24,25,26,27,28,29,30} Mild to moderate depression and anxiety characterize patients at the time of diagnosis.³¹ Twenty-five to thirty percent of patients undergoing mastectomy were found to have psychological or emotional problems serious enough to need referral to a psychiatrist.^{32,33}

Psychological coping mechanisms are interrelated with survival time in cancer patients.³⁴ Bloom specifies an interrelationship between social support, coping responses, and adjustment to illness.³⁵ Schoenfield reports that early identification of cancer patients in need of support may shorten the recovery period.³⁶ Fawzy writes that the greatest potential benefit of a structured psychiatric intervention comes to a patient newly diagnosed with cancer or in the early stages of treatment.³⁷

Work in the 1940s showed expression of feelings to be a necessary presupposition for acceptance of loss or change in the bereaved.³⁸ This was true of both religious and nonreligious people.

As far back as the Roman physician Galenus in the 2nd century, it has been recognized that emotions play a role in the development and course of illness. More specifically, the relationship between psychological characteristics and the development of cancer has been apparent for some time. Rigorous study of patients with various lung diseases showed that patients with lung cancer have "restricted outlet for emotional discharge" in comparison with patients suffering from other kinds of lung disease.³⁹ Greer and Watson examine the possibility of an integrated psychobiological control system that fails and permits cancer, once initiated, to grow and disseminate.⁴⁰ They identify the cancer-prone patient as "Type C."

Studies in the 1950s showed that the psychological profile of a patient can predict survival time. If a patient is able to externalize conflicts and the negative emotions associated with them, survival time is significantly longer. West and colleagues were impressed by the "polite, almost painful acquiescence of patients with rapidly progressive disease as contrasted to the more expressive and bizarre personalities of longer term patients."⁴¹ Bacon and his colleagues found that the typical breast cancer patient is incapable of outward expression of anger and aggressiveness.⁴² The emotional characteristics correlated with a worsening malignancy were depression, denial, repression, regression, defensiveness, and rigidity of beliefs. The emotional characteristics correlated with good

course, on the other hand, have included emotional resiliency, physical activity, flexibility of beliefs, a strong self-concept, and social autonomy.⁴³

Dafter stresses the need to express the whole range of feelings, not just the “bad” ones.⁴⁴ Others have said that the *expression* of *negative* emotions is associated with long-term survival of cancer. Patients who survive longer appear more able to externalize negative feelings and the underlying conflicts that give rise to them. Patients who die sooner are distinctly less able to communicate their dysphoric feelings, especially anger and hostility.^{45,46}

Willingness and ability to change are key to survival. In 1979 Rogentine and colleagues followed patients with Stage II malignant melanomas from immediately after surgery for the following 12 months.⁴⁷ They found that one of the two predictors of cancer recurrence was the patient’s own rating of how much he or she needed to adjust in order to cope with illness. Patients who did not suffer a recurrence within the first year after surgery were the ones who had registered a high adjustment score.

In the same year, Greer and associates showed that the breast cancer patients with recurrence-free survival after 5 years were those who used denial to cope with their illness or manifested a fighting spirit.⁴⁸ The psychological response that characterized patients with recurrence was stoic acceptance or a sense of hopelessness and helplessness.

Relationships. Data from large, well-controlled epidemiological studies suggest that lack of relationships is a major risk factor in disease, rivaling smoking, hypertension, high levels of blood lipids, obesity, and physical inactivity.⁴⁹ Earlier research showed that long-time cancer survivors tend to have closer, personal relationships than short-term survivors.⁵⁰

Clearly, close personal relationships are a key to survival. Married people have been shown to live longer and have a lower mortality from almost every major cause of death than people who are single, separated, widowed, or divorced.⁵¹ In particular, unmarried people are less likely to survive cancer.⁵² For a long time it has been known that they are also less likely to survive tuberculosis.⁵³ It has also been shown that less socially integrated people are more likely to commit suicide⁵⁴ and more likely to have an accident.⁵⁵

Studies have shown that social support is a buffer or moderator of life stress.^{56,57} The vulnerability of the individual under stress may be reduced if he or she receives social support in mastering the stressful situation.⁵⁸ Studies also show that social support has an effect on psychological well-being regardless of levels of stress.^{59,60}

Social relations may affect health by fostering a sense of meaning or coherence that promotes health. One study suggests that long-term social support may be more important for the chronically ill than emergency resources.⁶¹ A social support system provides the individual with a social identity and reduces his or her sense of isolation when others are found who are struggling with the same experiences.³⁵ Social contact can provide

opportunities to exchange information, obtain reassurance, and reduce the feelings of loneliness and isolation. Information is often more readily received from casual acquaintances than from family, relatives, and close friends.⁶²

The prevailing medical model. Unfortunately, patients who express negative emotions or reach out for support may be perceived by their physicians as unhappy, anxious, and less well-adjusted to their illness. Bell writes that “modern medical practitioners have clung tenaciously to the science of medicine while limiting the art of medicine to communication skills and bedside manner” (p. 482).⁷ Patients with life-threatening illness must be given permission to express their deepest concerns and fears of death, mutilation, pain, helplessness, and dependency. The separation of medicine and the person is a phenomenon limited primarily to the past two centuries. By the mid 19th century, researchers were primed by the Cartesian division of spirit and body to regard medicine and the scientific method as independent from the experience of the person.⁶³

In the past three decades, however, general systems theory has brought scientists to a much more complex understanding of the human body. In 1977, George Engel introduced a “biopsychosocial model” of health and illness.⁶⁴ Unless the physician addresses the psychological and social aspects of an illness, the patient will not heal fully.^{65,66} Chase Kimball elaborated on this further in his book *The Biopsychosocial Approach to the Patient*.⁶⁷ Both writers tried to integrate the various dimensions of personhood, which includes the transcendent dimension. One neglected aspect of psychosocial support is simply listening and acknowledging. Nouwen writes that “the basic meaning of ‘care’ is to grieve, to experience sorrow, to cry out with.”⁶⁸

Theologians have also begun to see the ill person as a multidimensional unity. Barnard has discussed the work of Paul Tillich, who saw the person as a psychological, social, and spiritual being in addition to his or her identity as a physical being.² Tillich wrote: “To speak only of physical health misses what is distinctly *human* about human beings, which is this indissoluble unity of several dimensions of existence.” Thus, to focus on just the physical is to constrict artificially the range of professional concern.

Importance of Groups in Treatment

Groups can offer an arena in which concerns in the spiritual, emotional, and relational areas are aired and openly discussed.^{30,69} Jacobs and colleagues cite the topics most often discussed: treatment side effects, impact of disease/illness on work life, coping, problems with self-esteem, and family and interpersonal relationships.⁷⁰ Berger also states the need for family support as illness threatens to take over the lives of both patient and family.⁷¹

Some physicians balk at the use of group support for patients with life-threatening illness: “Will it be good for my patient to sit around thinking morbid thoughts with other gravely ill patients?” Spiegel and Glafkides, after years of providing supportive-expressive groups for women with breast cancer, state that confrontation with dying becomes an occasion for mastery and problem-solving rather than demoralization.⁷² The group serves as a place

where death can become detoxified and patients find models for effective coping, learn to interact better with physicians, work out family issues, and focus on living life fully in the face of death.²⁹ Exposure to other physically deteriorating patients stimulates discussion of death issues without increasing negative affect. The group provides a solution to the pervasive fear of non-being by functioning as a community where memories of those who died can be mourned, preserved, and cherished.⁷³

One study found that individual psychosocial interventions are ineffective.⁷⁴ Adams discusses the advantages of group therapy over individual therapy.⁷⁵ The members of a group, he says, can provide models of successful coping to each other, thereby bolstering their own sense of self-worth and combating feelings of powerlessness and uselessness by helping one another.

Many studies use group therapy sessions as a venue to teach coping skills to patients with life-threatening illness. Spiegel and his colleagues, whose work was important in the development of our own project, facilitated groups for women with metastatic breast cancer more than 20 years ago. The groups allowed the women to teach each other coping skills particular to their shared illness and its symptoms. Open confrontation with death allowed some of the patients to enter into a richer mode of living. They were enabled to assume a sense of control over their lives, to communicate more widely with friends and relatives, and to live entirely in the present, without regrets for the past or anxiety over the future.^{57,76,77}

Telch and Telch took a heterogeneous sample of cancer patients and administered a group intervention that included instruction in affective, cognitive, and behavioral coping strategies.⁷⁸ This included modules on stress management and relaxation, communication and assertiveness, and constructive thinking and problem-solving. Although all of the patients showed a high degree of psychological distress at baseline, those who received the instruction in coping strategies showed on completion of the intervention significantly lower depression, tension, fatigue, anger, and confusion. Those who received the instruction also scored higher than those who merely went to a supportive group.

Fawzy and his associates^{79,80,81} have also looked at group effects on disease. One study⁶⁴ examined the immediate and long-term effects on psychological distress of 6 weeks of structured group therapy for post-surgical patients with malignant melanoma. The groups were designed to enhance problem-solving skills and stress management in addition to providing psychological support. At baseline, most of the patients, despite good prognoses, evidenced high levels of psychological distress. After the intervention, however, the 38 subjects showed some distress but much higher vigor and use of active coping skills than the 28 controls. The differences between the two groups were even more pronounced at 6 months. The intervention group manifested significantly lower depression, fatigue, confusion, and total mood disturbance. The group allowed patients to better understand their illness, to talk to others to gain information and support, and to become increasingly involved in their own care.

Our approach to groups. The uniqueness of our program is the inclusion of the spiritual dimension in addition to the psychological and social dimensions of the patient, in full knowledge of the prevailing medical model with respect to psychosocial care. Such a multidisciplinary approach is necessary for the complete healing of the patient, without losing sight of the logistic realities of modern medicine.

The Role and Needs of the Caregiver

Numerous studies look at the effects of caregiving on the person who looks after a patient suffering from dementia or life-threatening illness. Kiecolt-Glaser calls the profound effects on caregivers' lives a "living bereavement."⁸² Kiecolt-Glaser's research showed that in the 13 months between initial intake and later follow-up, spousal caregivers spent significantly greater time fighting infectious disease, especially of the upper respiratory tract, and made more visits to the doctor than an equal number of sociodemographically-matched controls. Those caregivers who reported low levels of social support at intake evidenced the most uniformly negative changes in immune function at follow-up. There was also a much greater incidence of depressive disorders among caregivers. In other research, Kiecolt-Glaser examined the effects of chronic stress on immunosuppression and found that caregivers appear to be more distressed and have weaker immune function than matched controls.⁸³ Family caregivers of more impaired patients tended to have fewer social contacts and greater depression and loneliness.

Rabins and colleagues found that 87% of caregivers suffered from chronic fatigue, anger, and depression; 56% were embroiled in family conflict, including arguments about who should care for the patient; 55% complained that they had no time for themselves, had lost friends, and given up hobbies because of the demands of caregiving; 31 % of caregivers feared for their own health; 29% reported having difficulty assuming new roles and responsibilities; and 25% experienced a sense of guilt.⁸⁴ Only 7% of caregivers had no complaints at all.

Esterling and colleagues found that both current and former caregivers experience significantly more depression and stress than controls, demonstrating that the physiological and psychological consequences of chronic stressors persist well beyond the cessation of the actual stressor.⁸⁵ Data show that caregivers' depressive symptoms do not change significantly after the death of the patient, continuing an average of two years longer. The longer the stressor has continued, the longer the resulting disturbance after the patient has died because recollections of the patient or of the caregiving are sufficient to sustain chronic stress after the actual caregiving ends. Esterling and his associates also found that caregivers who ruminate on their caregiving become more depressed and perceive more stress after the patient's death than caregivers who do not.

Various psychosocial interventions have been designed to address the needs of the caregiver. For example, the Center for Family Research at George Washington University Medical Center has run support groups for family caregivers in addition to support groups for patients experiencing the chronic phase of a disabling medical illness.⁸⁶ Smith and

Maher's caregiver support groups met weekly for 5 weeks after the death of the patient, allowing for a period of mourning followed by efforts to disengage caregivers and revitalize their lives.⁸⁷ Providing support for families of patients with life-threatening illness is undeniably important. Johnson and Stark write: "Family involvement is a crucial variable in how well a patient does physically and emotionally."⁸⁸ Moreover, it is good for the family itself. Chronic illness can upset the family in a number of ways, but often the family's needs go unexpressed and unvalidated.

Our approach to caregivers. In our program patients and family meet together in the same group. Concern is sometimes expressed, particularly by physicians, that putting patient and family in the same group may prove to be stressful for both. However, the combination of patient and family gives both a broader network of support and relief from the isolation and loneliness that occur so often with life-threatening illness. Finding that there are other patients and families sharing similar feelings and perspectives can dilute the self-criticism and guilt that come to caregivers believing that only they are inadequate and harboring negative feelings. The focus of the mixed group is on shared problems and on the positive and productive aspects of family coping. Duhatschek-Krause reports that when she suggested dividing families and patients into two groups for just a portion of a meeting, one man said that he and his wife would leave.⁸⁹ The group then voted unanimously to keep patients and families together. The only problem that we have experienced in this area is that less than half of our patients claim to have a family caregiver or a friend who is able to meet with the group. The majority of patients have attended the groups alone.

Special Needs of African American Patients and their Families

In our program, we divided the groups ethnically to see whether African American patients and families have special needs that are not being met in mixed groups. Literature suggests that the effectiveness of the small group is dependent, in part, on the racial composition of the group with respect to both participants and group facilitators.⁹⁰ Davis and colleagues have shown that perceptions of group atmosphere, success, and cooperation, in addition to participant feelings of satisfaction and enjoyment, are affected by the racial composition of the group. They concluded that mixed race groups (half African American and half Caucasian) were most at risk for conflict.⁹¹ Underlying this race effect on group process are, in part, issues that reflect racial conflict in society (e.g., stereotyping and segregation). Equally relevant, however, are sociocultural experiences that differ as a function of race and dictate norms for interpersonal style, emotional expression, psychosocial needs, and boundaries.^{92,93} The interaction of the race of the group facilitator with these sociocultural issues is also important. Research suggests that members of groups with same-race facilitators have a more positive experience and feel that the group is better able to meet their needs.⁹⁴

Impact of Groups

Spiegel and Yalom report a number of ways that their groups for women with metastasized breast cancer have had a positive impact.⁷⁸ Patients demonstrate a greater sense of meaning. They become “experts on living” who believe that they have something to teach. They want to influence the medical profession by changing physician attitudes toward patients with metastasized breast cancer. They want other women to know that a diagnosis of breast cancer does not mean death, but rather the beginning of “a different kind of life.” Death, in short, becomes “detoxified,” and patients are less apt to resort to denial as a way of coping. The groups also provided support to patients as they learned to communicate effectively with physicians and to insist on being part of the decision-making process.

Implementation of Change in Medical Practice

The SUPPORT project mentioned in Chapter 1 documented many deficiencies in end-of-life care for critically-ill hospitalized patients, including poor communication, delayed institution of do-not-resuscitate (DNR) status, excessive use of ICU care, and poor pain control. Physician behavior, however, has been difficult to change. No single approach has proven either its superiority over other approaches or its effectiveness in multiple sites and situations.⁹⁵ Davis and colleagues reviewed the literature on the effectiveness of continuing medical education (CME) and concluded that the only time it seemed to influence physician behavior in any sustained manner was when it was combined with incentives for change and organizational “facilitators.”⁹⁶ Several studies have shown that physician behavior can be changed and that change maintained through use of CQI methodology once the involved medical technology is understood and the main issue is appropriate performance.^{97,98,99}

Grol reports that at least 15 to 20 systematic literature reviews of interventions designed to change practicing physician behavior have been published since 1991.⁹⁵ These reviews have involved hundreds of different trials and many different intervention strategies. Overall, the results have been inconclusive: Interventions that were effective in one study were ineffective in others, and many interesting interventions have yet to be properly studied. Grol concluded that there is probably no one intervention that works all the time, and that successful change depends on good planning and implementation of a variety of interventions. The question becomes when to apply different types of interventions and how to link them effectively.

We believe that our program will ultimately help physicians and other clinicians to respond better to patients’ spiritual, emotional, and relational needs. In the early stages we cooperated with physicians to develop a program that suited the needs of their patients. We have tested the efficacy of this program and intend to use this manual to disseminate the intervention to physician practices at other locations.

CHAPTER 3

Clientele

Whom to Include

We recommend including patients (and their family caregivers, when appropriate) who are ready to address issues related to end of life in realistic and personal terms. Likelihood of responding to a group support mechanism is another obvious criterion for participation. The patients may or may not actually have a “life threatening *illness*” as defined by either their physicians or by themselves. Note, however, that they do need to be far enough along in their willingness to consider the issues that, with the support and encouragement available in the groups, they will address these issues with serious intent.

The reasons for this advice are as follows. At the beginning of our project, we sought to recruit patients with “life threatening *illness*” into the groups. In operational terms, we asked attending physicians or their staff to refer patients who were expected to live at least 6 months but the referring clinician would not be surprised if the patient died within two years. This approach caused a great deal of difficulty along several lines. First, many physicians resisted for a number of reasons, including their difficulty in identifying patients who might die within two years and the number of patients who would likely benefit from the program but were expected to live considerably longer than two years. In addition, many of them felt that their patients would be shocked to hear that their disease actually threatened their lives. Many others were concerned that their patients would dwell excessively on their medical condition and feared that they might “give up hope and give up trying” if they had to face such a dire possibility. As one physician angrily replied, “*You* don’t tell my patients that they have a life-threatening condition; *I* do.” He then went on to explain that, after indicating to a patient that the condition is life-threatening, the *immediate* next step is to help the patient die gracefully and peacefully without further use of life-sustaining measures.

Patients and their families agreed with some (but not all) of the physicians’ concerns. For example, many patients from the geriatric clinic faced advanced age, a heavy burden of illness, and a limited life-expectancy that they themselves recognized but nevertheless vigorously asserted that they did not have any life-threatening “*illness*” *per se*. Still, they were interested in joining the program, and would admit to having “serious medical condition.” A number of other patients had life expectancies of at least five years but were very interested in participating.

This approach to “life-threatening conditions” has served us well. We are recruiting patients who want to be in the program and appear to be benefiting greatly from their involvement. We may change our minds later on, and surely each service will want to evaluate its local environment and make up its own mind on whom to include. Nevertheless, this is our best advice presently.

With respect to formal exclusion criteria for suitability for groups, there are few. The most important issue suggested by our pilot work is that patients with personality disorders (particularly the narcissistic-borderline-histrionic cluster) or psychotic disorders be excluded. These patients have limited or distorted reality testing and may be very difficult to manage in a group setting. Their presence is also likely to impair group cohesion and discourage other members from participating.

What to Separate, What to Combine

Medical conditions. We had originally planned to divide the groups into five or six separate categories based on health condition: heart, lung, cancer, geriatric, and HIV/AIDS, and “other” if needed. Our experience developing groups quickly confirmed the separation of geriatric and HIV groups from the organ-based diseases (denoted “disease patients” hereafter) and from each other. During the pilot group process, geriatric and disease patients were mixed together. It soon became clear that the geriatric patients had a much different perspective on their situation than did the disease patients. The disease patients often were angry at their disease, whereas the geriatric group generally lacked a specific focus for directing anger. The geriatric patients generally had been facing and adapting to personal decline over a number of years. On the other hand, when the disease patients experienced decline in their functioning that might, for example, require reversal of roles in the family, this usually happened over a relatively brief period. While one might think that the disease group might learn from the geriatric patients in this regard, this disjunction proved difficult to manage and disrupted group cohesion and progress. As expected, the HIV patients need to meet separately not only for issues of confidentiality but also because they faced potent issues that the other groups did not.

We did find, however, that the different organ-based disease patients were able to meet together and share experiences and support effectively. Therefore, we ended up with three groups: geriatric, “disease,” and HIV. This separation has been working very effectively for us.

Our outcome data from the project confirmed our subjective interpretations of the importance of medical condition. With respect to their responsiveness, our three major divisions—organ-based diseases (cardiac, pulmonary, cancer); HIV/AIDS; and geriatric—were important. Within the disease group, there were three sub-categories: (1) those with their first serious organ-based illness with an uncertain prognosis; (2) those with chronic illness that is being managed or is in remission; (3) those experiencing their final illness, from which they will die in a known amount of time. The curriculum appeared most applicable to the disease groups, particularly for patients in sub-categories one and two. The HIV/AIDS patients were mostly HIV positive without full-blown AIDS, living relatively normal lives. They were also significantly younger than the disease group, by about 16 years (although disease duration was comparable). They were also more likely to be men, less likely to be married, and less likely to be religious than patients in the other groups. As a consequence, the HIV/AIDS group had some difficulty committing to the group and engaging in the curriculum.

Although the geriatric group was quite comparable to the disease group with respect to gender and other demographics, they were nearly 25 years older, on average. Most importantly, while many of them were multiply compromised (which, when combined with their advanced age, made death imminent), few had a specific disease to which they could point to as an immediate threat to their life. The issues of the geriatric patients were not those of the younger patients. The best way we found to conceptualize the older patients was that they were searching for a way to grow old with the awareness that the body will inevitably decline and fail. They were not facing the loss of half of their projected life expectancy and their families were not facing the loss of an essential provider or parent. Our older patients were also much more clear with respect to their religiousness and relationship to God. These differences are critical regarding responses to the curriculum. Although our older patients enjoyed and appreciated the groups, they did not appear to be as likely to change with respect to their spiritual or emotional selves. In time, a separate curriculum for older patients with non-specific but deteriorating health conditions may be developed.

Ethnic background. As a stipulation of receiving grant funding, we were asked to try to adapt the program so that it worked for minorities as well as for Caucasians. In the St. Louis metropolitan area, there are only two racial/ethnic groups of enough size to speak to this issue with any scientific rigor, that is, African Americans and Caucasians. We were aware of the literature on race and different types of groups, as reviewed in Chapter 2. Although there is considerable cultural diversity within the African American community,¹⁰⁰ we realized that minority persons report more beneficial experiences when participating in groups with homogeneous racial/ethnic composition and same-race facilitators.^{91,94} As Salvendy phrased it, “The culturally determined contrasts in perception, attitude, communication, and behavior, which minority members may exhibit in the group” can affect group processes in very significant ways.¹⁰¹

Our own experiences so far have been mixed on the racial/ethnic issue. On the one hand, some African American patients were irate when they learned they would be “segregated” from the Caucasians, apparently fearing that they would receive an inferior service. On the other hand, a number of African American patients were grateful for this approach. One woman said something like the following: “It’s a relief if I don’t have to deal with a number of issues that come up in mixed groups. For example, if I sit with the other blacks, the whites think we’re being exclusive. On the other hand, if I sit with the whites, the blacks may feel that I am unsympathetic to their issues and concerns. It’s hard enough to deal with the main issues of disease without having to deal with all these other issues at the same time.” Our African American group leaders also have noted that the African American patients have been able to open up and share in ways that *may* have been difficult in a mixed group. On the other hand, these group leaders believe that we just do not know for sure at this time.

Smaller institutions with fewer patients may not have the luxury of creating several groups, but an awareness of these considerations and potential impediments should facilitate the formation of groups, regardless of the size of the institution. One alternative might be to

offer groups only for the most populous patient group, whether it be geriatric, organ-based disease, or HIV patients. If other programs find ways to effectively manage these issues, we would very much like to hear about their successes so that we can pass their insights along to other people starting programs in similar situations.

Our recommendation at this point regarding ethnic background is that if race-specific groups can be formed at a given site, they should be considered. This would include race-matched facilitators. They are not required, however. If mixed-race groups are formed, it is imperative that facilitators be attuned to the experiences of whatever ethnicity is in the minority. In our work, the African American facilitators all saw positive benefits of their race-specific groups.

Spirituality and religious preference. Our group program has been designed to meet the needs of patients from many different religious backgrounds and also for patients who do not participate in an organized religion. Spirituality is nearly universal among human beings. The experience of a life-threatening condition or the process of aging causes people to face the end of life and evokes spiritual issues that may not have been addressed previously. By spirituality, we refer to a personally-embraced construct for explaining and responding to the mysteries of life such as the meaning of existence, illness, suffering, pain, and death. This construct may or may not be incorporated within a formal, organized religion.

From the very beginning, our group facilitators (all but one of whom are chaplains) have been aware of this issue and treated it with sensitivity and inclusiveness. In addition, most of our subjects are Christians of various denominations. For these reasons, providing an environment that welcomes and supports different religions and spiritual expressions has not been a problem for us to date, but we remain vigilant to identify and respond to issues if they arise. Our groups leaders have identified one phenomenon related to spirituality and religions, however. Some patients appear to use religious statements and mantras as a form of “veneer” that covers over their fears. Our process is not to confront this “veneer” issue directly but rather to provide a supportive environment in which they can, over time, face and manage their fears. At that time, their religious mantras may take on new meaning for them or they may find different spiritual constructs. Whether they keep old methods or adopt new ones is less important than that they have the supportive environment in which to tackle these inherently difficult and personally challenging tasks.

Comments on Recruitment and Retention

Recruitment was a significant challenge for this program. We found that avoidance of the “D” issue (death) is alive and well in US medicine, as least in our institution. This is true not only among health care providers but also frequently among patients and families as well. Although we were aware of these issues from the literature, the depth and resilience of this resistance did catch us by some surprise. On the other hand, death avoidance was not universal, and we did encounter a good many supportive clinicians and willing patients and families.

The most important ingredient for successful recruitment was the presence of a person, preferable a clinician (e.g., a physician, nurse practitioner, or physician assistant) who was *committed to both the concept and the accomplishment* of the program. We also sat in doctors' offices waiting for referrals, distributed our brightly colored pamphlets, and sent letters from physicians to their patients who were appropriate for the service. However, these strategies did not work well at all unless the referring clinician was committed to the concept and the reality of the program. Given this commitment, however, these specific recruitment strategies were helpful. As always, availability to respond quickly to all referrals is an essential ingredient to a successful recruitment strategy.

Both group and self-reliant participants received a coffee cup with one of the program's logos on it, as well as a number of "HUG" cards which they were told legitimized their request for a "Healing Uplifting Gift" from other participating human beings. Group members also received a tote bag in which to carry a journal, also identified by our logo. Whether these items helped retain patients in the two arms of the project, we cannot say, but they probably did not hurt. We will have more to say about retention as we go further along in delivering our program.

CHAPTER 4

Group Process

Group Interaction

The material on group process in Spiegel's manuals is well worth reading.^{102,103,104} In particular, what he and his colleagues have written on group process and topics of conversation will add a great deal to your sense of comfort in leading the group and your store of knowledge regarding the topics of importance in coming to terms with life-threatening conditions. The section called "Specific Examples of Counseling Tools" is useful to read in its entirety. Some of the process points are brought out very clearly in an interview conducted and reported by Bill Moyers.¹⁰⁵ They are summarized below:

- Caring for the patients is the single most important part of the group leader's responsibility. How to communicate that caring is the most important task.
- In working the process of the group, keep the group talking about what is happening in the present—within the group and in their lives. Too much discussion about past events or the problems that others present becomes superficial discussion. Bring out feelings as much as possible.
- Emotional expression can be facilitated by commenting on the feelings you hear in the comments of the member and those you see and hear in the responses of others in the group. Solicit reactions from one person to another. Bring out the ways in which one person's experience relates to that of another.
- Reinforce important aspects of any comments by reflecting on them. You can feel free to bring out one aspect of the comment at the expense of other aspects. Listen also for the message that is only hinted at, or what is not said.
- Encourage the group by noticing when a member is more "real" and less defended. Comment on the best in the group's interaction that day.
- Listen for and recognize the resources within each person, in the group, and in the members' respective social circles. Especially listen for and bring out their existing communication and coping skills. Do not be afraid to comment if one member is monopolizing, intellectualizing, or otherwise impeding the group's ability to work. You can comment in ways that encourage and do not shame the person.
- Allow for differing views between the patient and support person. Treat differences as natural and expected. Differences provide the opportunity to "break up the turf" and plant anew.

- In dealing with the general topic of the life-changing confrontation with serious illness, listen for particular topics. Listen especially for grieving. Explore what it means to grieve real losses.
- Each group should attend to the following question in some way: “How will you remember each other until we meet next time?”

Additional input on groups is available in an article by Louis E. LaGrand.²⁷ Some points are worth re-iterating:

- Confidentiality is expected.
- Love is the healing agent.
- Groups are characterized by acceptance.
- There is no pressure to speak.
- Sorrow is expected, recognized, and accepted. So is anger.
- Hope is the outgrowth of sharing and caring. Joy and peace are expected, recognized and accepted.
- Reading materials are suggested.
- Journaling is not just a way of thinking about the content of the group. It is also a way of remembering the people in the group throughout the month.

The Nature of Our Groups

Our groups are also different in important ways from the groups that Spiegel describes. Whereas his groups are a variant of group psychotherapy (supportive-expressive group therapy), the groups in this series are better considered as *adult affective education*. The facilitator offers subject material, but lets the group members deal with it in their own unique way. The groups deal with life issues and encourage sharing of experience.

The group facilitators are not expected to be psychotherapists. Rather, they are sensitive educators. Although many of the techniques used in facilitating the group are recognizable as counseling tools, it is also quite appropriate for group facilitators to share their own stories as might be helpful for the group and comfortable for the facilitator. These stories should not be presented as normative for the group, of course, but they often add a sense of communality that is reassuring to the members. Many of our facilitators were trained chaplains, but this form of training is not mandatory either. The facilitator functions as “mediator, mobilizer, and enabler.”⁷

The goal of the series is that each member will come away with a greater sense of hope, courage, and social connection. The process relies heavily on discussing experiences, expressing feelings and sharing support. Because the goal is to help individuals, the sequence of topics and the structure suggested for each group are meant to be flexibly applied.

The Dynamics

There is a rhythm or dynamic to the overall series. The initial sessions are concerned with forming group cohesion. The content of the first group is simply about groups in general and supportive-affective groups in particular. The next several groups cover basic skills of assertive communication, working with feelings, and managing symptoms. The topics are meant to be less emotionally threatening so that the group can learn to work together with trust.

From there, the topics are selected to open the important and more touching subject of relationship. Members next address connections with important others, including perhaps their caregiver. In the following group, members consider the spiritual and religious supports or conflicts in their lives. Ultimately, this subject is also about relationship, not only with others in their faith community but with God as well, by whatever name the individual members have come to know this Mystery.

It is only then that the prescribed topics turn directly to the subject of dying and death. The group members, of course, will have been talking about death in many ways in the previous sessions. However, in these last four sessions they are invited to focus on this reality of their lives. The last session, in particular, is a reflection on what it all means, including what being in this group has meant.

Although the topics are presented in a sequence, the material will be coming up in no particular order in the evolution of each group. Listen for it, work with it as it comes up, and then refer to the previous discussions when you hit that subject formally in the plan. The material is nothing more than a structure or skeleton around which to form the living material of each group.

There is a similar dynamic to each group. The group begins with the facilitator calling the members to be present to each other. That might be done with a reading or with silence or in some other way. Then the members are asked to bring each other up-to-date with what is happening in each household. The time given for this “check-in” must be adjusted based on the number of persons present. Remind the group of the time available and gently but firmly move along the check-in process. The next focus might be some reflection on what stuck with each member from last session. You might refer to your closing remarks at the last group. This again should be brief, and not everyone need speak. However, be alert for important material. Some persons do not come up with their most important ideas until they have had much personal reflection time. Then move to the topic of the present group. Ask if members have thought about the subject, using the reflection points you offered at

the end of the last session. Move into your own brief presentation on the material. The material is presented in a conversational style so that the members are participating in the material from the beginning. As the time for ending the group approaches, the facilitator again takes the lead and offers a summary of what he or she has heard the group saying, then offers a few thoughts to help the group begin to consider the next month's topic. The facilitator might suggest a few key items that the group members might use to help them think further about the material discussed that day, and one or two questions to help focus them on the subject of the next group. Suggest that members put these questions in their journal, on the refrigerator door, or somewhere else where they might see the questions daily.

Because the groups are run in this interactive style, each particular combination of persons will produce interaction and insights that are unique. Each series will be a little different in nature; you might say each group will have a "life of its own." As you start a new group, be awake to that unique life, and facilitate its development. Let the group members coalesce as they will, coming to be most authentically themselves. The elder groups may be different from the acutely ill groups by virtue of their relationship with illness. The acutely ill, regardless of age, will be in a focused relationship with their illness. The elder group members will be dealing with the general issues of aging. The groups will come to terms with death in their own way. For the acutely ill, it is now clearly on the radar screen. The elder group members may not yet be willing to face death in more than an oblique posture. All will be seeking to balance awareness of death with greater awareness of life. It is a time to really live, perhaps with greater intensity than ever before.

Although the structure of each group is more or less the same, *never fear to depart from the planned outline*, if that seems to be indicated. Good reasons for abandoning plans may be very obvious, like the death of a member. They may be subtler, embedded in the unique twist that the conversation has taken. You are not only permitted but may be required to make changes in the sequence or focus of each topic. As group facilitator, the fate of the group may depend on your ability to respond to its needs. (However, be sure that the diversion is not avoidance. Do allow for creative tension between the desire to be flexible and the desire to adhere to the overall plan of the session and series.)

If the group is leaving a topic, ask yourself or them if the material is too challenging in some way. Be especially careful of subtle avoidance embedded in the way a subject is handled. Intellectualization of a subject is common, but any number of otherwise useful responses can be exaggerated and used as a way of not coming to terms with another member's reactions.

Whatever the topic, listen for themes that run through a particular group's experience. Themes of fear and loneliness are common, for example. As they emerge, connect them to the particular topic of the day. The more you can interweave such recurring themes with the particular topic, rather than either forgetting the topic or interrupting the natural conversational flow, the better for the group's sense of ownership and competence.

Perhaps the most important issue with respect to the group dynamic is that process is more important than content. This is not to say that the content is meaningless. On the contrary, it is necessary, but not sufficient. What is most important are the bonding and commitment that develop within the group. Without those feelings, the content topics of the curriculum become just conversation. The curriculum is a vehicle or structure that carries the group members to the feeling that they are important and meaningful, to themselves and the group. What characterizes these patients best is the notion that they are now the members of a club who have experienced first hand the reality of death, and they can never “get back to normal” because of it (except by denial). This experience can engender fear, despair, and isolation, but it need not. The group allows the person to know that they still mean something despite their experience with death, and it does this with the help of others who have had the same experience. As a result, “content” becomes a vehicle for “process,” wherein lies the healing.

The Facilitator

At a minimum, facilitators should:

- have a basic understanding of group process;
- have some experience in leading or managing groups;
- have some experience with sick or dying people;
- be comfortable with *facilitating* rather than *directing* the groups;
- be adaptive and flexible;
- be open to feedback;
- recognize that the group process is imperfect and not everyone will benefit;
- be able and willing to actively and consistently validate strong feelings among the participants;
- be comfortable with his or her own spirituality, emotions, and relationships, especially with respect to health issues;
- be willing to honor all opinions and experiences of the group members, particularly around issues of religious denomination, images of God, and beliefs.

Training. Facilitators do not require formal training. They should, however, be very familiar with this manual and the curriculum. It is particularly helpful to have a group of facilitators in which experience leading the groups can be shared, preferably on an on-going basis. This type of “peer supervision” is a support and a safeguard against doing

harm inadvertently. It is also very helpful for the facilitators to have a model group experience. This need not entail the entire curriculum. However, facilitators who experience the group dynamic from the perspective of a participant (for at least one group), will be more sensitive to what is required of their group members.

We have found that group leaders who are in touch with and comfortable with their own spirituality feel more confident as facilitators. Spiritual issues permeate the group sessions, and the leader is often required to actively validate strong feelings around this issue. The group leader who is unsure or defensive about their own spiritual views may have difficulty in this process. It is probably best to evaluate this prior to beginning any groups.

With respect to on-going feedback regarding facilitator performance, it will often be helpful to create a self-reflection sheet for group leaders to use after every group session. This sheet would contain questions like:

- How was I feeling in the moments after the group ended?
- What seemed to happen in the group?
- How did the group members appear to respond? Were they engaged in the material and with each other?
- Did the group match my expectations? Those of the members?
- How do I feel about how I handled the group? What would I do differently?
- Did the members depart on good terms? Was there any unfinished business?
- Was sharing in the group possible? Did members validate each other?

Standardization of the role. The facilitator must be simultaneously friendly, non-threatening, and authoritative. If it is not obvious that the facilitator is in charge, the members will be uncomfortable. A successful group, especially at the beginning, requires evidence of a strong facilitator who is clearly in charge. Geographically, the facilitator should occupy a central position that demonstrates that he or she is the facilitator and has final authority on group process.

Facilitators should be perceived during the process as authoritative but safe people with whom one can be intimate and familiar. The facilitator's attitude should always be one of "these are my people; I am responsible to shepherd these people; I must demonstrate that I can be trusted; I must instill confidence in the group members." The unifying concept for all of the facilitator's behavior should be: "I am modeling 'To Love Well Is to Live Forever' for the members.

Throughout the group experience, the facilitator should use language that is comfortable to him or her, and then explain what it means and gauge the members' reactions. Words like "intimacy" may generate reactions in the members. Facilitators should be attuned to possible misinterpretations of what is said. Always explain what is meant and solicit feedback based on how the word or issue is defined. Facilitators should reflect back key elements of what members say. Facilitators should try not to press for personal revelations from members in the beginning, but encourage an interactive process. The facilitator's comments should shape a sense of intimacy in the group, but not too intimate at first. Interactivity is paramount.

At the end of the sessions, the facilitator should:

- Summarize each of the main points that have been addressed and the feelings and issues of the group regarding each point.
- Present the topic for the next meeting and talk with group members about their journaling tasks in anticipation of the next meeting. Discuss the purpose of the next topic.
- Confirm the date, time, and meeting place of the next meeting.
- Conclude with a "wrap-up" sentence that validates the group experience and leaves the members with a positive feeling at the end.

Dangerous territory. It is very important for the facilitator to realize the limitations of his or her role, training, and responsibilities. These group sessions are not meant to be group psychotherapy but, rather, *affective education*. Their pace and level of expression should be largely determined by the members and not pushed by the facilitator. It is very important for facilitators to have some awareness and knowledge of when a particular group member is in crisis, a danger to himself or herself, a danger to other group members, or in need of a more intensive intervention by a trained mental health professional. *This issue cannot be underestimated.* The power in the hands of the facilitator can be very great if he or she chooses to command it. But without the proper training, this is the road to disaster. The facilitator should resist attempts to "analyze" patients, probe issues of the unconscious, recover memories, make suggestions for life changes, tell patients what they "should" do or think, or criticize the patients in any way relating to their emotions or psyche. The facilitator is not the "expert," only a mechanism to promote self-healing and self-awareness.

Another area of potential danger is that of religious denomination. When people of different faiths with different religious experiences and beliefs come together, exchanges among group members may take on a renewed intensity. Without consistent and strong validation of *all* beliefs by the facilitator, such exchanges can tear a group apart. In addition, particularly devout group members may resent the facilitator for considering other avenues toward health *besides* the spiritual. Some group members will be very "religious" in the traditional sense, without appearing at all "spiritual." The opposite may

be true for others. Some may be very angry and rebellious with respect to religion. Others blindly accepting. The effective facilitator will be aware of these possibilities and remind the group of the larger needs that they are all considering—connection, meaning, hope, love—in addition to allowing the safe expression of any and all matters of faith.

Flexibility: Curriculum, Number of Groups, Frequency of Meeting, Caregivers

Although the structure of each group is more or less the same, never fear to depart from the planned outline, if that seems to be indicated. Keep in mind the main goal of each session, and make it your purpose to achieve that goal in the manner best suited to the size and composition of the group. Group discussion plans should always be adapted in this way.

In some cases there may be good reasons for abandoning the plan altogether. For example, the death of a member (see Chapter 6) may change everything. However, be sure that diversion is not avoidance. Do allow for creative tension between the desire to be flexible and the desire to adhere to the overall plan of the session and series. If the group is leaving a topic, ask yourself or them if the material is too challenging in some way. Be especially careful of subtle avoidance embedded in the way a subject is handled.

The group discussion plans are laid out as twelve monthly sessions. The twelve sessions can just as easily be delivered within a shorter time span by increasing the frequency of group meetings. Groups can be compacted. Groups five and six, groups eight and nine, and groups ten and eleven can be woven together with very little adjustment, reducing the number of plans from twelve to nine. With some further effort, the total can be further reduced, making practical a two or three month, weekly or biweekly commitment. It is also possible to deliver this program in the form of a weekend workshop. In our experience, monthly meetings for nine months (with three topics combined with other sessions) appeared just as effective as monthly meetings for twelve months. What seemed equally clear was that 12 months may not be needed and may be perceived by members and facilitators alike as too drawn out. Thus, a more intensive meeting schedule (e.g., twice per month) would reduce the duration and provide a more concentrated experience.

Some groups may wish to continue beyond the 12-month curriculum. This should be allowed and encouraged. Some groups may have to continue without the facilitator. If this occurs, it is important for the facilitator to identify a group member who can assume the facilitator's role. On the other hand, the dissolution of a group may be even more difficult. A process of disengagement must be considered well before the final group is set to occur. Issues of grieving and “embracing the future” without the group are important to consider. It is the job of the facilitator to anticipate the discontinuation of groups, to be attuned to where each group is with respect to the desire to continue beyond 12 sessions, and to keep the group members aware of their choices in this regard.

Many of our group participants chose not to include a caregiver with them in the experience. Some did not feel free to talk with a caregiver present, others claimed not to have a “caregiver” in the sense of someone who helps and supports them in relation to their

medical condition. Those who were accompanied by a caregiver reported that it was helpful for the caregiver to hear about their needs, fears, and wishes. This experience has taught us that it may be better to define the patient's group partner as a "support person" rather than as a "caregiver." A support person could be anybody who has an interest in the patient's well being, be it family member, friend, or spouse. Also, one alternative to including support persons in all meetings is to have "open" and "closed" meetings. For example, the first six sessions could be patient only, followed by a session that includes support persons. The first six sessions would serve to empower the patients with respect to understanding of and communication about their spiritual, emotional, and relationship needs. This would enable them to more effectively communicate with their support persons at the seventh session.

Further Thoughts on Process

Some of the comments that Spiegel makes in differentiating supportive-expressive group work from psychotherapy are especially applicable to the process of our groups and worth repeating here.

The supportive-affective group series is designed to support the participants' defenses and to allow them to use the resources that exist in themselves and among the other group members, all in the service of adjusting to the changes in life occasioned by the illness. It is not designed to break down defenses or denial. For that reason, probing questions or confrontation are not appropriate for these groups. Content must be meaningful, and members must be allowed and encouraged to share as honestly as possible, but it will more often be the right thing to simply reflect what the person is saying, and to encourage comments from others.

You might consider the image of listening on two channels. On one level, the leader is listening to what the individual is saying at the moment and how others are responding. On another level, the leader must also be listening to the overall flow of the individual and the group. There is an overall theme that will be developing in each person and in each group. If you can hear the theme, it will help you choose what to respond to and how. It is also useful to reflect the more general theme to see if an individual or "the group" will pick up on it. Spiegel speaks of this as attending to the "metaprocess."

Look for opportunities to demonstrate that what is being talked about is being acted out in the group as well. Affirm what is positive so that the group members grow in the sense that they have the skills to face this crisis and the social network to support them in doing so. It is as reasonable to discuss successes of individual group members in dealing with the topic at hand as it is to deal with difficulties; however, in doing so, be sure not to inadvertently shame some group members who are not so successful in that area. Successes should encourage those others, not shame them into silence. Be as accepting of problems as of failure; applaud success while noting how hard the achievement is/was and acknowledging that not everyone in the group will/has been able to do the same.

Beyond the particular content shared, the group interaction itself builds a powerful support network that in itself contributes to quality of life. There is a bias toward living in the present moment, sharing authentically, finding meaning by facing death and life together, and coming to see personal value as deeper than particular accomplishments or reputation. As a facilitator, your focus should be on listening and reflecting the themes as they emerge from the group, as the members listen to and share with each other.

If a member does demonstrate a need for more in-depth work to deal with significant problems, or if the defenses/boundaries of a member are not solid, deal with the situation by gently noting in the session the purpose of the group. Later make arrangements to have the individual see a psychologist for more in-depth work in addition to continuing in the group. Again, issues of this type are illustrated in Spiegel's manual.

Contact Between Groups

It is a positive event if group members have contact with each other between sessions. Group members may wish to create a telephone list. A telephone tree facilitates contact if the group members need to be notified of some event in the life of a particular member.

Facilitators should be careful not to commit to contact with group members between groups. It is reasonable to invite notification of important events, and to be available for emergencies. However, frequent involvement in the lives of all the group members can become burdensome quickly.

It is also important to support yourself by meeting with other facilitators. Develop a small group for peer supervision and emotional processing.

Journals (*Journal questions for each of the sessions are summarized in Appendix 1*)

Journaling is not a popular activity with all members. Many persons see it as a burden. They think of writing in a journal as something akin to homework. Remind the members that the journal is included as a suggestion for helping them be aware of their lives and for remembering events that they can bring to the next group. The regularity of journaling is more important than the quantity or style. A few words summarizing some feeling or event may be enough to fix it in the memory or make it available when the journal is reviewed.

Suggest that the members experiment with ways of doing this work. It is often helpful to make an entry just before sleep, reviewing the day. It is very useful to review the entries once per week, to see patterns that are developing. Certainly, it is helpful to review the journal just before each group meets.

Reflection questions are provided for the members. They may or may not be useful. You may suggest questions of your own to guide the members, incorporating material from the

group just completed and/or preparing their thoughts for the next session. You might ask them to make a few notes about their reaction to the readings that you have invited them to read.

With journaling, be persistent, but be flexible. Members who do not find the journal workable should be encouraged to suggest alternative ways of keeping the last group topic and the next group topic fresh in their minds. Journaling is also a way for group members to keep each other in mind, wishing well to each other in whatever form. Alternatives to journaling as means of reflection are:

- Use journal questions as ice breakers to start groups or as part of group discussion time. Ask a question and allow members to reflect in silence for several minutes. Have them jot down any ideas they have and then invite them to share with the group.
- Use guided meditation during the group session to encourage members to reflect deeply on their feelings. These can be appropriate published meditations or composed by the facilitator to express the unique experiences and outlook of the group. For example, after a simple invitation to relax, “guide” members into their childhood by walking into the house where they grew up. Ask them to choose their favorite room and sit down to talk with the most important person in their early lives. At the end of the meditation, invite members to reflect on the experience and share any insights they have gained with the group.
- Use meaningful readings, for example to open a session, and invite members to reflect and share.

CHAPTER 5

Group Curriculum

Group #1: Getting Started

The purpose of the first group is to help the members feel comfortable. The overall dynamic in the early groups is to build cohesion. The content goal is to teach the members about the process of the group; the experiential goal is that they experience the process in a semi-structured way.

Remember to introduce yourself. It helps if you are able to share something of your personal and professional experience of dying and living with life-threatening illness.

Let the group members introduce themselves. They may feel most comfortable with name tags or the like to help them remember each other by first name. This may be an important feature for future groups as well if you are meeting only once per month.

Gauge the amount of time you allow each person to speak by the time available for the group and the number of persons present. Give some guidelines for what to say, including the disease they are wrestling with, the feelings with which they struggle, and the particular issues that are problems in their life adjustment to the illness. Remembering that each person is larger than the illness, you might also invite some general comments about what each person particular enjoys or is proud of in their life.

Ask if some of the members have been in support groups before. Let them talk of their experience.

In the course of all this, bring out the general description of the nature and purpose of this particular group. The emphasis is on living with illness, living with a high quality of life with friends and family. Dying well is predicated on living well. The method, supported by scientific study and human experience, emphasizes expressing one's own experience and supporting the experience of others. Groups are a powerful way of working this combination of expression and support.

Note that care-givers are in the group for more than one reason. They are important to the well-being of the patient. The relationship between patient and care-giver is a critical one. The care-giver also needs support and encouragement. The care-giver may feel like an outsider in some respects, and reluctant to speak openly. Reassure care-givers that they are full members of the group. The goal is that all persons can learn to speak openly and listen respectfully and caringly.

Be sure to review the expectation of confidentiality and get assent on the matter. Members must be confident that their words will not be repeated directly to others in a way that might betray their identity.

Lay out a general outline of how the groups will be conducted:

- If you like, you can say that you will offer a reading to open and close each group.
- Each group will open with sharing of new developments in the lives of each member by each member. Members also are encouraged to share any reflections that may have arisen around the material shared in the last group.
- The leader will then open a discussion of the topic of the day. Members are invited to share reflections that may have come from the journaling. (At this point, you might want to say something more about the method and benefit of journaling. Alternatively, you can wait until near the end of the group.)
- The subjects to be discussed can be presented in brief at this point, if it will not detract from the flow of the group. Note the logic in the progression of topics. After the introductory group, we move into the basic skill of asserting one's needs. This topic will be repeated in the last group, although by that time it will be done in a much deeper way since the group will have come to know each other and themselves in new ways. Group Three moves into emotions, one of the three core dimensions of this program. The comes a group on basic skills in managing painful emotions and physical symptoms like pain that are common parts of life-threatening illness. In the following two groups, the social dimension is opened up. First, we will consider the social network, the web of familiar relationships in which we find our place. Second, we will consider those relationships that are truly intimate. In Group Seven we move into the third dimension, the spiritual. After a two group diversion to explore caregiver issues and decisions that go into the making of healthcare directives, we come back to the spiritual issues involved in coming to terms with dying. At this point, the members are ready to consider the positive spiritual attitudes of hope, gratitude and forgiveness. The cycle ends with a review of personal needs—what is essential and how to communicate it.
- Every topic will be brought out in conversational style. The group will process the topic, bringing in each person's personal experience; it is not beneficial to make the discussion merely conceptual. In each area, some members will have successful experiences to report. These are useful to bring out, but no one should push for another member to adopt any one strategy. Rather, the goal is sharing the wisdom of the group and allowing each member to take what seems useful.
- The topics will not constrain the conversation. The leader will continue to link what is said to the general focus of the group, but the members may take any angle on the material that seems relevant.
- The group will end with a reflection on what has been learned, summarizing main themes. The leader will review next month's topic and offer suggestions for journal work in the month to come. Bring out the private nature of the journal entries, but their usefulness in stimulating material for the next group discussion.

Journal questions for each of the group sessions are summarized in Appendix 1.

Ask how group members react to this model. Bring out that what is healing is the combination of support and expression. Support goes both ways; there is as much benefit in supporting others as in receiving support. There is as much to be gained in listening to another as in sharing one's own experience. Bring these features out in the immediate discussion. Let the group members share their reactions to the group process described. Some will be anxious, but others will have had positive experiences in groups elsewhere.

In the conversation, start to learn the psychological make-up of the group. In this first group, you will come to see the nature of the overall combination and the styles of the individual members. Without irrevocably stereotyping, begin to categorize individuals according to their style. This categorization, if not rigidly held, will help you determine the types of responses you might best make when that member is interacting.

Some examples are as follows:

- The person who talks at length.
- The person who has a negative attitude about nearly everything.
- The person who takes off on irrelevant tangents.
- The person who focuses excessively on self.
- The person who says very little.
- The person who focuses excessively on others.

Do not let any one member dominate either in time taken or forcefulness of presentation. Bring out the experiences of each member without pressuring anyone to speak. A "yes, and" attitude should be the norm. Strongly held beliefs, such as religious beliefs, are valuable and should be encouraged. However, individual members may express them in such a way that they feel coercive. Model for group members how such ideas can be expressed using "I" statements. Passion can be expressed without proselytizing.

Lay out housekeeping:

- Describe how to contact you if a member cannot attend. Attendance is important and each member's absence is felt by the group.
- Remind the group members that contact between sessions is encouraged. You might make available a sheet of paper on which a voluntary telephone list can be written and copied for the members. Be sensitive with this issue. Let the group decide if they are ready yet to share phone numbers.

Summarize then what has been accomplished. Note especially the themes you heard emerging. Reinforce those themes that are held in common. Note the particular individual issues as seems important.

Common themes in this first meeting are the shared sense of isolation imposed by the fear or discomfort of others. Implicit is often the self-imposed isolation resulting from depression or excessive focus on disease. There is sometimes envy of those who are well or the paradoxical desire to look sicker so others will take the disease more into account. There may be grieving for functions lost or celebration of life greater than disease. The support of religious faith may emerge. However, these are simply examples. Your work is to listen for the themes and the process of this particular group.

Offer your sense of the emotional and social impact of this first meeting. Share your own feelings as you care to do so, but do not take center stage. Find ways to reinforce the bonding of the group.

Discuss the use of the journal if you have not done so already. Emphasize its role in keeping not just the content but also the group itself higher in consciousness. If the members just go about their business in the month between group sessions, not calling to mind those with whom they have shared such personal information, the group will not be as effective.

Discuss alternatives to the use of a journal. Some persons may prefer just taking some quiet time. Others may like to put a list of the names of the group members on the refrigerator door or in a special place. There must be some way in which the members recall what has been discussed, consider what will be discussed, and feel the sense of connection that breaks through fear and loneliness.

Goals in journaling or some alternative way of remembering should be modest. Trying to commit too much time or energy to the enterprise will result in failure and discontinuation of the activity. Modest, sustainable goals should be encouraged.

Tell the group that you will be offering them specific questions or reflection points at the end of each group. You might have them, and some suggested readings, ready to hand out at this juncture. Some points will have the purpose of keeping them in touch with the most recent group session or reminding them of “action steps” that seemed to be indicated. Other points will lead the members to begin thinking about the next topic. This will make the next group discussion more useful, personally relevant, and lively.

Every group should address the following statement at some point: “How will you remember each other until the next time we meet?”

Then bring the group to a close. Assure the group that you also will be remembering each member over the next month.

Handouts for Group #1 and all subsequent sessions are summarized in Appendix 2.

Group #2: Asserting Your Needs

Open the group with a brief check-in. Invite each person to share new developments in the disease, coping with the disease, or life in general.

Then ask how the group experienced the first meeting. Ask what stuck with them as they reflected on the group over the last month. Remember that in this stage of the group process your primary goal is to facilitate the development of group cohesion. Listen for expressions of discomfort as well as of bonding, direct or indirect. Help process the former and reinforce the latter.

If it does not come up, ask if and how each member approached the general goal of staying mentally connected with the group across the month. Some will have journaled about the past group and the topic of today's group. Reinforce their attention. Others may have come up with a unique way of reflecting and staying connected, the two goals of the journaling. If so, allow them to detail what they did and encourage discussion.

Introduce the topic. Ask the members if they worked with the preparatory questions. Ask what ideas, memories, feelings, and the like emerged from this work.

The focus of the second group is becoming a more assertive representative of one's own needs with all members of the health care team. This is a relevant topic to most persons. There is a great deal of tension between the desire to keep the medical team favorably disposed and the desire to make sure particular issues in care are recognized and addressed. Walking this line is best done using techniques of assertiveness.

Having made this general introduction, normalizing the tension and the difficulty knowing how assertive to be with the medical team, ask the individual members what has been their experience in this regard as they have dealt with diagnosis and treatment. Bring out the common and unique themes as usual.

Be empathic with those group members who bring out the difficulties inherent in being assertive with their medical team. Two of the sidebars in the chapter recommended for this group speak to the practical problems of being assertive with a personal, primary physician:

- “You like your primary doctor usually. Even if he or she is not very helpful, you find a way to be an apologist for this person on whom you depend. This is not a bad reaction, but it sometimes keeps you from making changes or confronting problems.”
- “Doctors are also very busy. They don't get paid very much for spending time with patients.”
- “Communication is very difficult. Even when your doctor is really trying to lay out the important ideas, you may be so distracted by worry or anxiety that you don't take it in.”

When the time seems right, move to the general concept of assertiveness. Bring out the basic principles that define or differentiate assertive behavior:

- Non-assertive, submissive translates to *“your needs are important; mine are secondary.”*
- Passive-aggressive says the same thing overtly, but the behavior reflects an inner message of, *“and I don’t like that.”* It is the response of an angry person who does not feel safe to be overt with her or his anger.
- Aggressive translates to, *“your needs are secondary; mine are the important ones.”*
- Assertive behavior is based on mutual respect. *“In the assertive mode, you don’t think only of “rights.” Think relationship and mutual benefit. State your ideas; allow the other person to state his or hers. Work toward understanding and some kind of creative resolution of the problem, not toward winning at any cost. Think positively; if you believe someone must lose, you lose. That is, you may or may not win the immediate argument, but you lose an important relationship and/or opportunity for growth.”*

Note specific non-verbal behaviors that express these different types of behaviors. Eye contact is influenced by culture; what is real connection in one culture is aggression in another. Personal space, the distance of one body from another, necessary for the appropriate balance of connection and comfort during communication is also highly individualized. One must remain sensitive and continue adapting during the conversation. Assertiveness is a dance with another person, not a solo performance.

Verbal behaviors that support assertiveness include simple, specific, straightforward and direct communications delivered without stridency. The use of “I” statements is a helpful way to own one’s personal desires and to avoid attacks on the person of the other. The broken-record technique is good with persistent requests around a non-negotiable item.

There are a variety of ways to cushion the request or assertion. It is not good to be servile, but there are ways of saying what must be said without being unpleasantly blunt. In this era, we have fewer social conventions to help us be polite in our assertiveness. The largest part of the American culture tends to be somewhat aggressive in confrontation. We speak of “demands.” We are often “outraged.” These types of reactions are not based on a belief that “we can work it out.”

When this material has emerged in the discussion, begin to move the group to talking about how each member might be more assertive in communicating with the medical team. Refer again, empathetically, to the difficulties brought out earlier. Let the members offer each other suggestions.

It is helpful to ask members to offer particular situations that they face. Get the individual and group to interact about ways that the individual might handle the situation assertively. Do not cut off ideas, but do shape the discussion and reinforce consideration of those ideas that seem most practical. Recognize that it is not easy to be assertive in many situations; considerable flexibility is needed to apply any general principles.

Get reactions when a particularly good idea is put forward. Look for problems being assertive right there in the group, and try to bring them out for processing without humiliating the particular member. Model assertiveness in the way you handle the discussion. Role-playing is sometimes useful for this topic.

Remind members also that the solution does not have to be worked out alone or without aids. The idea of writing out questions or statements before the visit is a useful one. Clarifying responses by asking for a summary or taking notes and checking them out before leaving is also helpful. Taking a friend into the consulting room is a great support and a check later on what was heard. There may be a professional in the office, other than the doctor, who is available for education, organizing questions for the doctor, or otherwise solving problems; it is worth asking about.

Help the group consider feelings (the focus for the next group) that are “markers” for when one is not being assertive and is uncomfortable with the way medical care is going. Such feelings might be frustration, anger, resentment, sadness, humiliation or fear. Remind members that if they notice such feelings during a conversation it is possible to modify the direction of the interaction. If they are not noticed until later, it is still possible to bring the issues up next time. Writing out what the person wants to say in the next visit would be helpful.

It is also and always a useful thing for patients to remind the primary physician how important he or she is to them.

As the time to end the group draws near, take the floor again and begin to sum what you have heard the group members saying. Reflect the common themes and any individual issues that were important. Recognize those persons who wanted to work on their own situations but did not get to for lack of time. Encourage members to make notes about what struck them in this discussion, and put those notes in a place that they will visit regularly. Whether in a journal or otherwise, this practice will help the members remember not only material but also each other.

Then remind the group that the next session will deal with feelings/emotions. Suggest some focuses for journaling. You might use the questions provided with the outline of the groups, or other questions that are more appropriate to your style and intention. Simply observing strong feelings each day is an excellent practice.

Remind the group again that journals are a tool for taking notice of life, not a homework assignment. Encourage each member to find a comfortable time and style for addressing

the journal each day, and for reviewing it weekly. Encourage creative solutions that accomplish what the journal is intended to accomplish, but in other ways.

For related sources, see endnotes 106-110.

Group #3: Feelings

Open the group in the usual way. Allow members to check-in. Listen for those who are clearly bonding with other members and with the group as a whole. Be sensitive to those who are holding back. It may be time to help them enter the discussion more fully.

Review reactions to the last group. Ask if anyone tried out some of the methods for communicating more directly with their doctors. Then bring the group to focus.

In your presentation, you might remind the group members that the feelings present in them now will be more intense than those they experienced in more “ordinary” times of their lives. The inner emotional life now reflects the turmoil of the patient who is facing death more clearly. It is not that the patient is always upset. Even in the worst circumstances, there are unexpected moments of humor and many moments of forgetting, going about business as usual. However, it is also not unusual to find the patient sometimes struggling with strong emotions.

Begin with a general discussion of the ways in which different people handle emotions. Each person will have a dominant way of working with feelings. Any one person can manifest each of these different ways on different days and at different times.

In some cases, the patient may be trying to contain the feelings for fear of falling apart. That person will use intellectualizing statements to keep feelings at bay. He or she is not likely to be very forthcoming in group. It is not helpful to press the person to share feelings that may not be consciously known or may be too frightening to face. Look for the emotion as you lead the person into increasingly honest telling of the stories of his or her life. Comment on the feelings as they emerge and validate them as expected and consistent with healthy living. Help to distinguish between falling apart and allowing emotions to fit into the overall experience and expression of life.

In other cases, feelings may be very much on the surface. When the feelings dominate thought there is distortion. In this situation, the distortions will be in the direction of excessive fears or predominantly dismal outlook. The outward appearance will vary. In some cases, the feelings are quite apparent. In other cases, the feelings are evident only in the persistent, repetitive attitudes of the patient. Here the educational work will be to encourage greater input from the rational perspective. Bring out the ways in which the person is already succeeding, and the resources available that the person may be overlooking or discounting. Hopefully, this realization comes out of the stories he or she brings and in the telling of these stories becomes evident to the patient. There is no convincing such a person with rational argument made by another.

Others, farther along in accepting the illness, may be truly at peace with the dying process. However, even in those persons there is often real concern for those they are leaving behind.

As a general rule of thumb, note that men will have more trouble recognizing and expressing emotions. However, the individual genetic and social history will play the most significant role in the individual member's emotionality and comfort with emotions.

The more common problem will be the "holding in" of emotions for fear of disturbing others or of being overwhelmed by them. The most common types of feelings will be depression, anger, anxiety, fear, guilt and shame.

Allow for discussion to bring out the ways in which the members recognize these types. Let them "nuance" the types to fit their experience without dictating to the experience of others in the group.

Then move the presentation along by presenting on the various types of feelings that are commonly strong among persons facing death. With each presentation, you might allow for some discussion or reaction to keep up some interaction.

Depression may be the most common emotion in coming to terms with death. There is a sense of isolation. The patient often feels very alone, even singled out for this illness. There is an irrational sense of shame. The shame and emotional withdrawal compounds whatever loss of social support there may actually be as a result of others not wanting to deal with life-threatening illness. Self-esteem can also be threatened if the person feels himself or herself to be weak or bad as a result of developing such a severe illness.

Anger can be present as a result of the patient's sense of being cheated by life. It can also emerge when there is the sense that others are not responding as the patient would have wanted or expected. These kinds of reactions are natural enough. When the anger is not expressed so that it can be worked through directly, it develops in unhealthy ways. Resentment, bitterness, irritability can all drive away others. However, there are many ways in which anger can be helpful when processed directly, and not expressed by way of blaming others. Anger owned can actually improve the patient's survival time. When anger is suppressed, it will drive physical symptoms and increase depression. A patient can try to put on a happy face or even may come to blame himself or herself for the disease.

Guilt emerges when the patient blames himself or herself for doing things that led to the illness. A care-giver may also feel guilt for behaviors that may have led to the disease of the patient. When one considers the difficulty of predicting disease, it is safe to say that in most cases this guilt is irrational. However, in some cases it is helpful to own guilt and teach others to learn from one's mistakes. Guilt becomes an insurmountable problem when the patient turns it inward in a self-punitive way. It may emerge even as an irrational but

powerful sense of shame. Then depression develops. Whatever the case, the patient must find a way to work through guilt or shame to reasonable forgiveness and/or reparation.

Anxiety is a prominent feature of any life-threatening illness. It is not unusual to hear patients say that they cannot even use typical coping mechanisms. Many say that they cannot even prey in the tension of these days. Fear is part of the anxiety. There is fear of the unknown. Even persons of deep faith may wonder if what they have believed is true. There is ambivalence about facing the dying. Coming to the place of letting go is a gradual process with ups and downs. There is fear of being abandoned by others. Hypersensitivity is a form of this fear, expressed indirectly.

Emotions can be healing. Any emotion is a source of healing if the patient is able to stay with it, express it in conversation, and work it through. Certain emotions are natural parts of the healing process. A complete lack of emotion, a type of psychological numbness, is not desirable for the long term. It is not advisable to confront the patient regarding the absence of feelings, but there will be opportunities to reinforce emotion that does appear, in response to the patient's own story or to the stories of others.

Grief is not the same thing as depression. Grief is a healthy although painful feeling that expresses the loss of the patient and care-giver. In grieving, the patient comes to understand the universality of loss; empathy is increased; the meaning of everyday life is enhanced. Only when the patient tries to cut off grief too quickly, meeting his or her own expectations or the expectations of others (spoken or unspoken, real or perceived), does the patient invite trouble. Usually it comes in the form of depression.

Hope is another positive affect. It is embodied in the goal of living fully in the context of dying. Hope is not wishful thinking. It is an optimism that good will come no matter how bad things seem to be. It assumes that there is more to be understood than meets the eye now. It allows us to persevere without slipping into unproductive endurance. Hope begins with the sense of being loved. It comes to fullness in loving others.

Throughout this presentation, you will have invited the group to comment on what you have shared. Now allow for some summary reactions to what has been said. Listen for and reflect feelings that are not directly named. As members share, remind them that sharing feelings is the most reliable way to allow them to be resolved in healthy ways. Differentiate sharing feelings from venting. Gently point it out if you have the sense that the patient is simply repeating the same thoughts and feelings that have been stated over and over again. Your sense that the patient is complaining or simply appealing for pity may be clues. Sharing feelings will be evident in the extent to which you feel involved and empathic about the patient's presentation. Sharing feelings invites conversation in the form of identification with the feelings, sharing different reactions, exploring the roots of the feelings, or exploring responses to them.

In the course of the sharing, be careful not to direct how a person should feel. Coming to understand the nature and roots of his or her own feelings will be enough to move the

person to new feelings in almost all cases. The feelings often direct attention to important attitudes that can be addressed more directly.

When feelings are hard to elicit, simply go back to encouraging a truthful telling of the immediate situation. There will be feeling enough when an honest telling of the situation is arrived at. Remember that the honest telling of the situation always involves what the disease means in the life of person.

As the time winds down, begin to pull together what has emerged in the group discussion. Note the predominant feelings reported by members. Note that some members find it easier to talk about feelings than do others.

Remind the members that sometimes feelings do become problematic. When feelings become intense or enduring, members may need assistance in working with them productively. The next group will focus on such feelings. You might encourage the group members to notice their emotions with the idea of identifying those that are most common and most intense.

On the other hand, feelings are also part of a healthy life. In the current circumstances, strong feelings are perfectly normal and expected. If they are handled openly, feelings serve as a route to a more rich interior life and help to forge deeper relationships. Members might be encouraged to try sharing their feelings with others more than has been their custom. Tell them to observe the results if they do and to let the group know next time.

For related sources, see endnotes 23, 27, 111, and 112.

Group #4: Working with and Helping your Body

Open the group with a brief check-in as usual. Each person is invited to share what has been of most significance in his or her life over the last month. The group leader should also share any news about an absent member of the group. This may invite further discussion. As the group begins to bond, the content of the curriculum gradually recedes in importance relative to the relationships forming among the group members.

In opening the discussion around the content today, ask the group members how they worked with the material discussed in the last session. Listen for and reinforce ways that the group members kept each other in mind.

Make the link between the discussion of emotions in the last session and the issue of *problematic* emotions, which is part of the focus in the present session. Ask members what observations they made as they prepared for the present session. If some have read or reflected on the subject, reinforce this behavior, although without undue attention. It is another way of extending the impact of the group between sessions.

Then, begin to work in the material you want to present. Of the problematic emotional and physical symptoms to be considered, pain is usually the first and most anxiety-provoking subject. Pain is one of the most common and problematic symptoms in life-threatening illness. However, in any particular group, some members may have a very responsive and reassuring medical team. For these persons, it will not have as high an emotional valence.

Some key points to consider in discussing pain follow. Weave them into a discussion as much as possible, rather than presenting them in an organized way.

Management of the pain is facilitated by accurate diagnosis, psychological as well as physical. The patient can help the physician in this diagnosis by accurate reporting of the pain. Accurate reporting is inhibited by a variety of factors. The pain can be very distressing, affecting the clarity of observation or reporting by way of the emotional reaction. Others may not wish to appear to be weak or complaining, holding back essential information.

Encourage the clients to name the pain assertively. It should be described in terms of its location, temporal pattern, sensation and severity. Journaling the pain sensation on a daily basis increases the accuracy of the reporting. The more the patient presents such information in an organized, clear manner, the more credibility will be given to the reports by most medical teams.

It is also true, as a general rule, that the more decisive the pain intervention and the more clear the instructions, the more confident and cooperative is the patient. A sense that the pain is being effectively addressed will reduce emotional distress and overall medication use.

It also seems still to be true that acute pain associated with disease or necessary treatment for the disease is often under-treated. The patient can at least take an assertive stance regarding his or her pain management, and elicit family assistance in working with the medical team. Remember to refer to the material discussed in Group #2.

It is important for all involved to remember that pain cannot be measured objectively. There is no point in trying to judge whether the person is “really” feeling pain or having “real” pain. All pain sensation is a combination of physical and psychological events. The relative contribution of either does not change the sensation of the pain.

Medication use is an important part of pain management. Patients vary in their reactions to medicines. Some are unreasonably embarrassed by the need for medication, and fear dependence even when other circumstances make dependence a minor concern. The side effects of some medications, particularly those that affect mental alertness, are also a discouraging aspect of pain medication for many persons. Encourage the client to actively communicate with the physician regarding pain medicines. With sufficient attention, a reasonable balance between pain relief and unwanted side-effects can be achieved. Remind the patient that over-the-counter medications and herbals “do count.” They can have significant effects and side-effects, and they interact in important ways with

prescribed medications. The client must report their use accurately to physician and/or pharmacist.

Other physical symptoms that may be problematic are legion. They do not affect everyone, of course. Let the group members bring forward symptoms that are problems for them. Some examples include fatigue, shortness of breath, dry mouth, mucous in throat, nausea or vomiting, difficulty swallowing, constipation, and bedsores.

The discussion of problematic emotions might begin with a discussion of psychological factors that affect pain.

Psychological factors can affect pain sensation directly, for better or worse. It is impossible to determine accurately how much other factors might be influencing the experience of pain; however, it is worth struggling with the question. Common psychological factors that make pain worse include underlying and often suppressed anxiety, fear, anger and depression.

Psychological factors also influence the client's experience by way of his or her reaction to pain itself. Again, the direction of the influence may be positive or negative. Negative reaction to pain increases suffering. It has been said often that "pain is unavoidable; suffering is optional." In that axiom, "suffering" refers to the emotional distress caused by pain.

The alleviation of the emotional distress depends on knowing the root causes for the suffering. Does the patient feel afraid of what the pain means? Is the patient angry at having pain at all? Does the patient blame the team or someone else for not helping sufficiently? Has the patient developed depression?

Family factors can also influence the patient's reaction to pain. If family members or friends respond with excessive sympathy to the pain and encourage fear or dependency, expression of pain may unwittingly be reinforced. If they neglect the client's experience of pain, expression of pain may increase in an effort to change their response. Family relationships can also affect the core emotions, referenced above, that affect suffering.

The most lively and profitable part of the discussion is likely to be what persons have learned to do to ease pain or distressing emotions. Allow the members to suggest and describe methods that they have found useful. On the other hand, be careful that no member feels pressured to use one or another method. Sharing experiences is the goal. Members should feel free to take what may be useful from the discussion.

Relaxation is an effective way of coping for many persons. There are many taped instructions for relaxation. The most important feature is that the patient give himself or herself over to the experience of relaxation. In this way, it becomes transforming of even basic attitudes. If relaxation is used in a purely functional way, it is not as helpful. Slow, easy breathing is a common way of introducing relaxation.

Hypnosis and imagery are closely related techniques. Hypnosis is dependent on a therapist to make suggestions. Imagery (or self-hypnosis) can be done independently. Effective use of imagery often is integrated with relaxation. The images may be diverting, reassuring, transforming with regard to the pain experience. The content of the images is best drawn from the patient's experiences of relief and security. For many persons, religious images and themes are deeply meaningful.

Meditation as used for pain management is a means of focusing on the present moment. In the present moment are not only the sensations of pain (and other symptoms of disease) but also many dimensions of comfort—physically and psychologically. The client finds that he or she then can work with the pain or around the pain. Meditation is also a way of opening to the healing that is always present and active, no matter what the physical condition. Feeling supported also allows a more honest reflection on the actual physical condition. For example, a recent research study found that persons with home support were at once more realistic (“negative”) about their health condition and less distressed by it. It is just as powerful to feel the support of a Higher Power, whatever the name given. For specific exercises of mindfulness and breathing, consult *Full Catastrophe Living*, by Jon Kabat-Zinn.¹¹³

Physical therapy is an important part of pain management. The immobility often imposed by disease results in muscles that are tense and painful. Regular, unassisted exercise may be limited. The physical therapist can be of great assistance by maintaining flexibility and relaxation of the musculoskeletal system. Massage is soothing and restorative. Exercise is diverting and a healthy tension reducer.

In the course of discussing these modalities, it may be helpful to give some focused practice in their application. Choose one method based on your experience with it and the group's interest. If there are experienced persons in the group, honor and use their expertise. Then go on to review more psychological and social factors that enhance or disrupt a sense of relaxation and “letting go.”

Cognitively, mental confusion is very common. Medicines or disease may affect confusion. Ask the doctor to review the medications whenever there is an unexpected increase in confusion. Regular conversation about basic daily events is helpful.

Psychologically, it is important to be able to speak openly of moods and worries. With suppression of psychological distress, there is the danger of slipping into clinically significant depression or anxiety. Open conversation with others is very helpful, and one of the main things the groups seek to promote.

It is healthy for patients to maintain a sense of personal efficacy. There are many ways to do so, despite the ravaging effects of disease:

- Before anything else, clients do well to recall how they dealt with difficult circumstances in the past. What worked then is likely to point toward effective strategies now.

- Encourage the client to continue learning about the disease. As mentioned in the last group, speaking assertively with the physician and medical team gives a sense of active participation in treatment. It combats any tendency to passivity in the form of stoicism, dependency or despair. Of course, it is important to recognize that trying to direct the treatment team unilaterally is a form of over-control, and no more helpful here than it would be in any other setting.
- In difficult circumstances, it is important to find the balance between doing what is possible to do and not fighting what cannot be changed. The client and family can really help by accommodating environment or routine to the disease where possible to make effective, independent action possible within those accommodations.
- As will be the focus of Group Five, social support is critical. In chronic illness there is a tendency to become overly dependent, thus alienating or compromising (by eliciting excessive care-taking) effective care-givers, or the opposite tendency to withdraw from social contact, “hibernating” emotionally. Neither is an effective response. Interdependency remains the optimal system, with recognition of the limits imposed by disease.

For related sources, see endnotes 105 and 113-115.

Group #5: Living Well with Being Ill

We have in the last group focused on relief of psychological and physical symptoms associated with life-threatening illness. Techniques for the relief of pain and the management of emotional distress are essential. Without them, nothing much else will be helpful. Emotions also have been discussed in an earlier group, and they were integrated into the discussion of symptom relief. Working directly with feelings is one of the keys for using this group well and for negotiating any stressful situation. Coping skills must be refined and adjusted.

In this session, we focus on the more general issues associated with living well while facing death. As the diagnosis sinks in there is a gradual but essential shift in perspective on everyday life. However, as Doka points out, in our world “most people will neither quickly recover from the disease nor rapidly deteriorate.” During the long period of being ill, all the routine of life goes on. The same frustrations and sufferings exist. The demands of work and home are not appreciably different. There are new pressures associated with time and effort required to attend to treatment of the disease. The disease and the treatment both sap energy and create symptoms.

Living well with illness is a multi-dimensional process. If Group Five is given by itself, allow for a broad focus on several of these factors. In the broadest terms, these would include the emotional, social and spiritual dimensions of living well with life-threatening illness that are the general focus of this program. If Groups Five and Six are combined,

focus more on the continuum of relationships, from the least to the most intimate, that define the fabric of social support in each member's life.

By this time, the group should be working reasonably well together. A measure of trust has been established in the sharing around the relatively more objective topics that were introduced. In starting the group, give time for the updating by each member. If the members want to talk more in depth about any aspect of their life experiences or previous groups, allow considerable freedom in this regard.

At an appropriate point, reference the dimensions of emotional, social, and spiritual well-being. Review the problems of living well that go beyond particular coping skills or techniques. Speak about the sometimes jarring contrast between the ordinary demands of life and the extra-ordinary situation in which the members find themselves. Life is hard in the best of circumstances; it is particularly difficult when facing life-threatening illness. Note the periods of great trauma when the disease reaches a crisis, contrasted with periods in which even the patient can "forget" that he or she is sick. Let them respond on this more general level.

Unless the group seems to demand otherwise, move the focus gradually to the social factors. Emotions have been opened up in a previous group. Spiritual issues will be explored in detail in a later group. Note this, and briefly review the emotional and preview the social factors to emphasize the continuity of the groups.

The overall focus of the program is to come to terms with death and with dying so that each member can live as fully as possible in the present. There are emotional, spiritual, and social aspects to this process. Reference this goal, and note that there is a certain "madness" in this dual focus, but that it is also a rich source of transcendence.

In bringing the discussion to the social factors, discuss the importance of recognizing the importance of all relationships, even the most casual. There are naturally many more superficial relationships than deep ones in any life. The sheer weight of numbers argues for their importance in the social context, as opportunities for "loving well and living well." The next group will focus more specifically on developing intimate relationships. This group should emphasize the relationships of the everyday.

There is a restorative power in being connected. It is important to avoid the pitfalls of isolation. Isolation can result from the sense of being almost ashamed of life-threatening illness. There is a sense of vulnerability, certainly, and sometimes an irrational idea that one has been singled out.

Socially, there is the risk of isolation when others do not seem to understand or want closer contact. This distancing by others is also real. LaGrand calls it a process of alienation. It occurs often because the patient who faces his or her own mortality reminds others of their own mortality. This is almost always an unwelcome reminder. Unconsciously, the other may avoid contact or distance emotionally by trying to determine some reason the patient got cancer, AIDS, or other disease. There are irrational fears of catching the disease.

A study published in the late 1970s looked at the experience of dying children by asking them to arrange various human figurines. The investigators noticed that the figurine representing the child was gradually placed further and further away from the other dolls as the child moved closer to death. Whether the distancing represented in this study was a reaction to the distancing of others or initiated by the child it is a powerful and painful loss of contact at a time when support is needed more than ever.

Doka also reminds us that social support specifically for the disease seems to be more available at the time of the diagnosis and during crises rather than during the period between crises. Beyond the issues of alienation discussed above there is simply forgetting. Others do not live so consciously in the shadow of death. If it is possible for the patients themselves to “forget” they are sick, so much more so is it the case that others will not remember. Others do not always know what to do and how much to ask about the disease.

After introducing the idea that dying seeks to separate and that the real victory over death is in not allowing that separation, begin to consider the ways in which this group can help bring the victory. Honest and caring discussion among the group members is as always the key. In such discussion, there is already a rolling back of the isolation that gives death its victory.

It is a common mistake to assume that only the most intimate relationships are real or supportive. In fact, social networks are made up of relationships that vary widely in depth. The shallowest relationship can be very sustaining in its reliability. It is only important that such a relationship not pretend to be more than it is. That would lead to disappointment and a sense of betrayal. There would be tensions as one person seeks for more than the other wishes to give.

It is also not true that only support in which the disease is noted specifically is real or valuable support. It is important to come to understand the power of realizing connectedness in everyday encounters. The patient and others may be living in very different realities but the patient can come to experience the encounter on a much more profound level because of the perspective afforded by living with life-threatening disease.

The general message is to live today as fully as possible. This includes primarily living in relationship. Relationship means first that one is able to live with oneself. We are all complex persons, with many facets. There is not much to be gained by blaming oneself for being sick, going back to determine what “sins of omission or commission” might have caused the illness. The tragic events of our lives will happen, that we know, but “what happens when to which people and why” we cannot hope to figure out. There is no point in comparing one person’s fate to that of another. There is little to be gained by suppressing emotions. Emotions must be “ridden” rather than controlled. The analogy might be used of a white water canoeist who can choose the general path to be followed through the rapids, but must in general go with the flow of the river in order to survive. Similarly, emotions are too strong to be suppressed and too complex to be accurately predicted. It is natural to grieve the loss of capabilities.

Living fully also means using the strengths that are available. It is often reassuring to think of the social network that does exist. Beyond the discussion, an additional journal exercise might be to list the various people in the social network. Note the level of intimacy and the role each person plays. Consider persons at a distance who share regularly by letter or phone. The member might ask whether he or she is appreciating each member of the network for what the other offers.

Self-help, or mutual-help groups bring together persons who suffer the same fate. In our case, they bring together those who are facing their mortality in a new, real, and immediate sense. Of course, each member will be at a different stage of awareness. Each will encounter their death using different coping mechanisms. In the next group, on more intimate relationships, we will be the role of the group more fully.

The sorrow of this time is real, but the personal strengths and social resources are equally real. Allowing the joys and sorrows to be intermingled increases the sense of hope. Sharing grief does help to resolve it. In this way, grief can even become a source of growth.

For related sources, see endnotes 27 and 115.

Group #6: Intimate Relationships

Open the group with the check-in. Ask what members noticed over the last month about their social network. Notice which members could identify and speak to some sort of reliable social network and what they found was their place in the network.

Social connectedness is an important component of living well. Finding one's place in the social order is comforting and supportive. A reliable rhythm of social interactions and a secure sense of belonging without being a burden provide the underpinnings necessary to survive and even thrive under conditions of great difficulty. Every person needs to feel supported and needed.

After the check-in and review, open the subject of today's group. The focus is on intimate relationships. Intimate relationships are part of the overall social network. They are relatively few in number but great in importance.

Spend some time defining Intimacy. Many people are not familiar with the broader meaning of the term. In popular culture, it is often equated with sexual relationships.

Intimacy involves mutuality; however, it is also true that mutuality is a characteristic of any healthy relationship, of whatever depth. Intimacy involves in addition the ability and willingness to share yourself very honestly--as or almost as fully as you know yourself. It involves the willingness to listen and accept the other person in the same way. In such a

relationship, the people involved continuously change and adjust in response to the other person. Nevertheless, each person remains distinct, with a separate individual identity.

Intimate relationships are very precious. They do not develop easily or without emotional pain. Trust does not come easily nor is it easily recovered when it is lost. Very few persons have a relationship of absolute intimacy, a person with whom they can share everything, fully trusting the other to love them, almost as if they were one person. Actually, very persons know and love even themselves in that depth.

However, many persons have one or two relationships of some depth and with potential for growth. Ask the group members to consider who in their lives is such an intimate friend. As they speak of these relationships, bring out the ways in which they feel supported and needed in them. Be sensitive to the fact that for some patients the caregiver accompanying them to the group sessions may not be one of his or her intimates. This fact must be “normalized” so that it is not a source of embarrassment or an inhibitor of honest sharing.

Following that discussion, present briefly on how one cultivates intimacy. A few points that may be useful to mention are noted here:

- Intimate relationships are built on courtesy and conversation. The needs and interests of both parties must be considered.
- Sharing honestly what one is thinking and feeling is necessary to develop relationships. A person must be equally honest in recognizing and asking if the sharing is more than the other person can tolerate. However, it is a mistake to presume what the other person cannot take. Water finds its own level when allowed to flow freely.
- Ask what the other person is feeling and thinking. To be sure, it is important not to persist rudely if the other person makes it plain that he or she is unable or unwilling to explore the matter, but again, do not presume.
- Do not wait to start this work. Waiting until one is “sick enough” may be waiting until it is too late. Downturns in life-threatening disease can be sudden.
- Do not be afraid to bring up old issues. It is better to explore potentially difficult subjects than to let them eat at one or the other or both from the inside.
- Allow for conflict in the present. “Negative” emotions are as powerful as “positive” ones in building relationship if they are handled honestly in respectful conversation.
- Speak of the disease and its impact, as the person with the disease or as the companion. There is a balance to be achieved between fighting and accepting, grieving and rejoicing, hoping and resigning one's self to what will be.
- Do not be afraid to say words of love.

- Do not be afraid to say good-bye. As a matter of fact, say it often.
- Share faith.

If the person does have an intimate relationship, the disease will stress it. No relationship is perfect, and all flaws in the relationship will be highlighted under that stress. The potential benefits of an intimate relationship are great; it is worth the effort to counter these problems. Even if there are not obvious problems, it is worth the effort to simply improve the relationship for the added benefits that will result.

The stress of life-threatening illness comes in many forms:

- There is the fear of disease and dying. This fear is often unspoken. The unspoken fear is like the proverbial “elephant in the living room” that no one is willing to discuss. There may be withdrawal due to anticipatory grief. The disease is like the third person in the room; it changes the conversation. If the disease is not addressed directly, the resulting conversations feel even more superficial since everyone is aware of what is not being said. Family or friends may withdraw, emotionally or physically. This builds a sense of isolation.
- Old issues may arise. Past hurts that have never been resolved now loom large again.
- Another stressor is the fatigue, pain, or other physical symptom that burdens the patient. It is hard to overcome the discomfort to sit and talk in any depth. Eventually there comes a time when the burden is simply too great. Mental processes are not there. Energy is not there. The pain is too great.

It may occur that a group member believes that he or she has no friend with whom there is an intimate relationship or the potential to build one. It may be that some patient’s have outlived their intimates. After some exploration to be sure this is a reasonable conclusion, it is important to let the judgment stand. It is not helpful to try to talk the person out of their opinion, whether or not it seems reasonable. Be alert for indications of clinically-significant depression in such a case. However, it is also reasonable to fold that concern into a discussion of the way that the group provides for intimate relating of a different sort.

Help the group members discuss the impediments to intimacy that they experience. When a member has been successful at opening up a new relationship or re-vitalizing an old one, bring out the satisfaction that followed.

Remember also that the group is now an ideal place for developing a form of intimate relationship. The group is taking shape as a place in which the members can speak honestly about their feelings and thoughts. They are facing death together in a way that precious few other persons or groups could tolerate. In some cases, the level of conversation in the group may be deeper than that in any other relationship despite the fact that the members have known each other for such a short time. Such is the bonding effect

of sharing the experience of life-threatening, life-changing illness. Call attention to this developing intimacy. Encourage the members to use the lessons learned here to relate more effectively with persons in other parts of their lives. Encourage them to connect with each other outside of the scheduled group meetings.

As the time winds down, begin to put some closure on the discussion. Review the most important things that have been said about intimate relationships that exist and ways in which members might restore or develop intimacy. Remind the group members how important they have become to each other. Offer some ideas for the members to think about in preparation for the next meeting on spirituality. Connect today's session with that one by noting that spirituality is not only religious involvement but also a personal sense of connection with the Divine Mystery that is greater than themselves or their understanding. As such, it builds on several previous groups. We have been moving from relationship with self, through relationship with others, to relationship with life itself and all that is.

With that, bring the group to a close in your usual way.

For related sources, see endnotes 114 and 116-118.

Group #7: Spiritual Needs

Open the group as usual. Invite the members to bring each other up-to-date on changes and developments over the last month. Ask for any further reflections on the discussion of relationship. Note or ask about the status of any member not present.

Then review the topic for the day. Note the connection of today's topic with previous topics by commenting briefly on the various levels of relationship, and particularly on the continuum of relationship with self, with other persons, with those closest to us, and with that which is beyond us—God by whatever name.

Note also the difficulties speaking honestly about faith issues. It is very hard to share one's faith experience in a way that does justice to the depth of one's own belief while not preaching to the others. In the last century there developed even a general rule about not discussing religion or politics at parties because the subjects were divisive. Religion was seen as a cause of conflict.

Unfortunately, this approach “threw the baby out with the bath water.” Scientific research recognized that religion has remained important to most people, even if they do not discuss it freely. Research has also demonstrated that by-and-large the effects of religious commitment are very positive. There is even research demonstrating that intercessory prayer may have a positive effect, although science cannot address how such an effect might work.

Members should be encouraged to speak honestly about their own experience, without needing others to see things in the same way. Each member must strive to listen with

acceptance and a desire to understand, not a desire to convince or convert the other. A good way to approach this subject is to ask the members to share their personal “stories” of how they came to think about religion.

One source of conflict that we encountered was the very religious person who could not or would not reflect on any aspect of their medical condition other than through their religion. This may be a barrier to processing of emotions, planning for death, and identifying meaningful human relationships. On the other hand, it is important not to judge or stereotype the highly religious group member. Talking about what religion means and how it feels at a personal level may help to break through with certain members.

Ask the members to refer to their journaling and reading if they prepared for today’s session. Even if they did not prepare, ask each to reflect on their memories and ask them to start sharing those memories as they are ready to do so.

Questions having to do with religious involvement or the lack of it may be the most concrete and the easiest ones to start with:

- “What has been your religious history?” Listen for the development of religious faith over the life span, and the importance of that belief to the person.
- “How have your beliefs been reflected in prayer and other religious practices?” Be sensitive to persons whose beliefs are better described as secular humanism in one form or another. Help them articulate the way in which they have tried to live a good life.
- “Have you belonged to some type of religious body—church, temple, or the like? How has that involvement been important to you?” Listen for the presence of social support. Be sensitive to those persons who have not expressed faith by participation in “organized religion.”

Do not force the discussion in one way or another, but listen for the gist of each participant. Reflect and reinforce what has given each person meaning. Be sensitive to those persons who have not found much meaning in religion, or who feel badly about their lack of participation. Honor those with negative experiences, but do not allow the group to then avoid their positive experiences so as not to offend persons with strong negative feelings. Simply note the power in each, and honor the individual journey.

As the initial discussion seems to be winding down, bring out (if it has not already come out) how religious belief and practice has been affected by life-threatening illness. You might directly pose a question such as, “how have your religious beliefs and practices been affected by the disease you now face?” Listen for whether the person is still able to get to church and to socialize with the others there. Listen for the way in which the person prays now, and if there has been intensification of prayer or a sense of alienation.

This question often will lead to the discussion of spirituality as distinct from religion, if it has not emerged earlier in the discussion. Spirituality is hard to define, but it is not the same thing as religion. Spirituality might be described as the experience of relationship with the Eternal, under whatever name or metaphor the person speaks of this Divine Mystery (God, Yahweh, and Allah are only some of the names that persons might use). In Christianity, Judaism and Islam this relationship with the Divine is personal in nature.

From that point, it should be a short jump to the sense of meaning in life now. Has each day become more precious? It is said that when a person is brave enough to look deeply into the darkness, then he or she turns round the light is brighter than ever. What has each person come to see is truly important, that really matters? Encourage members to give their energy to pursuing those things. There is not always a good fit between what we say is important in life and that to which we actually give time, money and effort.

Other ways of asking the question, in no particular order, are suggested below. The main thing is to get the group members talking, to help bring out what has been their experience. The goal is to get to the big question of what is now most important to each member and, having articulated that which is of most value, how each member can focus his or her life more squarely on it:

- “What has given your life meaning? How well have you realized these things in your everyday life?”
- “What has been most important in your life? How well have you organized your life around this ‘pearl of great price?’”
- “What is most important to you now? How can you arrange things to ‘follow your dream’ and to live in the way that you want to live?”

Move to sum up what has been said in the group. Invite others to add to your remarks as they will. Remind the group members of the next meeting date, the focus, possible reading material, and the questions for journaling.

For related sources, see endnotes 111, 114, and 119.

Group #8: Asking for Help

Open the group as usual with a check-in procedure. Ask each member to say something of how life has been, with particular note of any changes in disease or living situation. Ask if there are any further reflections on the subject of the last session.

Note then that in today’s session the focus shifts to a more direct look at the relationship with those on which the patient must rely. This is likely to be a sensitive subject if family members or friends are part of the group. Members will find it difficult to speak frankly

about their feelings, for fear of upsetting these supporters and disrupting such critical relationships.

If Groups Eight and Nine are combined, consider the material under the general rubric of “Talking About Hard Things.” It is at this stage of the group that you are opening up more direct discussion of death. It is an anxiety-provoking subject. Facilitate the discussion by recognizing that it is not easy to talk about this subject.

For the particular focus of Group Eight, provide a conceptual framework. You might note that when a person becomes seriously ill, it follows that the ordinary routine will be disrupted. The nature of the disruption will vary from person to person.

Ask members to consider what kind of person they were before they were diagnosed with serious illness or before the illness or its treatment caused serious changes in their ability to carry out their previous routine. Ask them to consider how they had to change their usual way of being with important others in order to accommodate to the changes caused by the illness.

In the course of the discussion, note that with important others the ideal is that the relationship expresses love and that this love should grow, not diminish, in the experience of illness. However, the illness does stress the relationship, and the path toward growth in love will involve difficulties.

Review some of the ways that illness stresses important relationships. Examples follow, but bring out in the group the unique stressors that they have faced:

- If there is an intimate relationship between caregiver and patient, the caregiver is facing issues of loss just as marked as those faced by the patient.
- As the illness takes its toll on energy, physical appearance, and/or cognitive capacity, the patient is changed so much that he or she seems lost to the caregiver already.
- There is the added burden of trying to care for increasing needs of the patient as the caregiver becomes increasingly exhausted.
- There is a tremendous range of feelings, including depression, anger, anxiety, and guilt for all the preceding.
- There is a sense that one should do more.
- There are real financial strains, from both the costs of treatment and the loss of income.

Consider then the obstacles to openly discussing these stressors. Among other factors, consider that although the patient is often not oblivious to the stress on the caregiver, there may be thoughts and feelings that inhibit the discussion:

- Concern and compassion for the caregiver may be mixed with fear of losing the caregiver's willingness to help as the needs of the patient increase.
- This sense of dependency may result in fear of suffering deterioration in the quality of care as the caregiver wears out and/or a sense of guilt for the strain on the caregiver.
- Patients may not want to further disturb the family or friends, and worry that bringing up issues may do so.

On the other hand, family members may also fear to bring up their feelings, or may bring them up in indirect ways:

- The idea of death may be too threatening.
- The fear of losing the patient may be too frightening.
- Any "negative" aspects of dealing with life-threatening illness may be avoided for fear that this will compromise the patient's recovery.
- There may be a sense of feeling guilty for being angry or tired.
- There may be a sense that speaking about death or the fear of death will rob the patient of hope.

If Group #8 and Group #9 are combined, this is a good place to fold in discussion of Advanced Directives. See the notes on Group #9.

Let the members carry the discussion as much as possible. This will make the discussion more personal. If there is any sense that discussing the "negative" feelings will reduce the chance of recovery, confront this as an erroneous understanding of the role of a "positive" attitude. Painful and conflicted reactions are natural and it is possible to talk about them in a way that does not turn into a downward spiral but actually improves mood and functioning. Healing is a matter of being honest more than of being positive.

Pick up also that these are very natural strains and issues in the unique situation in which they find themselves. The problem is not so much in the strains and issues themselves, but in the absence of communication that may be present. Failure to communicate about significant events occurs when the individuals do not feel comfortable to discuss the natural feelings and thoughts that arise for fear that they will be offensive, hurtful, demoralizing or the like.

Pull together the discussion with a review of key elements in handling the subject of death in a healthy, hope-filled way.

Awareness is the first step. Without awareness of thoughts and feelings about death, they cannot be entered into conversation. Courage is the next. It will never be easy to open up this subject. It is a growth process, but it is hard to begin it. Nevertheless, it is necessary to break the conspiracy of silence that often surrounds serious illness. It is the silence that leads to emotional isolation and greater suffering than is necessary.

Present then the model of conversation as a process that helps such discussion. Conversation literally means “to turn around frequently.” This literal meaning suggests the image of conversation as a collaborative process. One person shares what is in him/her. The other listens and then shares his/her reactions.

We speak of conversation as the solution because no two people are going to have exactly the same reactions to the disease and the dying. One may be perfectly aware that this is the final illness; the other may be unwilling to face death at all. A family member or friend who has depended on the patient may be overwhelmed by fear, exhaustion, confusion, and guilt as the needs of the patient increase. A very private person may now have to give over even intimate bodily functions to the other. The experience and needs of each are unique.

The patient and family/friends are engaged in a slow dance throughout the course of the dying. As in any dance, the communication between partners determines the quality of the experience. In conversation, each can come to a level of sharing that is optimal for both. It is possible to gently open difficult subjects like asking for help, the change in relationship, and some of the losses associated with the illness.

The group today is an example of healthy conversation, in this spirit. Where appropriate, take the opportunity to move some members who are more reticent into the deeper material by asking how they are reacting to what you are saying. Listen for thoughts or feelings that are cautiously offered, reflect those thoughts or feelings, and encourage the members to engage in the back and forth of conversation.

Finally, review ways of coping with the anxiety. No person can stand an unmitigated, unrelieved journey into death and loss. Move the group to considering how patient and family/friends can help each other cope more effectively. Consider these dimensions of coping.

Acceptance seems to be the best overall stance in coping, accommodating to the reality of illness. There is simply no alternative to making adjustments. The patient and family/friends alike must acknowledge the need for help. It is humbling to ask for it and to receive it.

However, within that general stance of acceptance there is plenty of room for individual difference. Some members may be feistier. Others may seek more a sense of peace or detachment. Active coping is always appropriate for those issues about which the patient or family/friends can actually do something. Avoidance or denial do not work for long.

Remind the group of the power of relaxation. There are many approaches to relaxation, but regular use is the key to its life-changing impact. Relaxation is a focused and restful way of reducing the negative power of strong emotional reactions and restoring energy.

Diversion is a good thing. Life need not stop because illness has entered it. Too often, pleasurable diversions are put off because they seem inconsistent with the situation the patient or the couple is facing. It is almost as if family/friends are afraid to laugh. Sometimes family/friends feel guilt about enjoying themselves when the patient is so severely ill. On the contrary, pleasurable activities are not only permitted, they are necessary. Laughing is just as appropriate now as it ever was. As long as it is not forced, it will be refreshing and relieving. Encourage the members not to let disease and dying rob them of the restorative function of recreation, the bonding effect of pleasures enjoyed together, and the gift of humor.

As noted in previous groups, social support is critical. The patient and those close to him/her need the support of friends outside the relationship. These may be other intimates or simply those who make up the fabric of the broad social network. Remember the contribution that even the most casual but dependable relationship makes to the sense of connectedness. Listen for the ways in which the group members have picked up on the content of the previous classes and have started to work the social system and the intimate relationships to develop their potential.

The support of faith, prayer, religious community, and communing with the Creator/Life Spirit, however named, has been demonstrated to be most effective in reducing death anxiety and disability. It has been associated with longer survival.

Bring the group to a close with encouragement to continue the conversation at home. Remind the members to think of each other during the month. Note the questions that will be the focus of the journaling for the next group.

For related sources, see endnotes 115 and 120-122.

Group #9: Health Care Planning and Decision Making

Open the group in the usual manner. Give time for updates regarding the disease and other aspects of life in each member. Ask if there are any further reflections from last group.

Following on the previous group, the subject moves more into the direct discussion of dying and death. Ask how the members did with their journaling. In their reflections, listen for and bring out the concrete life issues that bear on the concept, "quality of life." How have the members begun to define the type of life and health care they want? Are members beginning to set limits on health care that would extend life under conditions that make life not worth living? Are they considering opportunities to discuss these subjects with those close to them and with their medical team?

Empathize with persons who find it difficult to discuss these issues, but be aware also that you may find that the discussion picking up quickly and strongly. These issues are often difficult to bring up in families, but once the door is opened it is not unusual to find strongly formed opinions that members are eager to voice.

Listen particularly for the patients' voices and reinforce any effort they make to express their views on the matter of living and dying. Listen for the emotional reactions of the caregivers and help them enter into a dialogue with the patient. Ask whether this information has yet been shared with other family members. If so, what have been their reactions? If not, what are the obstacles to doing so, and how might they be negotiated?

Be sensitive also to the varying perspectives on death. Those in an early stage of fighting a life-threatening illness may be just waking to the idea of death. They will want to keep a more conscious balance between accepting death and desiring death. With them, focus on that balance. Consider the freedom that comes with letting go the denial of death. Everyday life is experienced even more keenly. Relationships are strengthened by the willingness to discuss openly the "elephant in the living room."

As group leader, it may well be appropriate and helpful to share honest stories from your own experience as family member or professional. Be careful not to hold up an unrealistic ideal. Stories are encouraging when they represent the real human struggles of those involved.

If you have given the group members the Five Wishes Living Will, or some similar form, you might want to ask about their experiences in completing it. Some elements that might lead to productive discussion follow:

- It is difficult to be the person delegated to be the "health care agent." Decisions about life and death weigh heavily, and the advice from the health care team is sometimes hard to decipher. How comfortable does the health care agent selected feel with the role? How open has been the conversation?
- Pain is a symptom that most patients fear most. There is a trade-off between pain control and awareness. What are the desires of the patients in this regard? How do the caregivers react to these desires?
- Medical teams can be difficult to deal with on the subject of death and withdrawal of "life support." How do the members feel about their dealings with health care professionals up to now? How do they anticipate being able to deal with physicians who do not want to "give up?" What have members learned from the earlier module on assertiveness, and how is it emerging in their recent interactions with health care professionals?
- Are there circumstances under which the patient would definitely want life support for a limited time? Does the caregiver have preferences in this regard that should be taken into account by the patient? Does this lead to a deeper discussion between them?

Let this conversation become the heart of today's presentation. There is no one right way to deal with end of life health care issues. The most important contribution you can make is helping members talk openly about the subject. It is very hard for family members to broach this subject. Either the patient or the caregiver, or both, may believe that it is more sensitive and delicate not to bring the matter up for discussion. As a result, both sit with the tension, and neither is able to make a start dealing with the real decisions to be made.

Just as at home or in the medical office, different people are at different stages in terms of coming to meet death. For those who are at later stages of the living/dying process, it will be important to have the freedom to express the range of emotions they feel. Feelings of peace co-exist with feelings of fear and sadness. Help members in earlier stages to give these other members "permission" to speak freely.

As the discussion winds down, begin to summarize the particular points made by the members. Bring out the unique situations in which they find themselves, and see if you can help each pair or individual articulate what are the next steps to take. Involve the group as a whole in this process. Point out how the group process demonstrates the varying reactions to death and stages of meeting it. Point out how the group was able to allow each person to be where they are. Struggling to find this level of mutuality and respect actually strengthens each member in his or her own situation, and supportively encourages continued growth.

Encourage the members to take these steps before the next meeting. If there is significant anxiety, try to help the members most anxious to define the next step in clearly feasible terms. Allow for the possibility that others may not want to talk, or may even actively resist their efforts. Remind the members that they can call each other for moral support.

When you have helped each person come to a general plan for increasing communication with family, friends or health care team, bring the group to closure by reminding them of the next topic. Suggest journaling on the efforts they will make to carry out their plans for increased communication around end of life care. Bring up some of the particular questions to be considered vis-à-vis the next topic.

For related sources, see endnote 123.

Group #10: My Legacy

Bring the group together. After reviewing the status of each member present, bring the members up to date on any members not present.

By way of opening today's discussion, ask first if there are any further thoughts from last month's discussion. Today's discussion continues what has been an increasingly explicit discussion of death. Then ask the members how it was to journal or otherwise reflect on the questions for today's session. Was it easy or difficult for the members to think about

the way others see them, and the meaning their lives have for the people around them? What sort of feelings came up in the process of considering the value of those things the members accomplished in their lives?

Some members of the group may find it more difficult than others to enter this stage of the group. However, there is no way to enter fully into the search for health, fullness of life (“to live until we die”), or real healing (“loving well”) if we cannot enter at least a little into the reality of our death. Any search for healing that does not include the acceptance of death is running away from something rather than groping toward wholeness and love.

At this stage of life, there is a keen sense of life’s impermanence and fragility. The members can probably remember a time when it seemed they would live forever. Now the reality seems quite different. As we suggest in the motto, “to love well is to live forever,” there is truth in both experiences. The fragility and transience of life *cannot* be denied. The resilience and enduring quality of life *should* not be denied. Each individual has made some type of personal impact on those who really knew him or her. Some of those people live on for a time, and those whom they touch will live on longer. There is a rippling effect of decisions made and actions taken, not only “sideways,” but also forward through time yet to come. The impact of a life is not limited to what has been done, but includes what will yet be done. The time remaining is a time for new decisions and fresh action or healing words.

Life review is a way of coming to realize the effects of one’s life. Telling the story of one’s life is the most integrative and healing way to do the review. Making a story of life forces the individual to think in terms of the relative importance of events. It focuses attention on the motivations of self and others, and the way motivations have evolved over time. In the story itself it becomes clear if the same things seem to happen over and over again, or if life has unfolded in surprising ways. The emotional “tone” of the story makes very clear whether life has been perceived as a positive or negative experience. If the person seems stuck on some aspect of life—a lost opportunity or harm done or imposed by another, for example—that “stuckness” will be reflected in the story.

We tend to think in terms of an oral or written story and, indeed, these are the more common ways of presenting it. However, there are many ways to tell stories. Some persons do much better to pull out old photographs, selecting and arranging those that seem most important. Others begin better with a time line on which important events are arranged graphically. Encourage the members to think aloud about the different ways one might put together a “story board.”

Then move the discussion of the group toward what can be done with the story as there become evident different areas in which there is not good resolution of particular issues. The main thing is that members understand that they need not remain “stuck.” It is true that the “past is past,” but that does not mean that problematic emotions, troubling thoughts, or unhappy consequences cannot be worked with. Those things are all “present.”

This resolution can occur in many ways. One method is to re-work the story, when appropriate to do so. There may be many alternative ways to understand the events in question that would change the unhappy feelings or troubling thoughts. The past event may not seem the same to other persons. There may be opportunity for reconciliation with those from whom a member has been alienated. When possible, this is a very positive action, offering healing to both parties. Sometimes the best that can be done is to let go of the past and “turn over” the consequences to God, however understood. Some time of ritual in which the member seeks or offers forgiveness may be a helpful way to make this “turning over” concrete.

As this discussion comes to a close, remember also that reviewing life is only part of the answer. There is still life to be lived and each moment of it is important. This will move into the subject of the next group—living life now, in the moment. For today, just remind the group that this subject is on the docket. Note that good discussions with others at any time often lead to a sharing of insights, dreams, hopes, joys, sorrows and the like. All of this is meaningful.

In these moments, members may want to consider fresh ways of creating memories for others. Letters, tapes, or other media hold parts of the person that may be very precious to those who live on or perhaps even those not yet born. Taking time to tell stories with children or grandchildren builds a bond that will not be broken with dying. Collections of photographs in small albums, complete with commentary, tell vividly the stories of visits or special events.

Finally, we know and recognize that for persons of religious faith, there is a sense that life goes on. Death is a door to go through. If members bring up this way of seeing death at any time during the discussion, pick up on it, support their observation, and allow for discussion. At this time, facing the reality of death, anxiety is not unusual. Even persons who have been very active in their faith may now wonder, “is it really true?” Allow for the commonness of such questions, and encourage members to raise it with teachers or ministers of their faith community. Listen for the ways that even persons who have no religious faith may have a sense of life continuing in other ways.

At that point, bring the group to a close. A session like this one would benefit a great deal from some type of reflective text or poem, even if you have not done so before. Encourage the group members to follow up this session with some action that seemed good to them.

Then remind the group that the next session will focus on living in the moment. Bring their attention to the questions for journaling.

For related sources, see endnote 115.

Group #11: Hope and Gratitude

Open the group in the usual way. Allow the members to bring each other up-to-date regarding their illness and other experiences of their lives. The last group discussion may have resulted in new recollections or insights. Give time for them to be shared. They offer a natural segue to the material of the present group. The “stuff” of days past is what constitutes each individual today. Living today, in the moment, is the focus of today’s group.

As the members finish the discussion of the impact of last month’s group, move into a very brief presentation about the idea of living in the present and for as long as possible while facing the reality of dying. The following ideas may be helpful in this presentation. Do not feel compelled to use all of them. This topic can be addressed only from the individual perspective of each member, and by this time if the group is going well the members will be very anxious and able to carry on the discussion among themselves. You will be most useful as a facilitator of this discussion, guiding it toward useful ideas for building on what the members have been able to do so far.

This idea of living in the moment is an ideal at any stage of life, and it is difficult. We naturally spend much of our time in the past and in the present. To recall the events of the past or to anticipate the events of the future are not “bad” things to do. However, much of the time we are recalling or anticipating negative events. We may be regretting what we have done or not done. We may be worrying about what might yet happen. We become “stuck” in our anxiety, resentment, envy, remorse, and the like.

It is possible to live more and more in the present. When we live in the present and remember the past, we do so with acceptance. We see the ways that things have worked out, no matter how bad they seemed at the time. We grow in our sufferings. We see those things that have not yet been worked through. We enter them now and work them through. We surrender to what might happen in the future. In surrender, we commit to doing what we can, then letting the rest go. We ask for what help we hope for, and find gratitude for what help we are given.

For the members in the group, there is an even greater challenge. It is especially difficult to live in a present that is very much shadowed by the looming presence of death. The natural tendency is to be filled with worry about the future or regret about the past. The focus of today’s group is to process what it means to live in the present in these particular circumstances. This is the only way to find both hope and gratitude in what is a very hard time.

Hope and gratitude are healing affects.

Hope is not the same thing as wishful thinking. While it may be that initially a person may hope for some specific outcome, usually some form of recovery from the disease, living in the present while acknowledging the reality of dying leads to a greater reality. It becomes

clear that the dying will come; it is only not clear when and exactly how. It becomes clear that every other person who lives or has lived or will live faces this same reality.

There is comfort in the surrender to this reality. There is courage and liberation in facing squarely that which one has known all along [the dying] but of which one has been afraid to speak. There is empathy in understanding that in facing death, one is not alone; some realize their condition and others have not yet seen it, but the reality is the same. One finds freedom to fight the disease, because that is what the living do, but this fight is carried on in the understanding that sooner or later it will be time to give it over. Gritty determination, anxious desperation, or blind optimism have no place here; peace comes in being firmly grounded in the truth of the matter. Hope allows one to persevere, moving closer and closer to a true serenity.

Gratitude emerges as a companion to hope. It springs from an optimism that good will come no matter how bad things seem to be. It assumes that there is more to be understood than meets the eye now. Gratitude emerges also in the appreciation for life that is a natural result of living in the moment. Because one is more aware of death, one also is more aware of and appreciative of life, life now, as it is. There is less grouching about the way things are. There is appreciation for what others do rather than aggravation about what is not done. Hope begins with the sense of being loved. Gratitude comes to fullness in loving others.

This coming to hope and gratitude is a coming to wisdom. A selection of Psalm 90, paraphrased below, brings out this new burst of life. “Our life is over like a sigh. Our span is seventy or eighty years for those who are strong. Most of these are marked by emptiness and pain. Even so, they pass swiftly and we are gone. Who understands these things, our fragility and transience, in the flower of youth? Make us know the shortness of our life that we may gain wisdom of heart.”

In presenting this information, leave plenty of room for persons to identify with it as a developing reality. Each person will be in a different place. There is no point in offering an ideal against which the members will feel insufficient. There is hope in presenting a path along which everyone can find himself or herself walking. Members not far along will find solace in hearing that others who may be farther along were at exactly the place earlier. Everyone will be encouraged to know that this is a reliable path, that the journey to death is not one of unrelieved sadness and loneliness.

Sharing experience is part of being on this path. Lead the group discussion in this spirit. Listen for the ways in which members have found life “in the light of the shadow of death.”

There are many ways in which the group interaction has already helped to break up the sense of isolation and its associated helplessness and hopelessness:

- New ways of looking at the situation allow for freer choices. Developing a set of realistic options returns a sense of self-determination. Developing confidence in the

“wisdom of the group” enhances confidence that the individual has or can draw on sufficient and reliable resources.

- Dependence is re-framed as healthy interdependence. Each client draws support and gives support.
- Problem-solving occurs naturally by sharing experiences. (Advice-giving is a different thing, and lends itself to condescension. Methods of coping vary quite a lot from one person to another.)
- Sharing experience is healing in itself. Memories help in grieving. Reviewing the past can help in finding meaning in the present.
- Shared feelings are easier to manage. Most common feelings include depression, fear, anger, guilt and shame. Intense emotion leads to fears of “falling apart.”
- The disease is easier to face. There is not the sense of being alone or even singled out for the particular hardships.
- There is power also in realizing and empathizing with the sufferings of others. To be cared for and to care for others is healing. Love is the foundation of everything. As the theme of the group reads, “to love well is to live forever.”

As the group discussion begins to wind down, summarize what the members have shared about what it means to live in the moment. Ask members what they take from the group that will help them live in this way, with hope and gratitude, without denial of the difficulties they face and the end that is the common fate of all humans. Emphasize the importance of having companions like those in the group who share their awareness. Contrast this type of discussion with the experience of speaking with persons who have not yet come to own the reality of their own death. Comments from such persons can be very painful; most members will have had such experiences already.

Remind the group that the next session is the last scheduled group. There may be some grieving to be done. Listen for the reactions. Ask the members to reflect on what membership in this group has meant to them. Let them know that the next check-in will be longer than usual. Each member will be given time to speak to the experience.

With that, bring the group to a close.

For related sources, see endnote 111.

Group #12: The Final Session

Call the group together. Remind the members of what they already know, that this is the last scheduled meeting. There will be some grieving to be done. Listen for these feelings and help them come out. Do this simply, with reflective comments, rather than trying to resolve the feelings too quickly.

Ask the individuals to reflect on the journey of this last year and on what membership in this group has meant to them. Allow the check-to go on longer than usual, and to flow into the discussion of what members will do from this time on to make their personal journey richer. Each member should have time to speak to his or her experience of the group.

Help the members articulate how they plan to use all that they have learned in the groups to make living and dying a healthier process from this time on. Recognize that many members will intend to keep up contact in the future; encourage this intention and help the members explore how they might do so. Others will fold what they have taken from the group into their own social networks; ask them how their relationships with others, intimate or casual, have changed as a result of what they have learned.

From this day, each member's journey will go on, whether for a long time or a short one. However, long it may be, it is important that each member be encouraged to recognize, honor, and share with intimates his or her own "dreams and visions." Unusual experiences are usual in the time of dying and/or letting go. Sharing them is part of the process of developing bonds of love, and love is what heals. However, individuals are sometimes reluctant to speak of their dreams and visions. They may fear, not without reason, that others will not understand, and in their confusion will minimize such experiences. There is a painful sense of distance when one shares an intense, powerful and meaningful experience only to have it minimized or explained away.

To help the group sharing, you might tell, at an appropriate moment, a story of which you have been a part. For example, a man who knew well that his current illness was his last, reported dreams in which women were trying to help him undress. They told him they wanted to help him bathe. He resisted them, fearing their intentions. He was a private man, a man of sexual propriety, and a man cautious about his money. As he spoke of these dreams and visions, there was a progression. He experienced the women inviting him onto an amusement park ride, a ride on replicas of old cars. He now spoke more directly of his fear that they were inviting him too soon to die. Gradually, he came to terms with this invitation. In the end, he died as he was being washed by an attendant. It was a beautiful ending to his dreams.

It is a grace when such dreams and visions come and are worked out on the deathbed, but it does not always happen in this way. It is important that the patient not put off working such dreams. It is valuable to speak of unusual experiences and in so doing to allow them to work out whatever fears are standing in the way of a more peaceful dying.

Such experiences that cross the line of reality as we have come to know it are just as important for the caregiver. These may come as dreams or visions, before or after death. We tend to explain them away, but in so doing we turn away what are most valuable gifts for helping us in the leave-taking.

The same is true with regard to unusual sensory experiences. For example, a physician recalled entering the room of a friend who had been diagnosed with a virulent form of cancer. She was dying, and she knew it. The physician spoke indirectly and with a euphemism of her dying. She rejected the indirection and came right to the point. He put his hand on her shoulder, a place to which the cancer had spread. She immediately brightened and said that she felt great warmth. The physician became even more uneasy and began to rub the area self-consciously, as if to explain the warmth by making it a natural consequence. The mystery of the experience was broken. The tone of the conversation was cordial but shallow. An opportunity was lost. No one is really to blame, but it may be that by being aware of the possibilities and preparing ourselves for them, we can make better use of such mystical gifts.

Allow other members to share their stories. Encourage persons to own the experience of facing death, leaving this life or saying good-bye to another. This sharing may help all involved to actually be there, to be more fully present to the experience.

It is likely that this group will be one in which strong feelings are shared. There may be a sense of gratitude for the sharing of others. As facilitator, be an empathetic presence. Help shape a context in which it is permissible and safe to express such feelings. You will need time and support later to process your own feelings, but for now be the strong but comforting presence that allows others to feel their vulnerability and need. Note the expressions of gratitude, in general or toward particular individuals.

As the time and discussion winds down, begin to pull together the group. The last and perhaps most important contribution of the group social support is the support to leave when it is time. Model this way of saying good-bye in the group today.

You might end the group with some type of ritual. For example, you might ask each person what thought or wish, said in very few words, would best express their hopes for the group as a whole. A song or a poem might capture the sentiment. Perhaps some symbol, based on the ideal of "loving well," might be given out.

However it is done, bring the group to a close. Offer your own expression of the meaning of the experience for you as facilitator. Offer your wishes for the group as a whole and/or for individual members.

Make arrangements for the group room or a near-by space to be available for informal good-byes. You might consider having some light refreshments.

For related sources, see endnote 111.

CHAPTER 6

Crises

Death or Setbacks of Group Members

For any group process, the unexpected loss of a member can be an important event, especially if a sense of group cohesion has developed. If the loss of a member is due to illness, the impact of the event may be even more profound than loss due to other reasons. There are several important issues to consider when a loss occurs:

- **Closure:** Are there issues related to the lost member that are unresolved? Was anything left unsaid with respect to this person? These questions must be processed and time must be allocated that will undoubtedly take away from the planned topic of discussion. It is important to bring the loss to closure, but it is equally important not to allow the loss to take away from the work and time of the group (see below).
- **Role Issues:** The loss of any member will affect the established roles of the group. This will be especially acute if the lost member was particularly well liked, insightful, or influential in the group. The facilitator must be alert to this change and allow the group members to work themselves into new positions within the group. This process of role re-establishment should be allowed to unfold; it should not be formalized or pushed.
- **Group Survival:** The loss of more than one group member may be hazardous to the continuation of the group process. If too few members remain, those left in the group may not feel it is worthwhile to continue. This is an important practical issue that must be addressed outright. The facilitator must be in a position to balance the costs and benefits of continuing a reduced group. Group members may prefer to be introduced into a different existing group, although there are dangers to this choice also, for the new member and the existing group.

Using Crises to Promote Group Growth

See Spiegel and colleagues, *Brief Supportive-Expressive Group Therapy for Women with Primary Breast Cancer: A Treatment Manual* to understand the loss of a group member as a metaphor for loss of life.¹⁰³

Some Warnings About Handling Crises

- **Excessive focus**
Issue: not good to spend too much time on it; takes away from the other important work of the group.

- Personal involvement
Issue: facilitator must maintain a professional distance from crises, while at the same time showing empathy and concern.
- Resentment
Issue: members who are upset that the group did not “work”; i.e., the person died anyway

CHAPTER 7

Problem Solving and Feedback

Hazards to Good Group Process

There are a number of events, scenarios, personality styles, and dynamics that are a threat to good group process, learning, and sharing. These include, but are not limited to, the following, with some ideas for dealing with them when they emerge:

Some members may need more than “affective education”:

- If a member does demonstrate a need for more in-depth work to deal with significant problems, or if the defenses/boundaries of a member are not solid, deal with the situation by gently noting in the session the purpose of the group.
- Later make arrangements to have the individual see a psychologist for more in-depth work in addition to continuing in the group.

The person who talks at length and/or focuses excessively on self:

- Do not let any one member dominate in either time taken or forcefulness of presentation.
- Solicit the experiences of each member without pressuring anyone to speak.
- A “Yes, and...” attitude should be the norm.
- Strongly held beliefs are valuable and should be encouraged, but individual members may express them in such a way that they feel coercive. Model for group members how such ideas can be expressed using “I” statements.

The person who has a negative or resistant attitude about nearly everything:

- Negative comments should be used to demonstrate that “the group is more powerful than individuals.”
- Facilitators should point out that disagreement may exist; in fact, that disagreement and voicing of issues is what is important about the group process.
- The facilitator should strive to break down negativity through the examples of other members.
- It may be important to “go with” resistance for a time, especially early on when members may be anxious. Facilitators should emphasize that anxiety will serve the

group, and that everyone, including the facilitator, is nervous about the process. Emphasize that this is a gradual process, and that a relationship will develop over time, with everyone working together.

The person who takes off on irrelevant tangents:

- Remind the group about the topic of the day and suggest ways of linking the tangent back to the topic.
- Be sure the tangent is irrelevant; if not, allow some flexibility.

The person who says very little:

- Use aspects of nominal group technique to bring out opinions. In nominal group technique, group members take several minutes to write down their reactions to an issue or discussion topic. Then, short statements are elicited from each group member in a round-robin fashion, one at a time. No comment on other members' statements is allowed in the elicitation phase, and no talking or comment is allowed out of turn. The elicitation phase continues until all statements are exhausted. To facilitate later discussion, the group facilitator may want to write down the statements as they are made (e.g., on a flip chart). Once elicitation is finished, group members are allowed to ask for clarification of others' points. Then, a general discussion commences, with group members reflecting on the experiences of others as described by the statements. This technique ensures that everyone's story is told, and stimulates reactions and discussion of experiences that may never have been shared using a standard process. It also prevents one person from monopolizing the discussion or "stealing" another's issue or experience.
- Watch for nonverbals that signal that someone is ready to talk or wants to talk.
- Do not pressure.
- Facilitators should try not to press for personal revelations from members in the beginning, but encourage an interactive process.

The person who focuses excessively on others:

- Emphasize rules of acceptance, tolerance, and self-awareness.
- Redirect the other-focused person to his or her own experiences.

Cross talk:

- "Cross-talk" among members should be identified and not allowed to get out of hand.

- Facilitators should redirect the cross-talk as evidence of an interactive process; this puts a positive spin on the event without the facilitator appearing too restrictive.
- Play the “traffic cop” role; keep things moving without it being obvious to those being moved along.

Hazards to Group Success

No shows, late shows, drop outs:

- It is critical to emphasize the need for all members to make every effort to attend each meeting.
- Unavoidable problems will arise, but the member should call the group facilitator before the group to say that he or she will be unable to attend.

Rebellion:

- Issue: moving away from the purpose of the group; refusing to attend to the facilitator’s direction; complaining, discontent, etc

Lack of efficacy:

- Issue: the group does not appear to be having any impact; members feel they are getting nothing out of it; members do not understand the purpose of the group

Getting Feedback

- Feedback should be regularly solicited from group members.
- A form such as that shown in Appendix 3 should be considered.
- Some group members may prefer the distance of a form for airing their concerns, grievances, or issues.
- Feedback can be made voluntary. Group members may be allowed to complete the forms prior to the end of the group, or to take the form home with them.
- Ask informally how group members react to the group process model. Bring out that what is healing is the combination of support and expression. Let the group members share their reactions. Some will be anxious, but others will have had positive experiences in groups elsewhere.

CHAPTER 8

Branching Out to Physicians

As detailed in Chapter 1, one of the goals of the Coalition for Compassionate is to encourage supportive care skills among physicians and to support programs that reform physician approaches to end-of-life care. As a result, we have expanded our supportive-affective group program at Saint Louis University School of Medicine to include physicians. The goals of our physicians groups are to:

- foster among practicing physicians an appreciation for and sensitivity to the spiritual, emotional, and relational aspects of serious illness and dying;
- to reinforce the importance of spiritual, emotional, and relational health to general well-being by examining the role of each in the physicians' own professional and personal lives;
- to explore mechanisms by which end-of-life care can be more spiritually, emotionally, and relationally sensitive, within the limitations of the current medical environment and the demands of the modern medical occupation;
- to explore past motivations for entering a helping profession—especially those related to healing, caring, relief of suffering, and other human aspects of medical care—and how these relate to the spiritual, emotional, and relational needs of seriously ill and dying patients.

We have found that one question is sufficient for each group session, that each session must begin and end promptly and last no more than 60 minutes, and that physicians have a wide variety of opinions, attitudes, and experiences with respect to end-of-life care and their own professional and personal journeys. Most importantly, we require the participants to commit to only four sessions, rather than 12. At the end of the fourth session, the desire of the group to continue is evaluated and a decision is made.

The general outline for each of the first four groups is presented below.

Physician Group #1

Preliminaries.

- Outline goals of the group
- Lay down ground rules and expectations
- Introductions:
 - Who are you?
 - On what service do you work?
 - How many years have you worked as a physician?
 - Why did you agree to participate in this group?
 - Do you have any particular expectations?

Primary activity. Each member responds to the following statement: “Describe an experience that *you* had as a physician during which one of our core areas—that is, during which *your* spiritual, emotional, or relational needs—came to the fore. How did it affect your professional and personal life?”

Secondary activity. A short video clip is viewed (7 minutes taken from the television show ER) and each member writes down, independently and anonymously, their reactions to the following questions:

- Why did you decide to become a doctor?
- Has the work fulfilled your expectations?
- Are there times when none of it seems worthwhile anymore?
- What situations make you start to wonder about your values?
- Can you name one or two things that would make your life better?

These responses are used to start the next meeting.

Closing activity. Generally, our groups are closed with a reading or non-denominational prayer.

Physician Group #2

Primary activity. Responses to video clip (written down at end of last meeting) are distributed in summarized form. General discussion of responses to the five questions follows:

- Why did you decide to become a doctor?
- Has the work fulfilled your expectations?
- Are there times when none of it seems worthwhile anymore?
- What situations make you start to wonder about your values?
- Can you name one or two things that would make your life better?

Secondary activity. Distribute and explain paper on emotions (“What’s a Doctor to Do?” see Appendix 4). Distribute reflection and questions for next session:

- Reflect on this quote: “...I was more and more encountering a strange and enormous God. A God who reflected back to me always a tension between beauty and suffering; between joy and sinfulness; between past and future; between the individual and the community...More and more I found that I do not base such frail faith as I have on the feeling of “what a friend I have in Jesus” but rather on the continual inescapable sense of the power and the mystery and the danger and the profligacy of it all. I mean *all*, from the bizarre goings-on inside each atom, right through to the social complexity of history and class and gender and race and individual experience.” --Sara Maitland
- Questions:
 - When have you had a glimpse of God or the transcendent? When have you experienced the holy?
 - How did you know?
 - What happened to you?
 - What nurtures your connection to or relationship with the transcendent?

Closing activity. Group is closed with reading or non-denominational prayer.

Physician Group #3

Primary activities.

1. Discuss reflection and questions distributed at end of last meeting.
2. Discuss this related question:
 - What makes you resistant to, or what prevents you from, speaking of spiritual issues with patients?

Secondary activity. Distribute questions for Group #4 and process any reactions to them. There are two main questions:

- A patient once remarked: “I never get a chance to get to the real issue with my doctor.” What does this mean to you? How does one get to the *real* issue with a patient? How can a doctor take the lead in addressing spiritual, emotional, or relational questions with patients?
- What has been your experience of this group process? Has it been beneficial? In what ways? Do you wish to continue meeting?

Closing activity. Group is closed with reading or non-denominational prayer.

Physician Group #4

Primary activities.

1. Discuss question distributed at end of last meeting:
 - A patient once remarked: “I never get a chance to get to the real issue with my doctor.” What does this mean to you? How does one get to the *real* issue with a patient? How can a doctor take the lead in addressing spiritual, emotional, or relational questions with patients?
2. Discuss and make decisions about the progress and future of the group:
 - What has been your experience of this group process? Has it been beneficial? In what ways? Do you wish to continue meeting?

Closing activity. Group is closed with reading or non-denominational prayer.

It has been our experience that discussing any of these questions in 60 minutes is very difficult. Other sessions can be used to continue discussions started in previous groups. At this point in our program development, our physician group model has not progressed beyond the fourth group. Subsequent additions of this manual will contain the additions.

CHAPTER 9

Empirical Evidence

Preliminary evidence from our own program of supportive-affective groups indicates that this intervention is effective in reducing patient symptoms of depression, increasing spiritual well-being, and empowering patients to discuss spirituality with their physicians.

In our work, symptoms of depression were assessed with the Beck Depression Inventory (BDI).¹²⁴ This scale is very widely used both clinically and in research. It yields a total score that can range from 0 to 63, with scores of 10-15 representing mild depression, 16-20 moderate depression, and 21 and over moderate to severe depression. Any score over 30 is considered severe. The average score for our patients at baseline was in the 15-16 range (with a standard deviation of about 10), representing mild-to-moderate symptoms of depression.

Spiritual well-being was assessed using the Spiritual Well-Being Scale.¹²⁵ This is one of the most widely used “spirituality” scales in research. It conceptualizes spiritual well-being along a horizontal dimension (existential well-being, or the individual’s sense of life purpose and meaning) and a vertical dimension (religious well-being, or the individual’s sense of relationship to or communion with God or the transcendent). Each dimension yields a score that can range from 10 to 60, with higher scores indicating greater well-being. The average score for our patients at baseline was about 45 for religious well-being and about 40 for existential well-being (with standard deviations of about 11). These values are consistent with previous research on medical outpatients and indicate a conventional to moderate level of well-being along the dimensions.

We conducted a randomized controlled trial of the effect of our curriculum on patients facing death from organ-based diseases, HIV/AIDS, and geriatric frailty. About half of the 67 patients recruited for the study were randomly assigned to participate in the groups. The other half did not attend groups, but received monthly mailings at home on basic topics related to end-of-life. Our results indicate that group participants with organ-based diseases or HIV/AIDS improved significantly, relative to the control group, on symptoms of depression and religious well-being (but, interestingly, not existential well-being). The change in depression symptoms represented a decrease of nearly five points on the BDI (or about one-half standard deviation in the intervention group). Thus, the depression score changed from a mild-to-moderate level, on average, to an almost clinically insignificant level (of about 10). The change in religious well-being was even larger. Relative to the control group, patients who participated in the groups improved in religious well-being by more than six points (or about 0.6 standard deviation units). Overall, patients in the intervention groups were more likely at the end of 12 months to have initiated a conversation with their primary physician about spiritual issues or needs.

(It is of interest that these changes were not found among the geriatric patients. As we detailed in Chapter 3, the curriculum appeared more suited for patients with life-threatening diseases or conditions, rather than for people facing death as the result of advanced age and frailty. In addition, the geriatric patients started out in our study less depressed and more spiritual than their younger counterparts in the disease groups.)

As detailed in Chapter 2, previous research has shown that depression is a serious problem among medically ill persons, and that untreated depression can worsen symptoms, prolong recovery, and increase the probability of recurrence or exacerbation of some diseases. This is not to mention the negative effects it has on the patient's quality of life, ability to relate to others, and ability to truly live until death. With respect to religious well-being, previous research¹²⁶ has shown that this dimension is positively associated with self-esteem, adjustment to illness, a sense of hope, and the use of religious faith as a source of coping with diseases like cancer. It is negatively associated with social isolation, despair, and stress. Discussing spiritual needs with healthcare professionals is something many patients want to do as the approach death, but few ever do. Our program appears to facilitate this process and empower patients to bring this issue up with their physician.

In summary, our findings regarding depression, religious well-being, and spiritual conversation suggest that this curriculum can improve the lives of patients facing death. These results are particularly important in light of the Coalition's (Supportive Care of the Dying: A Coalition for Compassionate Care) emphasis on improving the spiritual, emotional, and relational aspects of care for people facing death. Our findings indicate that activities that promote health along these three dimensions—including the behaviors and attitudes of physicians, nurses, and other healthcare professionals—will improve the quality of life of patients facing death and help them to cope, prepare, and, most importantly, live until they die.

CHAPTER 10

Final Thoughts

Our supportive-affective group program was designed to address the spiritual, emotional, and relational needs of patients with life-threatening medical conditions. The work of Supportive Care of the Dying: A Coalition for Compassionate Care has shown that these three areas are vitally important to patients facing death, but also overlooked in the delivery of medical services. Our mission was to show that by attending to these basic psycho-social-spiritual needs, patients would experience enhanced well-being during the days they have left and be more prepared to do the difficult work of preparing to die on their own terms. Further, we brought these issues directly to the physician healthcare providers, with the intention of raising consciousness, dispelling myths about what patients want when they die, and demonstrating the importance to patient health and well-being of physician awareness of, support for, and attendance to the non-medical aspects of care.

This manual provides a way to replicate our experience. Your experience may vary from ours in unpredictable ways, but by following the general format of the program as laid out in this manual, you will have a greater chance at a successful intervention. This program will work for some and not for others. The important point is that patients (and physicians) have some mechanism for addressing the critical issues as they live with the prospect of death.

Keep in mind that what really matters is not dutifully following a curriculum, but creating a bond among the group members that is reflected in a commitment to each other. The curriculum is only a vehicle. Information is essential, but not sufficient. It allows people a reason to get together, while the coming together creates the bond. The ultimate success of the group is whether it leads the patient to know two things: “I am important” and “I mean something.”

More than anything else, we hope that this program facilitates the ability of people with life-threatening medical conditions to “live until they die.”

To Love Well is to Live Forever

APPENDIX 1

Journal Questions

Group #1:

- List the people, places, and things that have meant a lot to you in your life.
- Which of these are still a part of your life and which are not?
- What are your expectations for this group?

Group #2:

- What do you feel most comfortable discussing with those close to you? What do you feel most uncomfortable discussing?
- What kinds of situations make you the most nervous?
- What jobs have you held in your life? How did you assert yourself in job situations?
- What kinds of situations have you encountered where you needed to assert yourself? How have you gotten needs met in the past?
- Think about the doctors and nurses who have cared for you. With which ones did you relate the best? Why? What were they like?

Group #3:

- What are some of the most amazing or awe-inspiring experiences you have had in your life? What are some of the most frightening or threatening experiences you have had in your life?
- What are some unexpected events that clearly stand out in your memory, both good and bad?

Group #4:

- What makes you feel good? What calms you down? What improves your mood?
- What are the main ways your medical condition interferes with your life? What have you had to stop or give up?
- When you feel down, nervous, irritable, sick, miserable, etc., what do you do to make yourself better?
- What ways do you have for coping with the physical pain of your medical condition?

Group #5:

- Describe some times when you laughed really hard.
- Discuss some experiences that challenge your ability to cope with it all. How do you respond to them?
- What do you do to feel more like your “old self”?

Group #6:

- Consider the following: You have one month free of all obligations and responsibilities during which you can meet and talk with anyone you choose. With whom would you like to meet and what would you discuss?

- How has your illness affected your relationships with those close to you?
- Who cares the most about you? About whom do you care deeply?
- To whom do you go when you need to talk? Who leaves you feeling better after he or she talks with you? What type of things does this person say?
- Do you worry that talking about your health condition will make others feel bad? Does it make you feel like a burden? Does talking ever make you feel worse?

Group #7:

- What gives your life meaning? How does this relate to your everyday life?
- What is worth any sacrifice on your part?
- Do you pray? If so, what do you pray about? After you pray, how do you feel?
- Do you belong to a church or other religious community? If so, how has your involvement there affected your life in light of your illness?
- Have you ever experienced the presence of some power greater than yourself? For example, would you say that you have a personal relationship with God? Or is it something different from that? Please describe it as best you can.

Group #8:

- How do you feel about your primary caregiver? What does this person mean to you? What are some problems you might have with this person?
- How do you think your primary caregiver feels about you? What effect has your illness had on this person and his or her needs?
- If you do not have a primary caregiver, what does it mean to you that you do not have that resource?

Group #9:

- What does the phrase “quality of life” mean to you?
- What are some experiences in your life where anticipating a problem has helped to solve it when the time came?
- How would you change health care for people with your health condition?

Group #10:

- How do people see you? How do your closest relatives and friends describe you? Is this consistent with how you see yourself?
- Of all the things you have done in your life, of which are you the most proud?
- Think of ways that your life has made a difference in the lives of other people.

Group #11:

- What do you really want to get accomplished in the next year?
- Who are the people in your life who mean the most to you? Have you told them so? If not, would they appreciate knowing?
- Has your illness taught you anything about yourself that you did not know before?

Group #12:

- Describe some situations where you have successfully advocated for yourself: How do you feel about this?
- Why are you so important? Why do you deserve to have your needs met or your voice heard?
- How do your needs fit with the needs of others around you or those involved with your care? What is the best way to achieve a balance of needs?

APPENDIX 2

Group Session Handouts

Group #1:

- *Healing Your Body, Mind, and Spirit Together*, Care Notes #21256-3

Group #2:

- *Learning How to Talk with Your Doctor*, Care Notes #21255-5

Group #3:

- *Being Angry with God at a Time of Suffering or Loss*, Care Notes #21339
- *Feeling Overwhelmed by Illness*, Care Notes #21302-5

Group #4:

- *About Living with Chronic Pain*, Channing L. Bate #15107F-4-98
- *Managing Your Medications*, Channing L. Bate #70342B-4-98

Group #5:

- *Living Creatively with Chronic Illness*, Care Notes #20664-9
- *When the Healing Isn't Happening*, Care Notes #21366

Group #6:

- *Healing a Troubled Relationship with a Dying Loved One*, Care Notes #21350
- *When No One Wants to Talk About Your Illness*, Care Notes #21368

Group #7:

- *Finding God's Healing Power When You Feel Broken and Helpless*, Help Notes #21510
- *Wanting to Feel Closer to God*, Care Notes #20696-1

Group #8:

- *Caring for a Loved One with Terminal Illness*, Channing L. Bate #72935A-7-98
- *Coping When Someone You Love is Dying*, Care Notes #21263-9

Group #9:

- *About DNR Orders*, Channing L. Bate #39693B-10-97
- *End of Life Decisions—Making the Right Choice for You*, Channing L. Bate #71407C-4-98
- *Using Hospice Care When a Loved One is Terminally Ill*, Care Notes #20655-7

Group #10:

- *Making Sense Out of Suffering*, Care Notes #21204-3

Group #11:

- *Facing Chronic Illness with Hope and Courage*, Help Notes #21519
- *Hanging on to Hope Through a Serious Illness*, Care Notes #20612-8
- *When Your Prayers Go Unanswered*, Care Notes #20605-2

Ordering Information:*1. Care Notes and Help Notes may be ordered from:*

One Caring Place
Abbey Press
St. Meinrad, IN 47577
1-800-325-2511

2. Channing L. Bate pamphlets may be ordered from:

Channing L. Bate Co., Inc.
200 State Road
South Deerfield, MA 01373
1-800-628-7733

APPENDIX 3

Group Evaluation/Feedback Form

Directions. Circle one number (1-7) for each question. Then, on the lines that follow the question, write in your suggestions or comments for improving the group experience.

1. At this point, how *satisfied* are you *overall* with the group experience?

1	2	3	4	5	6	7
Not At All Satisfied			Moderately Satisfied		Very Satisfied	

Suggestions/Comments: _____

2. How would you rate the *group facilitator*?

1	2	3	4	5	6	7
Poor		Satisfactory			Excellent	

Suggestions/Comments: _____

3. How *useful* have the group *discussions* been to you?

1	2	3	4	5	6	7
Not At All Useful		Moderately Useful			Very Useful	

Suggestions/Comments: _____

4. Are the *topics* discussed by the group *meaningful* to you?

1	2	3	4	5	6	7
Not At All Meaningful			Moderately Meaningful		Very Meaningful	

Suggestions/Comments: _____

5. Is the *journal useful* to you?

1	2	3	4	5	6	7
Not At All Useful			Moderately Useful		Very Useful	

Suggestions/Comments: _____

6. How much *positive impact* has your participation in the group had on your general *well-being*?

1	2	3	4	5	6	7
No Positive Impact			Moderate Positive Impact		Large Positive Impact	

Suggestions/Comments: _____

APPENDIX 4

Handout - Physician Group #2

What's a Doctor to Do?

by Paul N. Duckro, PhD, and Rev. Susan Videen, PhD

There is no question that a patient quite often doesn't act "normal" when told that he or she has a life-threatening illness. The physician's explanation of the diagnosis and prognosis can be a model of clarity and sense, but the patient may not understand it, indeed may not even hear it. That patient may show no reaction at all—or break into hysterical weeping. A patient may question the physician's very qualifications—or sink into hopeless resignation. What's a doctor to do?

The feelings present in a patient at this time will be more intense than those they experience in more "ordinary" times of their lives. The inner emotional life now reflects the turmoil of the patient who is facing death more clearly. It is not that the patient is always upset. Even in the worst circumstances, there are unexpected moments of humor and many moments of forgetting, going about business as usual. However, it is also not unusual to find the patient sometimes struggling with strong emotions.

In some cases, the patient may be trying to contain the feelings for fear of falling apart. That person will use intellectualizing statements to keep feelings at bay. He or she is not likely to be forthcoming when questioned by the physician. It is not helpful to press the person to share feelings that may not be consciously known or may be too frightening to face. Look for the emotional honesty. Comment on any feelings that do emerge and validate them as expected and consistent with healthy living. Help to distinguish between falling apart and allowing emotions to fit into the overall experience and expression of life.

In other cases, feelings may be very much on the surface. When the feelings dominate thought there is distortion. In this situation, the distortions will be in the direction of excessive fears or predominantly dismal outlook. Any number of appearances will be evident. In some cases, the feelings are quite apparent. In other cases, the feelings are evident only in the persistent, repetitive attitudes of the patient. Here the work will be to allow greater input from the rational perspective. Point out any ways in which the patient is already succeeding, and the resources available that the person may be overlooking or discounting. Hopefully, this realization becomes evident to the patient. There is no convincing such a person with another's rational argument.

Others, farther along in accepting the illness, may be truly at peace with the dying process. However, even in those persons there is often real concern for those they are leaving behind.

As a general rule of thumb, note that men will have more trouble recognizing and expressing emotions. However, the individual genetic and social history will play the most significant role in the individual member's emotionality and comfort with emotions.

The more common problem will be the "holding in" of emotions for fear of disturbing others or of being overwhelming by them. The most common types of feelings will be depression, anger, anxiety, fear, guilt and shame.

Depression may be the most common emotion in coming to terms with death. There is a sense of isolation. The patient often feels very alone, even singled out for this illness. There is an irrational sense of shame. The shame and emotional withdrawal compound whatever loss of social support there may actually be as a result of others not wanting to deal with life-threatening illness. Self-esteem can also be threatened if the person feels himself or herself to be weak or bad as a result of developing such a severe illness.

Anger can be present as a result of the patient's sense of being cheated by life. It can also emerge when there is the sense that others are not responding as the patient would have wanted or expected. These kinds of reactions are natural enough. When the anger is not expressed so that it can be worked through directly, it develops in unhealthy ways. Resentment, bitterness, irritability can all drive away others. However, there are many ways in which anger can be helpful when processed directly, and not expressed by way of blaming others. Anger owned can actually improve the patient's survival time. When anger is suppressed, it will drive physical symptoms and increase depression. A patient can try to put on a happy face or even may come to blame himself or herself for the disease.

Guilt emerges when the patient blames himself or herself for doing things that led to the illness. A caregiver may also feel guilt for behaviors that may have led to the disease of the patient. When one considers the difficulty of predicting disease, it is safe to say that in most cases this guilt is irrational. However, in some cases it is helpful to own guilt and teach others to learn from one's mistakes. Guilt becomes an insurmountable problem when the patient turns it inward in a self-punitive way. Then depression develops. Whatever the case, the patient must find a way to work through the guilt to reasonable forgiveness and/or reparation.

Anxiety is a prominent feature of any life-threatening illness. It is not unusual to hear patients say that they cannot even use typical coping mechanisms. Many say that they cannot even pray in the tension of these days. Fear is part of the anxiety. There is fear of the unknown. Even persons of deep faith may wonder if what they have believed is true. There is ambivalence in the face of death. Coming to the place of letting go is a gradual process with ups and downs. There is fear of being abandoned by others. Hypersensitivity is a form of this fear, expressed indirectly.

Emotions can be healing. Any emotion is a source of healing if the patient is able to stay with it, express it in conversation, and work it through. Certain emotions are natural parts of the healing process. A complete lack of emotion, a type of psychological numbness, is

not desirable for the long term. It is not advisable to confront the patient regarding the absence of feelings, but there will be opportunities to reinforce emotion that does appear.

Grief is not the same thing as depression. Grief is a healthy although painful feeling that expresses the loss of the patient and caregiver. In grieving, the patient comes to understand the universality of loss; empathy is increased; the meaning of everyday life is enhanced. Only when the patient tries to cut off grief too quickly, meeting his or her own expectations or the expectations of others (spoken or unspoken, real or perceived), does the patient invite trouble. Usually it comes in the form of depression.

Hope is another positive affect. It is embodied in the goal of living fully in the context of dying. Hope is not wishful thinking. It is an optimism that good will come no matter how bad things seem to be. It assumes that there is more to be understood than meets the eye now. It allows us to persevere without slipping into unproductive endurance. Hope begins with the sense of being loved. It comes to fullness in loving others.

Remember that sharing feelings with another allows them to be resolved in healthy ways. Differentiate sharing feelings from venting. Gently point it out if you have the sense that the patient is simply repeating the same thoughts and feelings that have been stated over and over again. Your sense that the patient is complaining or simply appealing for pity may be clues. Sharing feelings will be evident in the extent to which you feel involved and empathic about the patient's presentation. Sharing feeling invites conversation in the form of identification with the feelings, sharing different reactions, exploring the roots of the feelings, or exploring responses to them.

In the course of the sharing, be careful not to direct how a person should feel. Coming to understand the nature and roots of his or her own feelings will be enough to move the person to new feelings in almost all cases. The feelings often direct attention to important attitudes that can be addressed more directly.

When feelings are hard to elicit, simply go back to encouraging a truthful telling of the immediate situation. There will be feeling enough when an honest telling of the situation is arrived at. Remember that the honest telling of the situation always involves what the disease means in the life of the person.

Feelings can become problematic. When feelings become intense or enduring, patients may need assistance in working with them productively. On the other hand, feelings are also part of a healthy life. When a person faces the prospect of death, strong feelings are perfectly normal and expected. If they are handled openly, feelings serve as a route to a richer interior life and help to forge deeper relationships. So, what's a doctor to do? Give your whole attention to the patient, accept his or her feelings without making judgment, reflect back the feelings so that the patient knows they've been heard, just BE there. In the face of strong emotions, it is more important to be than to do.

ACKNOWLEDGEMENTS

This work was supported by grants from *Supportive Care of the Dying: A Coalition for Compassionate Care*, Portland, Oregon, and from Project on Death in America.

ENDNOTES

- ¹ SUPPORT principal investigators. A controlled trial to improve care for seriously ill, hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995;274:1591-1598.
- ² Barnard D. Religion and religious studies in health care and health education. *Journal of Allied Health* 1983;12:192-201.
- ³ McSkimming S *et al.* *Living and Healing During Life-Threatening Illness*. Portland, OR; 1997 (p.1).
- ⁴ Ferrell B, *et al.* The meaning of quality-of-life for bone marrow transplant survivors: the impact of BMT on quality-of-life. *Cancer Nursing* 1992;15:153-160.
- ⁵ Ferrell B, *et al.* Quality of life in long-term cancer survivors. *Oncology Nursing Forum* 1995;22:915-922.
- ⁶ Ellison C. . Spiritual well-being: conceptualization and measurement. *Journal of Psychology and Theology* 1983;11:330-340.
- ⁷ Bell H. The spiritual care component of palliative care. *Seminars in Oncology* 1985;12:482-485.
- ⁸ Hiatt J. Spirituality, medicine, and healing. *Southern Medical Journal* 1986;79:736-743.
- ⁹ Kuhn C. A spiritual inventory of the medically ill patient. *Psychiatric Medicine* 1988;6:87-100.
- ¹⁰ Barnard D. Religion and religious studies in health care and health education. *Journal of Allied Health* 1983;12:192-201.
- ¹¹ Barnard D. Illness as a crisis of meaning: psycho-spiritual agendas in health care. *Pastoral Psychology* 1984;32:74-82.
- ¹² Lipowsky Z. Physical illness, the individual, and the coping process. *Psychiatry and Medicine* 1970;1:90-102.
- ¹³ Foglio J, Brody H. Religion, faith, and family practice. *Journal of Family Practice* 1988;27:473-474.
- ¹⁴ Sevensky R. Religion and illness: an outline of their relationship. *Southern Medical Journal* 1981;74:745-750.
- ¹⁵ Beavers W, Kaslow F. The anatomy of hope. *Journal of Marital and Family Therapy* 1981;7:119-126.
- ¹⁶ Korner I. Hope as a method of coping. *Journal of Consulting and Clinical Psychology* 1970;34:134-139
- ¹⁷ Carson V, Soeken K, Grimm P. Hope and its relationship to spiritual well-being. *Journal of Psychology and Theology* 1988;16:159-167.
- ¹⁸ Yates J, *et al.* Religion in patients with advanced cancer. *Medical and Pediatric Oncology* 1981;9:121-128.
- ¹⁹ Kaczorowski J. Spiritual well-being and anxiety in adults diagnosed with cancer. *Hospice Journal* 1989;5:105-116.
- ²⁰ Pargament K, *et al.* Religious coping efforts as predictors of the outcomes to significant negative life events. *American Journal of Community Psychiatry* 1990;18:793-824.
- ²¹ Kubler-Ross E. *On Death and Dying*. New York: Macmillan; 1969.
- ²² Aldrich C. The dying patient's grief. *JAMA* 1963;184:329-331.
- ²³ Bahnsen C. Psychological and emotional issues in cancer: the psychotherapeutic care of the cancer patient. *Seminars in Oncology* 1975;2:293-309.
- ²⁴ Crary W, Crary G. Emotional crisis and cancer. *Cancer* 1974;4:36-39.
- ²⁵ Ferlic M, *et al.* Group counseling in adult patients with cancer. *Cancer* 1979;43:760-766.
- ²⁶ Gottheit E, *et al.* Awareness and disengagement in cancer patients. *American Journal of Psychiatry* 1979;136:632-636.
- ²⁷ LaGrand L. United we cope: support groups for the dying and bereaved. *Death Studies* 1991;15:207-230.
- ²⁸ Parsell S, Tagliareni E. Cancer patients help each other. *American Journal of Nursing* 1974;74:650-651.
- ²⁹ Spiegel D, *et al.* Group support for patients with metastatic cancer: a randomized prospective outcome study. *Archives of General Psychiatry* 1981;38:527-533.
- ³⁰ Yalom I, Greeves C. Group therapy with the terminally ill. *American Journal of Psychiatry* 1977;134:396-400.
- ³¹ Cain E., Kohorn E., *et al.* Psychosomatic benefits of a cancer support group. *Cancer* 1986;57:183-189.
- ³² Jamison K, Wellisch D, Pasnau R. Psychosocial aspects of mastectomy: the woman's perspective. *American Journal of Psychiatry* 1978;135:432-436.
- ³³ Morris T, Greer H, White P. Psychological and social adjustment to mastectomy. *Cancer* 1977;40:2381-2387.
- ³⁴ Derogatis L., Abeloff M., Melisartos N. Psychological coping mechanisms and survival times in metastatic breast cancer. *JAMA* 1979;242:1504-1508.

-
- ³⁵ Bloom J. Social support, accommodation to stress, and adjustment to breast cancer. *Social Science and Medicine* 1982;16:1329-1338.
- ³⁶ Schoenfield J. Psychological factors related to delayed return to an earlier lifestyle in successfully treated cancer patients. *Journal of Psychosomatic Research* 1972;16:41-46.
- ³⁷ Fawzy F, Fawzy N. Malignant melanoma: effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival six years later. *Archives of General Psychiatry* 1993;50:681-689.
- ³⁸ Lindemann E. Symptomatology and management of acute grief. *American Journal of Psychiatry* 1944;101:141-148.
- ³⁹ Kissen D. Personality characteristics in males conducive to lung cancer. *British Journal of Medical Psychiatry* 1963;43:313.
- ⁴⁰ Greer S, Watson M. Towards a psychological model of cancer: psychological considerations. *Social Science and Medicine* 1985;20:773-777.
- ⁴¹ West P, Blumberg E, Ellis F. An observed correlation between psychological factors and growth rate of cancer in man. *Cancer Research* 1952;12:306.
- ⁴² Bacon C. A psychosocial survey of each cancer of the breast. *Psychosomatic medicine* 1952;14:453.
- ⁴³ Blumberg E, West P, Ellis F. A possible relation between psychological factors and human cancers. *Psychosomatic Medicine* 1954;16:276-286.
- ⁴⁴ Dafter R. Why "negative" emotions can sometimes be positive: the spectrum model of emotions and their role in mind-body healing." *Advances* 1996;12:6-19.
- ⁴⁵ Bahnson C, Bahnson D. Role of the ego defenses: denial and repression in the etiology of malignant neoplasm. *Annals of the New York Academy of Science* 1966;125:822-845.
- ⁴⁶ Bahnson C, Bahnson D. Ego defenses in cancer patients. *Annals of the New York Academy of Science* 1969;164:546-559.
- ⁴⁷ Rogentine G, et al. Psychological factors in the prognosis of malignant melanoma: a prospective study. *Psychosomatic Medicine* 1979;41:647-655.
- ⁴⁸ Greer S, Morris T, Pettingale K. Psychological response to breast cancer: effect on outcome. *The Lancet* 1979;2:785-787.
- ⁴⁹ House J, Landis K, Umberson D. Social relationships and death. *Science* 1988;241:540-545.
- ⁵⁰ Weisman A, Worden J. Psychosocial analysis of cancer deaths. *Omega: The Journal of Death and Dying*. 1975;6:61-75.
- ⁵¹ Ortmeier C. Variations in mortality, morbidity, and health care by marital status. In Erhardt L, Berlin J (eds), *Mortality and Morbidity in the United States*. Cambridge, MA: Harvard University Press; 1974.
- ⁵² Goodwin, et al. The effect of marital status on stage, treatment, and survival of cancer patients. *JAMA* 1987;258:3125-3130.
- ⁵³ Holmes T. *Personality, stress, and tuberculosis*. New York: International University Press; 1956.
- ⁵⁴ Durkheim E. *Suicide*. New York: Free Press; 1951.
- ⁵⁵ Tillman W, Hobbs G. The accident-prone automobile driver: a study of the psychiatric and social background. *American Journal of Psychiatry* 1949;106:321.
- ⁵⁶ Cobb S. Social support as a moderator of life stress. *Psychosomatic Medicine* 1976;38:301-314.
- ⁵⁷ Dean A, Lin N. The stress-buffering role of social support. *Journal of Nervous and Mental Disease* 1977;165:403.
- ⁵⁸ Caplan G. Mastery of stress: psychological aspects. *American Journal of Psychiatry* 1981;138:413-420.
- ⁵⁹ Andrews G, Tennant C, Hewson D, Vaillant G. Life events, stress, social support, coping style, and risk of psychological impairment. *Journal of Nervous and Mental Disease* 1978;166:307.
- ⁶⁰ Turner R. Social support as a contingency in psychological well-being. *Journal of Health and Social Behavior* 1981;22:357-367.
- ⁶¹ Finlayson A. Social networks as coping resources. *Social Science and Medicine* 1976;10:97-103.
- ⁶² Granovetter M. The strength of weak ties. *American Journal of Sociology* 1976;78:1360-1380.
- ⁶³ Kuhn C. A spiritual inventory of the medically ill patient. *Psychiatric Medicine* 1988;6:87-100.
- ⁶⁴ Engel G. A need for a new model: a challenge for biomedicine. *Science* 1977;196:129-136.
- ⁶⁵ Creech R. The psychological support of the cancer patient: a medical oncologist's viewpoint. *Seminars in Oncology* 1975;2:285-292.
- ⁶⁶ Francis V, Korsch B, Morris M. Gaps in doctor-patient communication. *New England Journal of Medicine* 1969;280:535-540.

-
- ⁶⁷ Kimball C. *The Biopsychosocial Approach to the Patient*. Baltimore: Williams and Wilkins; 1981.
- ⁶⁸ Nouwen H. *Out of Solitude*. Notre Dame, IN: Maria Press; 1974.
- ⁶⁹ Franzeno M. Group discussion among the terminally ill. *International Journal of Group Psychotherapy* 1976;26:43-48.
- ⁷⁰ Jacobs C, et al. Behavior of cancer patients: a randomized study of the effects of education and peer support groups. *American Journal of Clinical Oncology* 1983;6:347-350.
- ⁷¹ Berger M. Crisis intervention: a drop-in support group for cancer patients and their families. *Social Work in Healthcare* 1984;10:81-91.
- ⁷² Spiegel D, Glafkides M. Effects of group confrontation with death and dying. *International Journal of Group Psychotherapy* 1983;33:433-447.
- ⁷³ Duhatschek-Krause A. A support group for patients and families facing life-threatening illness: finding a solution to non-being. *Social Works and Groups* 1989;12:55-69.
- ⁷⁴ Gordon W, et al. Efficacy of psychosocial intervention with cancer patients. *Journal of Consulting Clinical Psychiatry* 1980;25:503-509.
- ⁷⁵ Adams J. Mutual help groups: enhancing the coping abilities of oncology clients. *Oncology Nursing* 1979;2:95-98.
- ⁷⁶ Spiegel D, Bloom J. Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosomatic Medicine* 1983;45:333-339.
- ⁷⁷ Spiegel D, Yalom I. A support group for dying patients. *International Journal of Group Psychotherapy* 1978;28:233-245.
- ⁷⁸ Telch C, Telch M. Group coping skills instruction and supportive group therapy for cancer patients: a comparison of strategies. *Journal of Consulting and Clinical Psychiatry* 1986;54:802-808.
- ⁷⁹ Fawzy F, et al. A structured psychiatric intervention for cancer patients: changes over time in methods of coping and affective disturbances. *Archives of General Psychiatry* 1990;47:720-725.
- ⁸⁰ Fawzy F, et al. A structured psychiatric intervention for cancer patients: changes over time in immunological measures. *Archives of General Psychiatry* 1990;47:729-735.
- ⁸¹ Fawzy F, Fawzy N. Malignant melanoma: effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival six years later. *Archives of General Psychiatry* 1993;50:681-689.
- ⁸² Kiecolt-Glaser J, et al. Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine* 1991;53:345-362.
- ⁸³ Kiecolt-Glaser J, et al. Chronic stress and immunity in family caregivers of Alzheimer's disease victims. *Psychosomatic Medicine* 1987;49:523-535.
- ⁸⁴ Rabins P, Mace N, Lucas M. The impact of dementia on the family. *JAMA* 1982;248:333-335.
- ⁸⁵ Esterling B, et al. Chronic stress, social support, and persistent alterations in the natural killer cell response to cytokines in older adults. *Health Psychology* 1994;13:291-298.
- ⁸⁶ Gonzalez S, Steinglass P, Reiss D. Putting the illness in its place: discussion groups for families with chronic medical illnesses. *Family Process* 1989;28:69-87.
- ⁸⁷ Smith D, Maher M. Group interventions with caregivers of the dying: the "Phoenix" alternative. *Journal for Specialists in Group Work* 1991;16:191-196.
- ⁸⁸ Johnson E, Stark D. A group program for cancer patients and their families in an acute care teaching hospital. *Social Work in Healthcare* 1980;5:335-349.
- ⁸⁹ Duhatschek-Krause A. A support group for patients and families facing life-threatening illness: finding a solution to non-being. *Social Works and Groups* 1989;12:55-69.
- ⁹⁰ Brown A, Mistry T. Group work with "mixed membership" groups: issues of race and gender. *Social Work and Groups* 1994;17:5-21.
- ⁹¹ Davis L, Cheng L, Strube M. Differential effects of racial composition on male and female groups: implications for group work practice. *Social Work Research* 1996;20:157-166.
- ⁹² Chau K. Needs assessment for group work with people of color: a conceptual formulation. *Social Work and Groups* 1992;15:53-66.
- ⁹³ Steward R. Black women and white women in groups: suggestions for minority sensitive group services on university campuses. *Journal of Counseling Development* 1993;72:39-41.
- ⁹⁴ Greeley A, et al. Training effective multicultural group counselors: issues for a group training course. *Journal for Specialists in Group Work* 1992;17:196-201.
- ⁹⁵ Grol R. Beliefs and evidence in changing clinical practice. *British Medical Journal* 1997;315:418-421.

-
- ⁹⁶ Davis D, et al. Changing physician performance: a systematic review of the effect of continuing medical education strategies. *JAMA* 1995;274:700-705.
- ⁹⁷ Conway A, Keller R, Wenberg D. Partnering of physicians to achieve quality improvement. *Joint Commission Journal for Quality Improvement* 1995;21:619-626.
- ⁹⁸ O'Connor G, et al. A regional intervention to improve the hospital mortality associated with coronary artery bypass graft surgery: the Northern New England Cardiovascular Study Group. *JAMA* 1996;275:841-846.
- ⁹⁹ Winkens R, et al. Effect of feedback on test ordering behaviour of general practitioners. *British Medical Journal* 1992;304:1093-1096.
- ¹⁰⁰ Sutton A. African American men in group therapy. In Andronico MP, et al. (eds). *Men in Groups: Insights, Interventions, and Psychoeducational Work* (pp. 131-149). American Psychological Association: Washington, DC; 1996.
- ¹⁰¹ Salvendy JT. Ethnocultural considerations in group psychotherapy. *International Journal of Group Psychotherapy* 1999;49:429-464.
- ¹⁰² Spiegel D, Spira J. *Supportive-Expressive Group Therapy: A Treatment Manual of Psychosocial Intervention for Women with Recurrent Breast Cancer*. Stanford, CA: Psychosocial Treatment Laboratory, Stanford School of Medicine; 1991.
- ¹⁰³ Classen C, Diamond S, Soleman A, Fobair P, Spira J, Spiegel D. *Brief Supportive-Expressive Group Therapy for Women with Primary Breast Cancer: A Treatment Manual*. Stanford, CA: Psychosocial Treatment Laboratory, Stanford School of Medicine; 1993.
- ¹⁰⁴ Spiegel D. *Therapeutic Support Groups*. Stanford, CA; 1993.
- ¹⁰⁵ Moyers W. *Healing and the Mind*. New York: Main Street Books; 1995.
- ¹⁰⁶ Dearnorff W, Reeves J. Working with your doctor, family, and friends. In *Preparing for Surgery: A Mind-Body Approach to Healing and Recovery*. New York: New Harbinger Publications; 1997.
- ¹⁰⁷ Bradshaw C. *CareNotes Series: Learning How to Talk with your Doctor*. St. Meinrad, IN: Abbey Press; 1993.
- ¹⁰⁸ Adler S, McGraw S, McKinlay J. Patient assertiveness in ethnically diverse older women with breast cancer: challenging stereotypes of the elderly. *Journal of Aging Studies* 1998;12:331-350.
- ¹⁰⁹ McGee D, Cegala D. Patient communication skills training for improved communication competence in the primary care medical consultation. *Journal of Applied Communication Research* 1998;26:412-430.
- ¹¹⁰ Beisecker A. Patient power in doctor-patient communication: what do we know? *Health Communication* 1990;2:105-122.
- ¹¹¹ Singh KD. *The Grace in Dying: How We are Transformed Spiritually as We Die*. San Francisco: Harper; 1998.
- ¹¹² Hinton J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative Medicine* 1999;13:19-35.
- ¹¹³ Kabat-Zinn J. *Full Catastrophe Living: Using the Wisdom of your Body and Mind to Face Stress, Pain, and Illness*. New York: Dell; 1991.
- ¹¹⁴ Lynn J, Harrold J. Controlling pain. In *Handbook for Mortals: Guidance for People Facing Serious Illness*. Oxford: Oxford University Press; 1999.
- ¹¹⁵ Doka K. *Living with Life-Threatening Illness: A Guide for Patients, Their Families, and Caregivers*. San Francisco: Jossey-Bass; 1998.
- ¹¹⁶ Berg S. Aging, behavior, and terminal decline. In Birren J., et al. (eds). *Handbook of the Psychology of Aging* (pp 323-337). New York: Academic Press; 1996.
- ¹¹⁷ Chochinov H., et al. Desire for death in the terminally ill. *American Journal of Psychiatry* 1995;152:1185-1191.
- ¹¹⁸ Creagan E. Attitude and disposition: do they make a difference in cancer survival? *Mayo Clinic Proceedings* 1997;72:160-164.
- ¹¹⁹ Oliver S. *What the Dying Teach Us: Lessons on Living*. New York: Haworth Pastoral Press; 1998.
- ¹²⁰ Lev E, McCorkle R. Loss, grief, and bereavement in family members of cancer patients. *Seminars in Oncology Nursing* 1998;14:145-151.
- ¹²¹ Olshevski J, et al. *Stress Reduction for Caregivers*. Philadelphia: Brunner/Mazel; 1999.
- ¹²² Vachon M. Psychosocial needs of patients and families. *Journal of Palliative Care* 1998;14:49-56.
- ¹²³ *Aging With Dignity. Five Wishes*. Tallahassee, FL: Aging With Dignity; 2000.
- ¹²⁴ Beck AT, et al. An inventory for measuring depression. *Arch Gen Psychiatry* 1961;56:53-63.

-
- ¹²⁵ Ellison CW. Spiritual well-being: conceptualization and measurement. *J Psychol Theol* 1983;11:330-340.
- ¹²⁶ Ellison CW, Smith J. Toward an integrative measure of health and well-being. *J Psychol Theol* 1991;19:35-48.