SUPPORTING CANCER PATIENTS AND FAMILIES:
A WORKBOOK FOR PSYCHOTHERAPISTS

A graduate project submitted in partial fulfillment of the requirements
For the degree of Master of Science in Counseling,
Marriage and Family Therapy

By
Kayo Matsumoto

August 2012
The graduation project of Kayo Matsumoto is approved:

________________________________________  __________
Dana J. Stone, Ph.D.  Date

________________________________________  __________
Rie Rogers Mitchell, Ph.D.  Date

________________________________________  __________
Stan Charnofsky, Ed.D., Chair  Date

California State University, Northridge
DEDICATION

This project has been dedicated to my father, who passed away from cancer, all the cancer survivors and their families at the Wellness Community with whom I have humbly worked, and all the people who were affected by cancer.

献辞

がんと闘った父、松本憲吾、そして、すべてのがん患者とその家族に捧げる。
ACKNOWLEDGEMENTS

I would like to express my gratitude to my loving husband, Mike Thompson, who has supported me and encouraged me in so many ways. I am incredibly fortunate to have him in my life. I am also thankful for my mother, Michiko Matsumoto, back in Japan, and my two beautiful children, Ken and Lina. Completion of this project and thus the Master’s degree means a lot to me as a proud daughter and a role model mother.

I would like to thank my excellent clinical supervisors, Jodi McIntosh and Anne Gessert, who kept guiding me and inspiring me, and connected me to valuable opportunities of supporting people with cancer and their families.

I would also like to express my appreciation to my graduate project committee members, Dr. Stan Charnofsky, Dr. Dana Stone Harris, and Dr. Rie Rogers Mitchell. Their guidance and direction has been essential in the completion of this project.

謝辞
いつも海の向こうから応援してくれているママに、心からありがとうの言葉を持げます。一人でおばあちゃんの介護を続けるママ、そして、がんと闘い、私のウェディングドレスを見ることなく逝ってしまったパパを思いながら、この修士論文を完成させました。これからも臨床心理士として、がん患者とその家族のサポートを続けていきます。ママの期待を裏切らないようがんばります。見守っていて下さい。
# TABLE OF CONTENTS

Signature page ii
Dedication iii
Acknowledgement iv
Abstract vi

Chapter I: Introduction 2
  Introduction 2
  Background 2
  Statement of Problem 5
  Purpose of Project 7
  Summary 8
  Terminology 9

Chapter II: Literature Review 12
  Overview of Cancer 12
  Cancer Patients’ Physical Stresses 15
  Cancer Patients’ Psychological Stresses 16
  Family/Caregivers’ Psychological Stresses 18
  Social Problems 21
  Psycho-oncology 23
  Psychosocial Support 25
  Psychological Intervention Analysis 28

Chapter III: Project Audience and Implication Factors 32
  Introduction 32
  Development of Project 32
  Intended Audience 33
  Personal Qualification 34
  Project Outline 35

Chapter IV: Conclusion 37
  Conclusion 37
  Counseling Consideration for Psychotherapists 38
  Limitations of the project 39
  Suggestions for Further Research 40
  References 42

Appendix A 64
ABSTRACT

SUPPORTING CANCER PATIENTS AND FAMILIES: A WORKBOOK FOR PSYCHOTHERAPISTS

By

Kayo Matsumoto

Master of Science in Counseling

Marriage and Family Therapy

Cancer is a devastating disease. The realities of the illness and its treatment, however, are only a part of the cancer patient’s life. Cancer causes a whirlpool of emotional and social problems in the lives of both patients and their families. Cancer patients and their families need to manage their emotional reactions to this life-threatening disease, get through treatment, and redefine their life priorities. They may be challenged to adjust to new family roles, and reestablish their social support systems. Such problems cannot be resolved with a simple prescription. In addition to medical support, cancer patients and their families need psychosocial support.

This project features a workbook designed for mental health professionals who will be, or are interested in, working with cancer patients and their families. This project contains a literature review of previous studies and research regarding psychosocial support for cancer patients and their families. Such studies indicate that although concepts of Health Related Quality of Life (HRQOL) are more socially accepted, and thus, more psychosocial support for cancer patients and their families is available, there still are many cancer patients and families who struggle with difficult cancer-related problems, and feel
isolated and hopeless.

The purpose of this workbook is to help mental health professionals support cancer patients and their families. This workbook includes, therefore, useful information about cancer, psycho-oncology, psychosocial needs of cancer patients and their families, and psychotherapeutic interventions to meet such needs. The workbook also contains information about hospice care, palliative care, and loss and grief.
CHAPTER I

INTRODUCTION

"Getting cancer can become the beginning of living. The search for one's own being, the discovery of the life one needs to live, can be one of the strongest weapons against disease." Lawrence Leshan

Introduction

While most cancer-related books start with grim statistics and emphasize problems, *The Total Cancer Wellness Guide* (Thiboldeaux, 2007, p.3) begins with a rather hopeful foreword: “The news about cancer is better than ever. Even though more people are being diagnosed, fewer people are dying from the disease, and people are living longer and better with cancer. They are also learning how to live well within, through, and beyond it.” This hopefulness is the very attitude of this project. This workbook is to help mental professionals build effective support for all the people whose lives are affected by cancer, in place to buffer against challenges of this devastating disease, and to increase cancer patients’ and their families’ sense of hope and control.

Background

According to The American Cancer Society (2012), advances in treating cancer have dramatically increased over the past fifty years. During the 1960s, only 35% of those who were diagnosed with cancer survived for five years, but the number had gone up to 49% in 1977. The same five-year survival rate between 1987 and 1989 was 56%, and the most recent date, between 2001 and 2007, shows a staggering 67%. Substantial medical advancements in the early detection and treatment of multiple types of cancer has significantly extended the life expectancy of patients to the point that many people diagnosed with cancer can be cured, and can be managed as a chronic disease (Adler,
Despite such encouraging data, however, more than 10.5 million people in the United States live with past or current diagnoses of some type of cancer (Ries et al., 2007): 1.4 million Americans were projected to receive new diagnoses of cancer in 2007 alone (Jemal et. Al., 2007). While more than half a million Americans were estimated to die from cancer in 2007, numerous others are being effectively treated and will survive cancer-free for many years. Still others will have a type of cancer that is chronic and that will need to be controlled by intermittent or continuous treatment (Jemal et al., 2007). Such cancer survivors face the risk of substantial and permanent physical impairment, disability, and inability to perform routine activities of daily living, as well as the psychological and social problems that can result from the diagnosis and its sequela (Ekman, Fagerberg, & Lundman, 2002), and all of which contribute to poor quality of life (Aguado, 2012). Improving cancer patients’ quality of life before, during, and after treatment is a critical concern for practitioners (Puterman & Cadell, 2008), and has contributed to the development of psychosocial oncology (Holland, 2004).

According to Holland (2004), psychosocial oncology combines medical analysis and practice as they relate to psychology and oncology. Holland explained psychosocial oncology as a holistic view of cancer and its impact on cancer patients. Psychosocial oncology practitioners are concerned with the impact of cancer on a person’s emotional health as well as behavioral and social factors that may have an effect on the process of cancer (Puterman & Cadell 2008). Cancer patients’ psychosocial well-being is extremely important since it has an impact on their Health Related Quality of Life (HRQOL). (Holland, 2004). For instance, psychosocial interventions have proven efficacious in
helping breast cancer patients to better cope with the illness and live more fully (Turns, 1998), and there is clear evidence that various psychotherapies for cancer patients affect specific symptoms, such as reducing anxiety and depression (Ferlic, Goldman, Kennedy, 1979; Gustafson & Whitman, 1978; Mulder, van der Pompe, Spiegel, & Antoni, 1992).

Notions on how to deal with cancer’s impact on the individual have changed in the past half century from an initial preoccupation with response rates, remission rate, and curability to a newer interest in expanding the cancer survivor’s quality of life (Gatuszka, 2006).

According to the Center for Disease Control and Prevention (2012), the concept of Health Related Quality of Life (HRQOL) and its determinants have evolved since the 1980s to encompass those aspects of overall quality of life that can be clearly shown to affect health, either physical or mental. Levin, Li, Riskind, and Rai (2007) defined Quality of Life as a multidimensional construct, which reflects patients’ assessments of their current levels of functioning in a variety of areas in their lives including physiology, social activity, cognition, emotion, health perception, and general life satisfaction. Cella (1994) explained that Quality of Life is best understood as representing the gap between one’s actual functional level and one’s ideal standard. Patients who are able to adjust their expectations in duress are also able to adapt better to their illness and treatment.

As there has been an increased interest and awareness in psychosocial oncology and Health Related Quality of Life (HRQOL), there have also been increased numbers of psychosocial support systems for cancer patients (King & Hinds). Oncology social workers play important roles in providing cancer patients with counseling, education, and referrals to community resources such as cancer support organizations peer support groups.
to cancer patients (Cancer Net, 2012). Some nationwide, large-scale cancer support organizations (e.g. the American Cancer Society) have established websites with abundant information, and others (e.g. the Cancer Support Community) also provide in-person psychosocial support groups facilitated by mental health professionals. There are also numerous numbers of cancer related websites and online cancer support groups, which provide space for mutual support among cancer survivors. Moreover, abundant literature, which is designed to provide psychosocial support for cancer patients, is available in books, magazines, and pamphlets from doctors’ offices and hospitals (Cancer Net, 2012).

Statement of Problem

While there has been increased awareness of Quality of Life, and as a result, development of psychosocial support in general, the mental health needs of cancer patients and their caregivers have not been sufficiently addressed (Adler, 2008). Oncology social workers’ responsibilities cover broad areas including being a liaison between cancer patients and their medical teams, helping them navigate the health care system, referring them to community agencies that have support programs, and helping them decide on financial options (Cancer Net, 2012). Although websites of organizations and online support groups are handy and inexpensive, a flood of information often makes cancer patients feel intimidated and overwhelmed. Thiboldeaux (2007) indicated that too much information about cancer could become a source of such undesired emotion, in contradiction to its nature and purpose.

As such difficulties of acquiring mental health support, or the lack of quality of mental health support, cancer patients constantly face the emotional stress of living with a diagnosis of cancer and its treatment. Patients may also face fear of recurrence, and the
distress imposed by living with the day-to-day physical problems including constant pain, fatigue, impairment, and disability. These stressors can create new, or worsen preexisting psychological distress for cancer patients, their families, and other caregivers. In one U.S. comprehensive cancer center’s study of cancer patients aged 19 and older, the prevalence of significant psychological distress ranged from 29 to 43 % for patients with the 14 most common types of cancer (Zabora et al., 2001), and their distress included clinical diagnoses of depression, adjustment disorders, and anxiety. Even patients who do not develop clinical syndromes may experience worries, fears, and other forms of psychological stress that cause them significant distress (Zabora et al., 2001). Chronic illness can bring about guilt, feelings of loss of control, anger, sadness, confusion, and fear (Charmas, 2000). Anxiety, mood disturbance, fear of recurrence, concerns about body image, and communication and other problems with family members are common in cancer patients as well (Kornblith, 1998). Patients may also experience more generalized worries such as fear of the future, inability to make plans, uncertainty and a heightened sense of vulnerability. Possible development of a second cancer, changes in sexual function and reproductive ability, and changes in one’s role within the family and other relationships are among other concerns (Kangus, 2008).

Family members also have psychological needs (Roberts & Clarke, 2009). The diagnosis of life-threatening illness creates family members fear of losing their loved one, and concern about the suffering the patient will endure. Family member’s psychological distress could be as severe as that of the patient. A meta-analysis of studies of psychological distress in both patients and their caregivers found that the psychological distress was generally parallel over time, although when the patient received treatment,
caregivers experienced more distress than patients (Hodges et al., 2005).

Children of those who are diagnosed with cancer or siblings of pediatric cancer patients are especially vulnerable to stressful family situation (Harpham, 2004). Adolescents and children may suffer from severe symptoms of post-traumatic stress when a parent is recently diagnosed with cancer and when parents tend to underestimate the problems (Harpham, 2004). While only a fraction of children and siblings of cancer patients develop diagnostic post-traumatic stress disorder (PTSD), their distress can cause emotional problems later in life. Much is known about the psychological effects that cancer has on a patient and a spouse, but the consequences of a parent’s cancer on children are more poorly understood (Medical News Today, 2007).

**Purpose of Project**

The purpose of this workbook, therefore, is for mental health professionals who work with cancer patients and their caregivers/families to understand their psychosocial needs, and provide tools and information to support patients and families. The workbook will help mental health professionals to enhance awareness of psychological distress that cancer patients and their caregivers may experience. The workbook will also help mental health professionals to provide psycho-education for cancer patients and their caregivers to help them regain a sense of control, increase hope, find meaning of life, and decrease feelings of aloneness.

The ultimate goals are, therefore, for all the people who are affected by cancer to understand the relationship between their illness and psychological reactions, to regain a sense of control and hope, to make meaningful lifestyle adjustments, to develop a new attitude towards cancer, and to improve their ability to access appropriate information and
resources.

**Summary**

In order to better understand significance of psychosocial support for cancer patients and their families, it is necessary to review previous studies and research regarding psychosocial support for cancer patients and their caregivers. Chapter II, therefore, will present a review of the literature, and will be followed by Chapter III, which will introduce the development of the workbook, the intended population, qualification needed in order to use this workbook, and a brief outline of the workbook. Chapter IV will include a summary, discussion and recommendations for future research and development. A fully developed workbook and other information will be presented in the Appendix section.
TERMINOLOGY

Cancer burden – A measure of the incidence of cancer within the population and an estimate of the financial, emotional, or social impact it creates. The burden of disease is not borne equally by all population groups in the United States (American Cancer Institute, 2012).

Comorbidity – either the presence of one or more disorders or diseases in addition to a primary disease or disorder, or the effect of such additional disorders or diseases (Rosenbaum, & Rosenbaum, 2005).

Family care giver – unpaid caregivers, primarily family members but also include friends and neighbors of the care recipient (Family caregiver Alliance, 2012).

Five-year survival rate – The percentage of people in a study or treatment group who are alive five years after they were diagnosed with or treated for a disease, such as cancer. The disease may or may not have come back.

Health Related Quality of Life (HRQOL) – Multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life. A related concept of HRQOL is well being, which assesses the positive aspects of a person’s life, such as positive emotions and life satisfaction (Anderson, 1992).

Hospice, also known as hospice care – the hospice philosophy or viewpoint accepts death as the final stage of life. The goal of hospice is to help patients live their last days as alert and pain-free as possible. Hospice care tries to manage symptoms so that a person’s last days may be spent with dignity and quality,
surrounded by their loved ones (American cancer Society, 2012.)

Incidence, or cancer incidence – The frequency with which cancer occurs, or estimated new cancer cases by sex (American Cancer Society, 2012).

Metastasis, or metastatic cancer – Cancer that has spread from the place where it first started to another place in the body. A tumor formed by metastatic cancer cells is called a metastatic tumor or a metastasis. The process by which cancer cells spread to other parts of the body is also called metastasis (American Cancer Institute, 2012).

Mortality – The number of deaths during a specific time period (American Cancer Society, 2012).

Palliative care – an area of healthcare that focuses on relieving and preventing the suffering of patients. Palliative care is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life (Jones, & McPherson, 2010).

Prevalence – The numbers of cases alive on a certain date (National cancer institute, 2012).

Psycho-oncology, Psychosocial-oncology – Psycho-oncology is a holistic view of cancer and its impact on cancer patients. Psychosocial oncology practitioners are concerned with the impact of cancer on a person’s emotional health as well as behavioral and social factors that may have an effect on the process of cancer (Puterman & Cadell, 2008).

Quality of Life (QOL) – Broad multidimensional concept that usually includes subjective
evaluations of both positive and negative aspects of life. Although health is one of the important domains of overall quality of life, there are other domains including jobs, housing, schools, and the neighborhood. Aspects of culture, values, and spirituality are also key aspects of overall quality of life. (Center for Disease Control and Prevention, 2012.)

Relative risk – a measure of the risk of a certain event happening in one group compared to the risk of the same event happening in another group. In cancer research, relative risk is used in prospective (forward looking) studies, such as cohort studies and clinical trials (National cancer institute, 2012).

Residual disability – Inability to perform one or more important daily business duties, or inability to perform the usual daily business duties for the time period usually required for the performance of such duties (National cancer institute, 2012).

Sequela (pl. Sequelae) – A morbid condition following or occurring as a consequence of another condition or event (National cancer institute, 2012).

Stage – The extent of a cancer within the body. If the cancer has spread, the stage describes how far it has spread from the original site to other parts of the body (American Cancer Institute, 2012).

Survival – The population of patients alive at some point after the diagnosis of their cancer (American Cancer Institute, 2012).
CHAPTER II

LITERATURE REVIEW

In this chapter, literature regarding psychosocial support for cancer patients and their caregivers will be reviewed. The chapter will begin with general information and statistical data on cancer and an overview of cancer patients, followed by a discussion of physical and psychological problems of cancer patients and their caregivers. This section will include special concerns of specific populations, including gender, age, culture, and types of cancer. Then, current status of psychosocial support will be explored, and finally, the chapter will conclude with an analysis of the significance and efficacy of past psychosocial interventions and methods.

Overview of Cancer

Statistics. As described in the introduction section, while cancer is still the second highest cause of death among Americans, close to the highest of heart disease (Jemal et al., 2007), death rates are declining. According to the annual report, Cancer Statistics, 2011, by American Cancer Society (2012), between 1990 and 2007, the most recent year for which data is available, overall death rates decreased by about 22% in men and 14% in women.

The overall rate of new cancer diagnoses, also know as incidences, among men, decreased by an average of 0.6% per year between 2004 and 2008 (Eheman, 2012). The same rate among women declined 0.5% per year from 1998 through 2006, with rates leveling off from 2006 through 2008 (Eheman, 2012). And yet, according to the National Cancer Institute (2012), an estimated 1.6 million people were diagnosed with cancer in 2011, and more than 547,000 people died of cancer in the same year. Regarding cancer’s
reach, 1 in 10 American household now includes a family member who has been diagnosed or treated for cancer within the past 5 years (Adler, 2008), and 41% of Americans can expect to be diagnosed with cancer at some point in their lives.

**Cancer and aging.** According to Yancik and Ries (2000), approximately 60% of individuals who have been diagnosed with cancer are age 65 or older. The Centers of Disease Control and Prevention (2012) also reports that the risk projection of getting cancer increases with age. For instance, 0.43% of women who are now 30 years old will be diagnosed with breast cancer sometime during the next 10 years, but the rate increases to 1.45% for 40 year-old women, 2.38% for 50 year-old women, and 3.45% for 60 year-old women (Yancik & Ries, 2000). That is, 3 or 4 out of every 100 women who are 60 years old today will get breast cancer by the age of 70. Likewise, the probability of getting prostate cancer indicates a clear increase with age (Yancik & Ries, 2000). For instance, 0.01% of 30 year-old men today will get prostate cancer in the next 10 years, 2.30% for 50 year-old men, and 8.5% for men who are 70 years old. This data indicates as many as 6 or 7 out of every 100 men who are 60 years old today will get prostate cancer by the age of 70. Indeed, the risk of getting cancer increases with age (Yancik & Ries, 2000). In addition, older adults with cancer are more likely to present comorbidity with a preexisting chronic disease and increased functional impairment and disability, which can compound the stresses imposed by cancer (Hewitt et al., 2003).

**Pediatric cancer patients.** Although the overall death rate among cancer patients is decreasing (Eheman, 2012), and the death rate of pediatric cancer patients has decreased 1.3% per year from 2004 through 2008, cancer incidence rates among children aged 19 and younger in the same period increased 0.6% per year, which is a continuing trend from
1992 (National Cancer Institute, 2012). Other data indicates that 13,500 children are diagnosed with cancer every year in the United States; 1 in 5 children diagnosed with cancer will die; and one in 300 boys and one in 333 girls respectively will develop cancer before the age of 20 (Jeff Gordon Children’s Hospital, 2012). Also, pediatric cancer is a leading cause of death by disease among children aged between 1 and 14 in the United States (American Cancer Society, 2012). What is worse is that young cancer patients often have a more advanced stage of cancer when first diagnosed, and yet in 2009, only 4% of the budget of National Cancer Institute was used for pediatric funding, and the FDA has initially approved only one drug for any child cancer in the last 20 years (Jeff Gordon Children’s Hospital, 2012). Half of all chemotherapies used for children’s cancers are 25 years old (Jeff Gordon Children’s Hospital, 2012).

Cancer as a chronic disease. As mentioned above, while many people still die from cancer every year, numerous others are being treated and will survive for many years cancer-free, or with their cancers being controlled by intermittent or continuous treatment (Jemal et al., 2004). As a result of advances in early detection and treatment, in the past two decades the 5-year survival rate for the 15 most common cancers such as lung cancer and breast cancer has increased for all ages from 43 to 64% for men, and from 57 to 64% for women (Jemal et al., 2004).

In spite of the improvement in cancer treatment, many cancer survivors are left with residual disabilities and nonreversible pathological alteration, and require long periods of supervision, observation, and care (Adler, 2008). In addition to the damage caused by the cancer itself, side effects are caused by chemotherapy, radiation, hormone therapy, and surgery (Rosenbaum, & Rosenbaum, 2005). All these cancer treatments often
lead to substantial permanent impairment of several organ systems with resultant
disabilities (Aziz & Rowland, 2003). Treatment protocols by themselves for some cancers,
such as breast, prostate, and colon cancer, could last for months (Adler, 2008). Also,
patients on certain chemotherapeutic regimens for breast cancer or some forms of
leukemia sometimes remain on chemotherapy for years (Adler, 2008). Even after
completing treatment, cancer survivors often require care from multiple specialists and
primary care providers to manage the long-term sequelae of the illness and its treatment
(Hoffman, 1996).

**Cancer Patients’ Physical Stresses**

As discussed in the previous section, improvements of increased survival rate are
sometimes accompanied by permanent damage to cancer patients’ physical health. Adults
with cancer, or with a history of cancer, more frequently report having fair or poor health
(30%), other chronic conditions (42%), one or more limitations in the ability to perform
activities of daily living (11%), other functioning disabilities (58%), and an inability to
work because of health conditions (among cancer patients under age 65)(17%) (Hewitt et
al., 2003).

Likewise, the American Cancer Society (2012) indicates that a medical history of
cancer at least doubles an individual’s likelihood of poor health and disability. Individuals
with a history of cancer also have significantly higher rates of other chronic illnesses such
as cardiovascular disease (American Cancer Society, 2012). Also, when cancer and other
chronic illness co-occur, poor health and disability rates are 5 to 10 times higher than
otherwise expected (Hewitt et al., 2003).

Moreover, receiving a diagnosis of cancer is a traumatic experience that may
trigger immediate adverse health consequences beyond the effects of the disease or treatment (Mulder, van de Pompe, Spiegel, & Antoni, 1992). Fang (2012) revealed that the risk of cardiovascular death increases immediately after a cancer diagnosis. Within the first week of being told they had cancer, patients were 5.6 times more likely to die from a heart attack or other cardiovascular complication than people of similar backgrounds who were cancer-free in those first seven days.

Cancer patients indeed undergo dramatic physical changes. Their physical stresses can certainly create and escalate psychological stresses. Such physical and psychological stresses are intertwined and they could last for long period of time, even when there are no longer any signs of the disease (Adler, 2008). Psychological stresses of family members and caregivers are also significant. Studies indicate families/caregivers experience as high rates of psychological symptoms as cancer patients. In the next section, psychological stresses of cancer patients and their families/caregivers will be reviewed. The section will include both general and population-specific psychological problems, and will be followed by an assessment of the social impact of such problems.

**Cancer Patients’ Psychological Stresses**

Psychological distress and mental health problems among cancer patients and their families/caregivers are overwhelming. As mentioned in the introduction, although the majority of cancer patients and their caregivers have normal psychological functioning (Kornblith, 1998), emotional distress is common in cancer patients and their caregivers (Zabora et al., 2001).

Spiegel and Giese-Davis (2003) reported high rate of psychological symptoms within cancer patients such as clinical depression, adjustment disorders, and anxiety.
Studies also found Posttraumatic Stress Disorder (PTSD) in both adults and children with cancer, as well as in parents of children diagnosed with cancer (Kangas et al., 2002). Indeed, experiencing a life-threatening illness or caregiving loved one who has cancer can be a qualifying event for PTSD according to the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (APA, 2000).

Even patients who do not develop clinical symptoms may experience worries, fears, and other forms of psychological stress that can cause them significant distress (Mosher, & DuHamel, 2012). Cancer can bring about guilt, feelings of loss of control, anger, sadness, confusion, and fear (Charmaz, 2000). Carroll-Johnson (1998) also found that among their emotional stresses, the three most common stressors that cancer patients’ experiences are loss of hope, loss of control, and sense of isolation. In addition, anxiety, mood disturbance, concerns about body image, and communication and other problems with family members are common in cancer patients (Kornblith, 1998).

Similarly, Adler et al. (2008) indicated that patients might experience more generalized worries such as fear about the future, inability to make plans, uncertainty, and a heightened sense of vulnerability. Other worries include, thoughts about possible development of a second cancer, changes in sexual dysfunction and reproductive ability especially among young-adult patients, and changes in one’s role within the family and other relationships (Adler et al., 2008). Lu et al. (2009) also argued that although cancer patients’ levels of distress generally decrease over time, their emotional reactions might continue long after treatment. Likewise, uncertainty and unmet expectations about the extent and rate of recovery are often experienced by cancer patients (Chmid-Buchi, Halfens, Dassen, & van den Borne, 2008).
Deteriorated self-image is especially critical among women with breast cancer. Women diagnosed with breast cancer are at risk of developing severe psychological morbidities including depression, anxiety, negative thoughts, suicidal thoughts, a fear of dying, a sense of aloneness, sexual and body image problems, as well as an overall decrease in quality of life (Al-Azri, Sl-Awisi, & Al-Moundhri, 2009).

**Suicide.** The risk of suicide increases immediately after a cancer diagnosis (Spiegel, & Classen, 2000). Within the first week of being told they had cancer, when stress from the diagnosis would have been highest, patients were 12.6 times more likely to commit suicide than people of similar backgrounds who were cancer-free in those first seven days. The stress of cancer leveled off over several months, but after a year, suicide risk levels for cancer patients were still 80% higher than for individuals in cancer-free control groups.

**Families/Caregivers’ Psychological Stresses**

Caregivers of cancer patients, predominantly family members and friends, often provide substantial amounts of emotional and logistical support and hands-on personal care to their loved ones (Kotkamp-Mothes et al., 2005). Distressed psychological states are common in cancer patients’ families/caregivers (Adler, 2008), and their distress can be as serious as that of the cancer patient (Lederberg, 1998). The diagnosis of a life-threatening illness for a family member creates fear of losing the loved one, and concern about the suffering the patients will endure (Daly, 2009). Hodges (2005) indicated that psychological distress in both patients and their caregivers (predominantly spouses or partners) was generally parallel over time, but when the patient received treatment, caregivers experienced more distress than the patient.
Segrin (2007) also found that primary caregivers of women with breast cancer (predominantly husbands, but also partners, daughters, friends, and others) experience as many symptoms as the women with breast cancer, including anxiety, depression, and fatigue. Gregorio (2011) indicated that spouses of cancer patients are at-risk for poor psychological and physical health as they cope with the complex nature of the disease and fears of losing their partners. Their study indicated that caring for a patient with cancer has an observable impact on spouses’ physical health and immune functions. Moreover, they indicate that the subjective experience of cancer-specific stress, more so than the patients’ recurrence status, is associated with a greater level of physical symptoms such as headache, backache, indigestion, shortness of breath, and immune deregulation.

Stress level of families/caregivers after the patient is “cancer-free” (after treatment) also remains high, most likely because some treatment-related sequelae, such as pain, fatigue, and neuropathy persist even after the treatment was successfully done (Gregorio, 2011). Regardless of recurrence status, therefore, families/caregivers, especially spouses, must cope with the physical demands associated with these symptoms (Gregorio, 2011). Such stress associated with cancer is chronic, and may extend for years post-diagnosis (Nijboer et al., 1998). Mortimer et al. (2005) found longer breast cancer duration and greater cancer-specific intrusive thoughts of families/caregivers were associated with suppression of delayed-type hypersensitivity responses to skin test antigens.

Families/caregivers of cancer patients who are in progressive, fatal stages are especially vulnerable. The responsibilities of care may include complex physical and medical tasks, financial administration, patient advocacy, decision-making, emotional
support and coordination of care (McCorkle, & Pasacreta, 2001). If cancer patients are unable to communicate with medical teams or experience difficulty with decision-making, family members might often act as proxies (Henoch et al., 2012). Caregiving can have negative consequences on the health of caregivers including fatigue, sleep problems, depression, anxiety, burnout and increased mortality risk (Stajduhar, & Cohen, 2009). In addition to meeting the demands associated with caregiving, families/caregivers also have to face the grief and loss associated with their loved ones’ impending deaths (Candy, 2010). All these stresses could limit caregivers’ abilities to provide informal care and support to the cancer patients and has broader implications for their own health.

Parents of pediatric cancer patients. Stress is particularly great for parents of children with cancer (Bruce, 2006). Studies (Pediatric Cancer Foundation, 2012) have consistently shown that parents of pediatric cancer patients have higher rate of PTSD and Post-traumatic Stress Syndrome (PTSS) than their children with cancer. It suggests that the experience of parenting a child with cancer may be more traumatic than actually having the cancer (Bruce, 2006).

High stress levels in family caregivers can also interfere with their ability to provide the emotional or logistic support patients need (Laderberg, 1998). This can worsen the patients’ stress and lead to cascading consequences of elevated stress. Because of the changes and necessary adaptation in the family brought about by the caregiving needs of the patient, family members are sometimes considered “second-order patients” (Laderberg, 1998).

Aging caregivers. Aging caregivers, especially those who also have other physical disabilities, experience substantial stress, which causes more depression and other
adverse health effects (Kurtz et al., 2004). Schultz & Beach (1999) indicated that caregivers who provide support to their spouses with cancers are 63% more likely to die within 4 years than those who do not provide care to their spouses with cancer.

**Children & siblings of patients.** Children of adult cancer patients and siblings of pediatric cancer patients are particularly vulnerable (Lederberg, 1998). Both populations experience frequent psychological problems, acting-out behaviors, and problems in school (Lederberg, 1998). Siblings of cancer patients may experience their own fears and anxieties, and yet may receive less attention from parents while their sisters and brothers are in treatment (Lederberg, 1998). Both elementary school age children and adolescents revealed eight major feelings: deprivation, displacement, anger, loneliness, guilt, ambivalence, fear of death, and constriction of social life (Bender, 1990).

Indeed, psychological impacts of cancer are devastating for those who live with cancer and their families/caregivers. Such problems are exacerbated by, or produce significant new social problems (Preyde, 2009). In the following section, such social problems will be explored.

**Social Problems**

Cancer can lead to substantial social problems for cancer patients, such as inability to work and thus, reduced income (Carroll-Johnson, Gorman, & Bush, 1998). Financial stress resulting from low income, as well as the cost of health care, or a lack of health insurance, can result in substantial stress for cancer patients (Carroll-Johnson, Gorman, & Bush, 1998). For those who are underserved, these effects are magnified by the presence of any psychological and social stressors that predate the onset of cancer, such as low income, lack of health insurance, and weak or absent social support (Adler,
Families/caregivers also undergo substantial changes in their social lives. Often, they sacrifice their own jobs and devote themselves to caring for their loved ones (Mitschke, 2008). The estimated value of families’/caregivers’ non-reimbursed care and support exceed $1 billion annually (Hayman et al., 2001). Furthermore, when their loved ones experience acute or long-term inability to care for themselves or carry out their family roles, the rest of the family often steps in to take up their roles (Mitschke, 2008). Taking on these responsibilities requires considerable adaptation and readaptation as the course of the disease changes (Hayman et al., 2001). These experiences can certainly add to the stress resulting from concerns about the family member with cancer.

Pediatric cancer patients’ social lives are also significantly impacted. Physical and neurocognitive disabilities resulting from treatment may prevent childhood cancer survivors from fully participating in school, social activities and eventually work (Francoeur, 2001).

**Socioeconomic status considerations.** Cancer patients with low socioeconomic status (SES) have more advanced cancers at diagnosis, receive less aggressive treatments, and have higher risks of dying in the five years following cancer diagnosis (Byers, 2008). The American Cancer Society (2012) supports the need to focus on SES as an underlying factor in cancer disparities by race and ethnicity.

Racial and ethnic disparities in the diagnosis and treatment of cancers and in the risk of death after cancer, have been documented by many studies (Byers, 2008). Also, there is compelling evidence that individuals with limited health literacy have worse outcomes, including lower treatment adherence, more frequent hospitalizations, and higher
mortality than those with adequate health literacy (Matsuyama, 2010). Limited education, low socioeconomic status, and minority race are risk factors for both limited literacy and cancer outcomes, and may be important indicators of disparities in healthcare outcomes for patients with cancer (Kutner et al., 2003).

The low health literacy has been shown to be higher among African Americans than among non-Hispanic Whites (Matsuyama et al., 2010). Similarly, the National Cancer Institute (2012) data suggested that among racial and ethnic groups, the highest cancer incidence rates between 2004 and 2008 were among black men. Race and ethnicity, to be sure, are important indicators of cancer. The difference in death rates by racial/ethnic group may also reflect differences in risk factors, as well as access to and use of screening and treatment (NCI, 2012). Kohler warned (2002) that while the sustained decline in cancer mortality rates is good news, the persistence of disparities among racial and ethnic groups continues to concern us (North American Association of Central Cancer Registries, 2012).

Considering all the physical, psychological, and social problems cancer patients and their families/caregivers experience, it is significantly critical to provide comprehensive psychosocial support. Such needs have contributed to the development of psychosocial oncology (Holland, 2004). In the next section, psychosocial oncology and its significance and contribution will be reviewed.

**Psycho-oncology**

Psychosocial oncology is the field of interdisciplinary study and practice at the intersection of lifestyle, psychology, and oncology (Brusilovskyi, Mitstifer, & Salzer, 2009). It is concerned with aspects of cancer that go beyond medical treatment and include
lifestyle, psychological and social aspects of cancer. The field is concerned both with the effects of cancer on a person’s psychological health, as well as the social and behavioral factors that may affect the disease process of cancer and its remission (Carroll-Johnson, Gorman, & Bush, 1998).

The objectives of psychosocial oncology include as follows: conducting comprehensive care that takes into account: physical, emotional, social and spiritual care, which inevitably will lead to attention to individual, family, and society: the patient and families are the unit to be treated: emotional support and communication with the patient, family, and treatment team must be through a frank and honest communication (Soothill, et al. 2005). Promoting autonomy and dignity of the patient are essential, along with a sense of preserving and restoring all abilities, both practical and emotional (Kash, 2005).

Health related quality of life (HRQOL). Psychosocial oncology is a field committed to enhancing cancer patients’ and their families’ Quality of Life (QOL), or more specifically Health Related Quality of Life (HRQOL) (Center for Disease Control and Prevention, 2012). The concept of HRQOL and its determinants have evolved since the 1980s to encompass those aspects of overall quality of life that can be clearly shown to affect health, either physical or mental (Certsers for Disease Control and Prevention, or CDC, 2012). The CDC, however, currently defines HRQOL at the individual level as physical and mental health perceptions and their correlates --- including health risks and conditions, functional status, social support and socioeconomic status (SES).

Not surprisingly, many cancer patients with all the above stresses claim low HRQOL (Arndt et al., 2004). For instance, Richardson (2008) reported individuals between the ages of 30 and 64 years who were limited by cancer reported poorer HRQOL.
measured as higher prevalence of poor or fair self-reported health, more physically unhealthy days, more painful days, and more inadequate sleep days. Assessment of HRQOL, therefore, is crucial to efforts in improving clinical outcomes (Arndt et al., 2004). Bottom lay (2002) also argued HRQOL is increasingly more accepted by clinicians as a possible way to collect more meaningful data about patients’ subjective experiences with cancer treatment.

As interest and awareness in psychosocial oncology and HRQOL increases, there have also been increased quality and quantities of psychosocial support systems for cancer patients (Arndt et al, 2004). In the next section, the current status of psychosocial support, including strengths and shortcomings, will be reviewed.

**Psychosocial Support**

Psychosocial care has been defined as “concern with the psychological and emotional well-being of the patient and their families/caregivers including issues of self-esteem, insight into an adaptation to illness and its consequences, communication, social functioning and relationships (NCHSPCS: National Council for Hospice and Specialist Palliative Care Services, 1997).” According to the American Cancer Society (ACS) (2012), psychosocial support includes mental health counseling, education, spiritual support, group support, and many other such services. Play therapy may also be offered to small children (Carroll-Johnson, Gorman, & Bush, 1998). These services are usually provided by mental health professionals, such as psychologists, social workers, counselors, specialized nurses, as well as clergy and pastoral counselors.

Psychosocial support is critical for cancer patients and their families/caregivers because most people struggling with a new cancer diagnosis feel as if this is the worst
thing that has ever happened to them (Carroll-Johnson, Gorman, & Bush, 1998). Older patients have often learned coping skills to help them get through the hard times in their lives, but younger patients may not have done this. In addition, is there are children in the family, or a child himself/herself becomes a cancer patient, there are other special issues to address (ACS, 2012).

Currently, a wide variety of psychosocial support services and programs for cancer patients and their families/caregivers are offered and provided through city and community hospitals, cancer centers, and universities. Typically, the first thing a mental health caregiver will do is a psychosocial assessment. This evaluation is done to find out the needs of the person or family, depending on who is being seen. This could already be therapeutic since the patients or family members share their concerns and feelings with the expert who has worked with many other patients and families. Based on this assessment, the patient and family members may be referred to another member of the team who can attend to a certain need (Spiegel & Classen, 2000).

**Shortcomings.** Despite the definition and description by cancer support and cancer research organizations, however, psychosocial support does not seem to be developed and dispersed well enough. Both cancer patients and their caregivers reported that their providers failed to understand their psychosocial needs and to recognize and adequately address their psychological stresses such as depression and anxiety (Nelson, 2007).

**Lack of resources.** The first problem is the awareness of medical providers (Nelson, 2007). Cancer patients’ providers appeared to be unaware of available resources that can offer support or at least did not make any referrals, and providers generally did not
consider psychosocial support to be an integral part of quality care for the oncological patients (Nelson, 2007)

**Lack of service.** Another problem is accessibility. Small hospitals or those in rural areas may not offer many services. In such cases, support could be limited to ones from agencies in the community, private counselors, places of worship, or peer support groups and programs (Nelson, 2007).

**Lack of awareness.** Overall, what cancer patients want from health professionals is information, emotional support and practical strategies in a manner that is timed to suit their individual needs, and to assist them to live with changes after treatment of cancer (Krychman, Amsterdam, Carlson, Carter, & Castirl, 2004). Studies have indicated, however, that patients are not satisfied particularly when they have unique or special concerns around their cancer (Nelson, 2007). Horden and Street (2007) indicated, for instance, that issues of intimacy and sexuality are significant concerns among cancer patients. With the increasing emphasis on the provision of psychosocial support for cancer patients, and emerging body of literature has highlighted the importance of providing the opportunity for patients to discuss issues of intimacy and sexuality. Health professionals, however, struggle with this level of communication in clinical practice (Nelson, 2007).

This tendency is partly derived from the fact that the majority of health professionals were found to be embracing more medical approaches to their patients’ issues of intimacy and sexuality after cancer (Horden and Street, 2007). Cancer patients, in stark contrast, perceive that cancer has interrupted their sense of self, including how they experience changes to the intimate and sexual aspects of their lives. There is critical incongruence, however, between the way patients and health professionals constructed
sexuality and intimacy (Horden & Street, 2007).

Also, it is not only structural constraints or a lack of education that prevents health professionals from communicating with patients about sexual and intimate changes after cancer (Kneier, 2010). Feelings of personal vulnerability and uncertainty have driven the majority of health professionals away from this topic, even when they were aware that their patients had these concerns (Kneier, 2010). The majority of health professionals have managed to avoid the topic altogether, or assume that somebody else would be more skilled in this area of patient communication. Horden and Street (2007) concluded that providing opening communications and checking personal assumptions about cancer patients’ sexuality and intimacy are vital for patient-centered support.

Upon the overview of psychosocial support, the literature review in the next section will be narrowed down to psychological support. Past and current psychological theories, approaches, and interventions developed for cancer patients and their families/caregivers will be analyzed, partly upon which this workshop is developed.

**Psychological Intervention Analysis**

Although studies show that cancer patients and their families/caregivers report the need for high levels of psychological support, there is generally limited knowledge regarding the types of interventions likely to be effective in meeting their complex needs (Hudson, 2010). Nelson (2007) also mentioned that, although psychological issues and needs have been identified, research has not yet established effective remedies. The following studies include some approaches for cancer patients and their caregivers.

**Support group.** Support groups are probably the most rapidly growing interventions method for both cancer patients and their families/caregivers (Spiegel, 2000).
Edelman (2000) also indicated that cancer support groups have become increasingly available to patients over the last 2 decades. Although various support groups differ in their philosophies, membership, and aims, the majority can be categorized as predominantly "supportive" or "psychoeducational" in their approaches (Edelman, 2000). The goals of support groups for cancer patients are to foster mutual aid, to help members cope with stresses associated with cancer, and to enhance coping abilities to deal with future stressors, such as anticipated surgeries and chemotherapies (Spiegel, 2000). Support groups, therefore, focus on cancer penitents’ or caregivers’ individual coping and mutual aid. While the goal of psycho-educational approach is educating through discussion and experience, the psycho-educational group would focus on individual learning (Spiegel & Classen, 2000).

Spiegel et al (1989) also argued that supportive–expressive group therapy is a standardized psychological treatment for cancer patients that encourage them to express feelings and concerns about their illnesses and their effects on their lives in a supportive environment of a therapist-led group. The women who participated in such therapy lived a mean of 18 months longer than the women in the control group. Goodwin (2001) also supported Spiegel’s findings. Her study showed improvement in the three elements that Spiegel et al reported (e.g. survival, mood, and pain management) by the supportive-expressive group therapy.

Cohen (2000) assessed the effectiveness of cognitive-behavior (CB) group intervention versus relaxation and guided imagery (RGI) group training, and concluded that psychological distress of breast cancer patients was significantly reduced in both intervention groups. The RGI group was more effective in reducing levels of fatigue and
sleep difficulty, whereas the CB group was more effective in reducing external health locus of control. Adherence to self-practice at home was significantly associated with reduction in psychological and physical symptoms. Psycho-educational support intervention had beneficial outcomes for family caregivers (Spiegel, & Classen, 2000).

Eager et al. (2010) found that interventions aimed towards psycho-education, problem-solving and cognitive restructuring could show demonstrable effects on caregivers’ well being, and Hudson also supported this by finding that psycho-educational support interventions had beneficial outcomes for family caregivers (Hudson, 2010). Edelman (2000) also argued that the majority of evidence suggested that patients who attend psycho-educational groups experience greater benefits than do those who attend purely supportive groups. Also several studies with favorable treatment effects include interventions that targeted specific needs of caregivers such as therapy for sleep deprivation and training in problem-solving skills (Hudson, 2010). This finding is commensurate with these of other authors who have advocated the importance of targeted interventions for this population (McCorkle, & Pasacreta, 2001).

Noble interventions that showed low grade but favorable trends were facilitation of family meetings and pain management (Hudson, 2010). The development of these and other new intervention approaches is vitally important to the evolution of psychological support for cancer patients and their families/caregivers. Grande et al. (2009) recommended that future work in psychological support for cancer patients and their families/caregivers should focus on clear definition and operation of intervention goals that include: separate and specific assessment of patients’ and families’ needs, greater focus on preventive intervention approaches, facilitation of the positive aspects of
caregiving, development of valid and reliable measures in cancer assessment, and better understanding of the “active” components of intervention. Eager et al. (2010) also argued that possible explanations of ineffective interventions were inappropriate outcome measures, non-specific goals that do not target patients’ and families’ needs, and ineffective research evaluation designs.

Group intervention works well with children of cancer patients’ families (Chung, 2004). After group intervention to reduce emotional and behavioral problems in siblings of children with cancer, siblings reported significantly reduced symptoms of anxiety and depression, and parents also reported notable reductions in their children’s behavior problems (Chung, 2004).

In sum, this literature review provided an overview of cancer statistics, cancer patients’ and their families’ psychosocial problems, concept of psycho-oncology, and analysis of psychological intervention for cancer patients and their families.
Chapter III

PROJECT AUDIENCE AND IMPLICATION FACTORS

Introduction

As presented in the previous chapters, cancer can be extremely distressing to patients and their families, and they are at an increased risk for various psychological symptoms. Given the improved survival rates, focus has begun to shift toward supporting patients and their families with the psychosocial impact of cancer and its treatment. This project was designed to offer mental health professionals a tool for better understanding the general experiences of cancer patients and their families. The project has implications for mental health professionals’ ability to understand the distressing period of life cancer patients and their families have to face, to empathize with them, to assess the needs of both patients and their families, and to treat them in a clinical setting. This chapter will focus on the development of the project, as well as the outline of the workshop.

Development of Project

The goal of this project was to develop a workbook for mental health professionals who will be, or are interested in working with cancer patients and their families. It was developed through an extensive literature review in the area of psycho-oncology; health related quality of life (HRQOL); and past and current psychotherapy approaches for cancer patients and their families. Feedback from mental health professionals with expertise in psycho-oncology was also highly referred. The material of this workbook was carefully developed and modified with the review of a wide variety of books, journal articles, and websites, manuals from cancer support
organizations and hospices.

The single most valuable resource of this project development was, however, my own clinical experience with cancer patients and their families. My responsibilities include conducting individual psychotherapy, support groups, and screening/assessment procedures with cancer patients and their families. Such individuals are very diverse in terms of their age, types, and stages of cancer. Those individuals enabled me to critically analyze and evaluate literature, and to repeatedly revise the project drafts. Some of the patients even allowed me to interview them and gave me priceless opportunities to get to know them on a personal level. Nothing was more valuable than the time I shared with those cancer patients and their families. Their expressions of fear, anger, and pain were stunning. Their articulations of hope, acceptance, and transcendence were magnificent. They demonstrated great humor, and genuine and sincere support for their fellow cancer patients and their families. They kindly accepted me into their community, and tolerated my immature questions and comments, and occasional emotional meltdowns. It is my sincere hope that mental health professionals who will work with cancer patients and their families be humble, respectful, and prepared to learn from them.

**Intended Audience**

The targeted population of this workbook is mental health professionals who will be, or are interested in working with cancer patients and their families. This population includes licensed marriage family therapists, social workers, psychologists, nurses, and graduate/post graduate level psychology/counseling/social work interns. Mental health professionals who read this workbook do not need to identify themselves as having
expertise in working with cancer patients and their families, or prior trainings in working with such clientele. The workbook may also be helpful and beneficial to other individuals, including cancer patients and their families/friends to understand the needs of anyone affected by cancer.

This workbook is designed to provide mental health professionals with introductory material on psychosocial support for cancer patients and their families. It is my hope that this workbook be utilized by mental health professionals as a guide to support, empower, and educate cancer patients and their families to maximize their sense of control and minimize unwanted loneliness.

**Personal Qualifications**

This workbook can be used as material of a workshop with the purpose of training mental health professionals to work with cancer patients and their families. The workshop should be presented by a mental health professional (licensed marriage family therapist, marriage family therapist intern, psychologist, licensed clinical social workers, social worker, or oncology nurse) with a specialization in working with cancer patients and their families, with extensive work experience in providing direct psychological support for this population. Experiences with both support groups and individual psychotherapy is preferable. Qualifications also may include experience in primary screening and interview/intake processes to assess suitability for support group membership, and crisis intervention with such populations.

In addition, although medical and ontological knowledge may not be required, an understanding of cancer (i.e. diagnoses, treatments, side effects, and medications) will be ideal. Also, since cancer patients are often prescribed with psychotropic medication,
especially anti-depressant, anti-anxiety, and soporific medication, a familiarity with basic psychopharmacology is essential.

Furthermore, it is helpful for the presenter to have additional experiences in grief counseling, crisis counseling, and working with individuals with other chronic diseases. Finally, the presenter should also be culturally competent and sensitive to participants from different cultures (i.e. the presenter should be open to diverse cultures, religions and spirituality, and sexual orientations).

Workbook Outline

Introduction

Part I: Cancer Outlook

Understanding Cancer

Cancer Survivorship

Health Related Quality of Life (HRQOL)

Psycho-oncology

A Bill of Patient’s Rights

Part II: Cancer Patients

Psychosocial Care for Cancer Patients

Cancer Patients’ Psychological Stressors

Understanding Cancer Patients’ Minds

Anticipatory Grief

Common Mental Disorders (DSM-IV-TR) Among Cancer Patients

Psychological Symptoms Among Cancer Patients

Psychotherapeutic Interventions
Types of Intervention
Assessment
Treatment Plan
Treatment
Psychoeducation
Discussion Topics in Psychotherapy
Integrating Therapeutic Approaches
Part III: Families/Caregivers
  Understanding Family Caregivers
  Anticipatory Grief of Family Caregivers
  Family Dynamics and Life-Threatening Illness
  Psychoeducation Tools for Family Caregiver
  Caregiver Burnout
Part IV: Loss and Bereavement
  Loss and Bereavement Issues
  Death and the Family System
  Understanding Children’s and Adolescent’s Bereavement
  Children’s and Adolescent’s Emotional Response to Death
Part V: Resources
  Selected Readings
  Contacts and Resources
Conclusion

Being diagnosed with cancer can be an extremely painful and traumatic experience. It will affect not only the person with cancer but family, friends, colleagues, and beyond. The whole family is the patient, not just the person with cancer. The family needs treatment, not just the person with cancer, because they all suffer from the physical pain caused by emotional pain, and emotional pain caused by physical pain. Cancer patients and their families need to maintain hope. Although what is being hoped for may change during the course of the illness, hope is essential to life.

I predict that there will be increasing demand for psychosocial support for cancer patients and their families due to the heightened awareness of psychotherapy among the general public, increasingly developed evidence based psychotherapy methods for this population, expanded research of psycho-oncology, and dispersed awareness of “patient-activeness.”

As mentioned in the previous chapter, the purpose of this workbook is to increase mental health professionals’ knowledge and awareness of psychosocial needs of cancer patients and their families. This workshop features introductory material for such mental health professionals, and it can be used as a quick reference guide in both private and public settings, or as a training guide in a variety of settings such as cancer support organizations, counseling clinics and agencies, hospitals, nursing homes, and hospices.

After reviewing an extensive amount of information about the psychosocial support for cancer patients and their families, it is concluded that the proposed workshop
will be of great value to mental health professionals who will be and are interested in working with cancer patients and their families.

Counseling Consideration for Psychotherapists

My mission in this project is to provide educational material for mental health professionals about the needs of cancer patients and their families. Through this workbook, mental health professionals will learn how cancer patients and their families feel alone, hopeless, and out of control, and how mental health professionals can maximize their capability to address patients’ and families’ needs.

It is important to mention, however, that I strongly believe that acquiring knowledge is just the beginning of walking side by side through a rough road with cancer patients and their families. Psychotherapist’s own aptitude, determination, and genuine interest in this population is much more crucial than knowledge. Psychotherapists are required to have extremely sophisticated levels of mental and emotional maturity, spirituality, and tolerance. Descriptions of cancer patients’ physical symptoms can be extremely graphic. It could be disturbing to observe their gradual hair loss and deteriorating health condition such as dramatic emaciation, and it could be heartbreaking to greet them coming in to the room with a portable oxygen tank, or in a wheelchair. Yet, psychotherapists who work with this population are expected to fully bear the emotional and physical pain.

Psychotherapists also need to be mentally ready to discuss hard topics such as death and dying, and be able to do so comfortably and genuinely. A client may declare switching from cancer cure to palliative care, may wish for an assisted suicide, and may even die during the course of therapy. A therapist may also experience her/his own or
family member’s serious illness and even death. Countertransference is a common experience among psychotherapists who work with cancer patients and their families.

Beginning psychotherapists are especially vulnerable and tend to dwell on their feeling of uselessness, hopefulness, and isolation. It cannot be emphasized enough, therefore, that self-care of the psychotherapists is tremendously critical. Sharing thoughts and feelings at supervision meetings, attending study groups and workshops, seeking consultation from other psychotherapists working with this population are all also extremely important.

**Limitations of the Project**

As previously mentioned, this workbook is an introduction for mental health professional who will work with cancer patients and their families. Each chapter may lack depth, therefore, especially the sections of treatment theories and methods. Also, since this workbook is intended to take a holistic approach of supporting cancer patients and families, some of the contents are beyond psychotherapists’ scope of duty. Psychotherapists should constantly be aware of their professional boundaries.

Another limitation is that this workbook does not include a treatment plan that mental health professionals can use to treat cancer patients and their families. Although conclusions drawn from the literature review have some implications for clinical interventions with cancer patients and their families, in my opinion, these findings are not persuasive enough to single out a single effective approach. Therefore, this project lacks specific goals, interventions, and outcome measures applicable to this target population.

This project, however, includes all-around and extensive information about working with cancer patients and their families, further research suggestions, a proposal of
collaboration with medical professionals, especially oncologists and gerontologists, a vast amount of recommended readings, and reference lists of related organizations, agencies, and websites.

**Suggestions for Future Research**

Suggestions for future development of the workbook include a more specific focus on psychotherapeutic interventions targeted to narrower categories, such as types of cancer, stages of cancer, and whether the patient is under treatment or in remission. More thorough development focused on distinct population by gender, age, sexual orientation, and cultural background and language is also important. I am particularly interested in developing a workbook exclusively focused on cultural and racial minorities.

Also, further comparative research on effective intervention approaches, including both traditional and novel methods, is highly recommended. My particular interest is family psychotherapeutic interventions in oncology settings. A relatively new method, Medical Family Therapy, draws my interest, and research of this method is my next goal.

Furthermore, I realized that career concerns are extremely critical for relatively young cancer patients and their families. Applying career development theories, especially career transition theories, toward cancer patients will be extremely valuable.

Finally, the future addition of pediatric cancer patients to the workbook is highly anticipated. I did not include this area in the current version of the workbook since I have not had opportunities to work with this population. According to my research (Carroll-Johnson, R., Gorman, L. M., & Bush, N. J., 1998), however, psychosocial support for pediatric cancer patients and their families is another critical subject in
psycho-oncology that should be addressed more.
REFERENCES


Psychology, 74(6), 1143-1152.


Bottomley, A. (2002). The Cancer Patient and Quality of Life The Oncologist. *The


http://www.cdc.gov/hrqol/concept.htm


Practice, 17(3), 13-323.


Fernandes, C., Muller, R., & Rodin, G. (2012). Predictors of parenting stress in patients
with hematological cancer. *Journal of Psychosocial Oncology, 30*(1), 81-96.


distress at the end of life. *Palliative and Supportive Care* 2, 65-77.


McCorkle, R., & Pasacreta, V. (2001). Enhancing Caregiver Outcomes in Palliative Care


cancer patients, Clinical Psychology, 9, 5


Appendix A

A WORKBOOK FOR PSYCHOTHERAPISTS
WORKING WITH
CANCER PATIENTS AND THEIR FAMILIES

Kayo Matsumoto
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>65</td>
</tr>
<tr>
<td><strong>PART I: CANCER OUTLOOK</strong></td>
<td></td>
</tr>
<tr>
<td>Understanding Cancer</td>
<td>67</td>
</tr>
<tr>
<td>Cancer Survivorship</td>
<td>68</td>
</tr>
<tr>
<td>Health Related Quality of Life (HRQOL)</td>
<td>70</td>
</tr>
<tr>
<td>Psycho-oncology</td>
<td>71</td>
</tr>
<tr>
<td>A Bill of Patient’s Rights</td>
<td>72</td>
</tr>
<tr>
<td><strong>PART II: CANCER PATIENTS</strong></td>
<td></td>
</tr>
<tr>
<td>Psychosocial Support for Cancer Patients</td>
<td>74</td>
</tr>
<tr>
<td>Cancer patients’ psychological stressors</td>
<td>77</td>
</tr>
<tr>
<td>Understanding Cancer Patients’ Minds</td>
<td>79</td>
</tr>
<tr>
<td>Anticipatory Grief</td>
<td>81</td>
</tr>
<tr>
<td>Common Mental Disorders (DSM-IV-TR) Among Cancer Patients</td>
<td>83</td>
</tr>
<tr>
<td>Psychological symptoms among cancer patients</td>
<td>84</td>
</tr>
<tr>
<td>- Anxiety</td>
<td>84</td>
</tr>
<tr>
<td>- Anger</td>
<td>85</td>
</tr>
<tr>
<td>- Depression</td>
<td>87</td>
</tr>
<tr>
<td>Psychotherapeutic interventions</td>
<td>89</td>
</tr>
<tr>
<td>- Types of intervention</td>
<td>89</td>
</tr>
<tr>
<td>- Assessment</td>
<td>93</td>
</tr>
<tr>
<td>- Treatment plan</td>
<td>94</td>
</tr>
<tr>
<td>- Treatment</td>
<td>96</td>
</tr>
<tr>
<td>- Psychoeducation</td>
<td>97</td>
</tr>
<tr>
<td>Discussion topics in psychotherapy</td>
<td>100</td>
</tr>
<tr>
<td>Integrating therapeutic approaches</td>
<td>104</td>
</tr>
<tr>
<td><strong>PART III: FAMILIES/CAREGIVERS</strong></td>
<td></td>
</tr>
<tr>
<td>Understanding family caregivers</td>
<td>105</td>
</tr>
<tr>
<td>Anticipatory Grief of family caregivers</td>
<td>107</td>
</tr>
<tr>
<td>Family Dynamics and Life-Threatening Illness</td>
<td>108</td>
</tr>
</tbody>
</table>
Psychoeducation tools for family 110
Caregiver Burnout 111

PART IV: LOSS AND BEREAVEMENT
Loss and Bereavement Issues 113
Death and the family system 114
Understanding Children’s and Adolescent’s Bereavement 117
Children’s and Adolescent’s Emotional Response to Death 118

PART V: RESOURCES
Selected Readings 120
Contacts and Resources 122
INTRODUCTION

To the reader

This workbook was created in order to enhance your understanding of cancer patients and their families. I believe that the information presented in this workbook will serve to aide your ability to empathize with, assess the needs of, and treat cancer patients and their families in a clinical setting.

Please note that this workbook has been designed for mental health professionals working with cancer patients and their families. The target population includes marriage family therapists, social workers, and psychologists in the process of obtaining their licenses, as well as those who are already licensed to practice, yet may lack experience of treating cancer patients and their families.

Readers do not need to specialize in working with cancer patients and their families, but knowledge of fundamental counseling skills and theories is highly recommended in order to effectively apply this workbook information to clinical work. However, the most important characteristics of mental health professional when working with cancer patients and their families are empathy, sensitivity, and maturity.

The pages that follow feature a variety of facts, materials, and resources for you to utilize in your clinical settings. Some materials can be forwarded to your clients as handouts for psychoeducational purposes.

I hope this workbook provides a valuable resource in your work with cancer patients and their families. Supporting these families can be extremely difficult for even the most experienced mental health professionals, but it is, indeed, rewarding and fulfilling.

Flourishing summer, 2012
PART I:
CANCER OUTLOOK

UNDERSTANDING CANCER

Many of you reviewing this workbook may have already encountered clients with cancer or their family caregivers. Others may not have had the opportunity to work with cancer patients. Either way, as a mental health professional, it is critical to have basic knowledge about cancer in order to work effectively with cancer patients and their families. Here is some general information about cancer.

What is cancer?
- Cancer is an invasive, uncontrolled replication of cells in the body.
- Lifestyle and environmental factors are indicated as being the cause of about 60% of existing cases of cancer.
- Cancer risk is high in individuals who have family members with cancer.

What causes cancer?
Currently, it is thought that cancer is caused by multiple factors. The followings are contributing factors:
- Chronic stress
- Diet and nutritional deficiencies
- Environmental toxins
- Excess exposure to sunlight
- Food additives
- Free radicals
- Genetic disposition
- Heavy metal toxicity (mercury, arsenic, lead, etc.)
- Hormonal dysfunction
- Immune-suppressive drugs
- Intensive toxicity and digestive imbalance
- Oncogenes (genes responsible for initiating cancer)
- Pesticides and herbicides
- Polluted water
- Tobacco and smoking
- Viruses

Who is at risk of developing cancer?
- Anyone.
- Aging is considered a risk factor: most affected are adults middle-aged or older.
- Nearly 80% of all cancers are diagnosed at ages fifty-five and older.

How to diagnose cancer?
- The best approach to beat cancer is prevention and early diagnosis.
Early diagnosis is the prerequisite for cure.

Pap smear for detecting cervical cancer, the colonoscopy examination to detect colon polyps, and prostate-specific antigen (PSA) blood test for prostate cancer detection.

“Caution,” the seven danger signals are:
- Changes in bowel or bladder habits
- A sore that does not heal
- Unusual bleeding or discharge
- Thickening or lump in breast or elsewhere.
- Indigestion or difficulty swallowing
- Obvious change in a wart or mole
- Nagging cough or hoarseness

Breast, colon, prostate, melanoma, lung cancers, and leukemia are especially important to be detected at an early stage.

Unfortunately, most cancers grow for months or years before they cause symptoms that lead to their detection by examination, CT scan, MRI, X rays, or PET scans.

Other tests include complete blood counts (CBC), serum chemistry profiles, blood cancer markers, and immunological tests.

**Cancer statistics**

**Incidence**
- The median age at diagnosis for all types of cancer is 66 years of age. Approximately 1.1% of the cancer population was diagnosed under age 20; 2.6% between 20 and 34; 5.5% between 35 and 44; 14.2% between 45 and 54; 23.4% between 55 and 64; 24.9% between 65 and 74; 20.6% between 75 and 84; and 7.7% 85+ years of age.

**Mortality**
- From 2005-2009, the median age at death for cancer of all types was 72 years of age. Approximately 0.4% died under age 20; 0.8% between 20 and 34; 2.4% between 35 and 44; 8.9% between 45 and 54; 18.3% between 55 and 64; 24.8% between 65 and 74; 28.9% between 75 and 84; and 15.5% 85+ years of age.

**Survival rate**
- The overall 5-year relative survival for 2002-2008 is 65.4%.

**Lifetime risk**
- Based on cancer rates from 2007-2009, 41.24% of men and women born today will be diagnosed with cancer at some time during their lifetime.

**Prevalence**
- On January 1, 2009, there were approximately 12.5 million men and women alive in the United States who had a history of some type of cancer – 5.8 million men and 6.7 million women.

*Source: National Cancer Institute, Surveillance Epidemiology and End Results (SEER)*
CANCER SURVIVORSHIP

A cancer survivor is any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life. The terms “cancer patient” and “cancer survivor” are often used interchangeably.

The goals of treatment are to “cure” the cancer if possible and/or prolong survival and provide the highest possible quality of life during and after treatment. Many cancer-free survivors, however, must cope with the long-term effects of treatment and the fear of recurrence.

Also, although many patients’ cancers never come back after initial treatment, sometimes, cancer comes back (recurrence) after 10 years or even more, when patients’ lives are back to normal.

Tips for therapists

✓ Your client may have negative notions about being called a “cancer patient” or a “cancer survivor.” Some of them feel guilty and stigmatized. The best way to decide how to refer to your client is to ask them. Don’t assume, but ask!

✓ The end of the treatment is not the end of cancer. Patients’ battles barely started. Your client may claim:
  “I feel abandoned.”
  After a series of treatments, such as chemotherapy and radiation therapy, some of them even “miss” treatment even though they had terrible side effects during such treatment. At least, they felt that they were cured, treated, and taken care of.
  “I am scared.”
  During treatment, cancer patients are often preoccupied with physical burdens (side effects of treatment such as fatigue, nausea, pain, etc). Once these symptoms are gone, however, they are attacked by emotional distresses, such as fear, anxiety, and depression.
  “I will never be the same.”
  Emotional scars do not heal easily. Those who had mastectomies (removal of the whole breast) or lumpectomies (removal of a part of the breast) are especially prone to negative self-image.
HEALTH RELATED QUALITY OF LIFE (HRQOL)

Cancer patients often feel that their Quality of Life (QOL) is deteriorated or violated (See areas of quality of life in the table below). QOL is one of the most discussed topics among cancer patients in support group settings. What is QOL?

**Quality of Life (QOL)**
Individuals’ perception of their Quality of Life depends on “their position in life in the context of the culture and value system in which they live, and in relation to their goals, standards, and concerns.” (WHO, 1993)

**Health Related Quality of Life (HRQOL)**
Health Related Quality of Life depends on “the value assigned to duration of life as modified by impairments, functional states, perceptions, and social opportunities as influenced by disease, injury, treatment, or policy.” (U.S. Department of Health and Human Services, 1990)

<table>
<thead>
<tr>
<th>Physical Well-being &amp; Symptoms</th>
<th>Psychological Well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional ability</td>
<td>Control</td>
</tr>
<tr>
<td>Strength/fatigue</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Sleep &amp; rest</td>
<td>Depression</td>
</tr>
<tr>
<td>Overall physical health</td>
<td>Enjoyment/leisure</td>
</tr>
<tr>
<td>Fertility</td>
<td>Fear of recurrence</td>
</tr>
<tr>
<td></td>
<td>Cognition/attention</td>
</tr>
<tr>
<td></td>
<td>Distress of diagnosis and treatment control</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social Well-being</th>
<th>Spiritual Well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family distress</td>
<td>Meaning of illness</td>
</tr>
<tr>
<td>Roles and relationship</td>
<td>Religiosity</td>
</tr>
<tr>
<td>Affection/sexual function</td>
<td>Transcendence</td>
</tr>
<tr>
<td>Appearance</td>
<td>Hope</td>
</tr>
<tr>
<td>Enjoyment</td>
<td>Uncertainty</td>
</tr>
<tr>
<td>Isolation</td>
<td>Inner strength</td>
</tr>
<tr>
<td>Finances</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
</tr>
</tbody>
</table>
Have you heard the word, “psycho-oncology”? It is an interdisciplinary field of study and practice at the intersection of lifestyle, psychology, and oncology. It includes a wide variety of aspects beyond medical treatment of cancer.

**Areas involved in psycho-oncology**
- The clinical disciplines: surgery, medicine, pediatrics, radiotherapy
- Epidemiology
- Immunology
- Biology
- Pathology
- Bioethics
- Rehabilitation medicine, clinical trial research
- Palliative care
- Psychiatry
- Psychology

**Psychotherapeutic areas**

**Psychotherapists’ roles as members of psycho-oncology team**
- Provide a comprehensive care of cancer patients and their families in emotional, spiritual and social areas.
- Consider cancer patients and their families as a single unit to be treated, and provide emotional support.
- Promote autonomy and dignity of the cancer patients.
- Encourage cancer patients’ rehabilitative attitude towards their full recovery.
- Minimize cancer patients and their families’ sense of loneliness, feelings of lack of control, and hopelessness.

**Tips for therapists**
- Cancer patients are often physically exhausted and distressed from their medical treatment including surgery, chemotherapy, radiology, and their side effects.
- Although cancer patients acknowledge they benefit from medical advancement, they often mention “lack of personal touch.” (For instance, doctors read CT Scan results, rather than use the palpitation method of diagnosis.)
- Although social workers and oncology nurses are available at most hospitals, their psychological care services are limited, not to mention their services for family members.
- Therefore, the psychotherapist role to care for cancer patient and their families’ emotional needs is critical.
A BILL OF PATIENT’S RIGHTS
Association of American Physicians & Surgeons

A BILL OF PATIENT’S RIGHTS
All patients should be guaranteed the following freedoms:
To seek consultation with the physician(s) of their choice;
To contract with their physician(s) on mutually agreeable terms;
To be treated confidentially, with access to their records limited to those involved in their care or designated by the patient;
To use their own resources to purchase the care of their choice;
To refuse medical treatment even if it is recommended by their physician(s);
To be informed about their medical condition, the risks and benefits of treatment and appropriate alternatives;
To refuse third-party interference in their medical care, and to be confident that their actions in seeking or declining medical care will not result in third-party-imposed penalties for patients or physicians;
To receive full disclosure of their insurance plan in plain language, including:
  CONTRACTS: A copy of the contract between the physician and health care plan, and between the patient or employer and the plan;
  INCENTIVES: Whether participating physicians are offered financial incentives to reduce treatment or ration care;
  COST: The full cost of the plan, including co-payments, coinsurance, and deductibles;
  COVERAGE: Benefits covered and excluded, including availability and location of 24-hour emergency care;
  QUALIFICATIONS: A roster and qualifications of participating physicians;
  APPROVAL PROCEDURES: Authorization procedures for services, whether doctors need approval of a committee or any other individual, and who decides what is medically necessary;
  REFERRALS: Procedures for consulting a specialist, and who must authorize the referral;
  APPEALS: Grievance procedures for claim or treatment denials;
  GAG RULE: Whether physicians are subject to a gag rule, preventing criticism of the plan.

### Cancer patients circle of care

This section below lists the type of professionals, outside of the medical team, that may be helpful to cancer patients and their families. It is important to understand what types of specialists are available, and the services they can provide.

<table>
<thead>
<tr>
<th>Professionals</th>
<th>Job description</th>
</tr>
</thead>
</table>
| Social Workers                                     | - Assess cancer patients and their family caregivers’ emotional, social, spiritual, and financial needs.  
- Develop a plan of care to meet identified needs.  
- May provide direct counseling, and facilitate support groups.  
- Refer patients and families to appropriate community agencies and services including home care, childcare, transportation, financial problems, and other concerns.  
- Set priorities for the many responsibilities the patients and families have.  
- Provide bereavement support.  
- Guide patients and families through the system, including how to apply for Social Security Disability or food stamps, fill out insurance forms, and get financial assistance.  
- Most hospitals have social workers on staff.                                                                                                                                                                                                                           |
| Oncology Social Workers                            |                                                                                                                                                                                                                                                                                                                                                       |
| Psychologists, Marriage Family Therapists          | - Provide professional counseling/psychotherapy, including individual, couple, and family therapy.  
- Facilitate cancer patient support groups and family support groups.  
- Provide psycho-education.  
- Offer sex therapy and provide information for post-treatment cancer patients about intimacy.                                                                                                                                                                                                                          |
| Psychiatrists                                      | - Prescribe psychotropic medication.                                                                                                                                                                                                                                                                                                                  |
| Rehabilitation Specialists (physiatrists, physical therapists, occupational therapists, rehabilitation) | - Physical therapist helps patients strengthen a body part or function weakened by cancer treatment.  
- Occupational therapists help patients adjust their |
| **counselor, speech therapists)** | routines of getting dressed or moving around the home so they can continue with normal activities even with physical disabilities.  
- Speech therapists help patients learn how to communicate after a laryngectomy or when the patients have mouth or facial tumors that interfere with speech.  
- Enterostomal therapists help patients with ostomies and give advice and guidance on how to adjust patients’ daily routines after surgery. |
| --- | --- |
| **Nutritionists & Dietitians** | Many patients experience loss of appetite due to nausea. Other symptoms include feelings of fullness, dry mouth, and a change in the way food tastes, heartburn, or fatigue.  
- Nutritionists and dietitians suggest food substitutes if taste change is experienced, recommend recipes specially designed for people who are undergoing cancer treatment.  
- Most hospitals have registered dietitians or nutritionists. |
| **Hospice care providers (May include nurses, physicians, psychotherapists, social workers, clergy, and volunteers)** | Hospice care can be provided in the home with backup care in the hospital or in a special unit of a hospital called a hospice or palliative care unit.  
- Home hospice programs are most common.  
- Hospice care is aimed at physical comfort, especially pain control and emotional support both for the patient and for the family.  
- Provide bereavement counseling for family and friends after a person dies. |
| **Chaplain/ Clergy** | Provide spiritual counseling.  
- Provide consultations to community clergy.  
- Assess patient & family spiritual needs  
- Assist with memorial preparations. |
| **Volunteers** | Provide companionship & support patients and families.  
- Provide needed non-medical services. |

*Source: Carroll-Johnson, Gorman, & Bush, Psychosocial Nursing Care (1998)*
**Model vignettes**

Juliet, a 42-year-old oral cancer patient, is seeing a speech therapist weekly to be ready to go back to work. She sees a nutritionist once a month for advice on diet that will not bother her sensitive esophagus. She sees a social worker to ask about finances while she is out of work. She also participates in a support group once a week at a local cancer support community.

Steve, a 78-year-old lung cancer patient, needs a lot of spiritual help, and sees his clergy frequently to pray together. He experiences depression and sees a psychiatrist for anti-depressants. He also goes to a psychologist, who specializes in existential therapy.

Laura, a 58-year-old metastasized pancreatic cancer patient, recently found out that no other chemotherapy would work for her type of cancer. She decided to stop curable treatment altogether and to switch to hospice care. Hospice staff visits her every other day, a therapist, who specializes in the use of pets for psychological comfort, visits her once a week. The hospice volunteer comes to her home to help with housework.

**Tips for therapists**

- As can be seen in the above vignettes, cancer patients, especially proactive individuals, can receive support from many professionals.
- Psychotherapists job is to provide cancer patients and their families with emotional support within their scope of practice. It is ideal to work closely with other professionals.
- If you provide individual therapy or facilitate group therapy, keep in mind that cancer patients need flexibility and they may not be able to attend therapy regularly. In addition to their medical appointments, they may also be undergoing treatment, such as chemotherapy and radiation treatment.
CANCER PATIENTS’ PSYCHOSOCIAL STRESSORS

Cancer patients are experiencing tremendous psychosocial stressors. However, they may not address their stressors in individual counseling settings or support group settings for various reasons. For instance, some cancer patients may not be aware of the impact of their stressors, and others may not want to be labeled as “weak.” Cancer patients may hesitate to bring up sexual problems caused by their illnesses or treatments, or other delicate issues such as chemical dependency and financial difficulties. Therefore, psychotherapists working with cancer patients should be familiar with common stressors cancer patients may suffer, and carefully observe signs of such stressors.

**Chronic stressors**

*Physical stressors*
- Fatigue and low energy (Fatigue is the #1 symptom of cancer patients undergoing treatment)
- Pain
- Nausea and vomiting

*Emotional stressors*
- Depression in response to diagnosis and treatment.
- Anxiety in response to treatment and possible recurrence of cancer.
- Appetite disturbances
- Sleep problems

*Social stressors*
- Interpersonal relationship turmoil
- Sexual or romantic relationship problems
- Unemployment or underemployment
- Job discrimination
- Financial problems

These stressors may cause serious behavioral symptoms such as self-medication with alcohol or other drugs.

---

**Model vignette**

Katherine, 48 years old, was diagnosed with pancreatic cancer. The side effects of the aggressive chemotherapy she experienced were intolerable. Therefore, she first overdosed on the Vicodin that her psychiatrist prescribed. Then, to address her fear of death, Katherine started smoking marijuana, and within a few weeks, she started heroin. She sometimes sneaks out of her home in the middle of the night, and randomly drives around for hours.
Remember!

- Chemical dependency is an important factor to acknowledge in the initial assessment process.
- Consult with supervisors or colleagues on difficult cases, especially if substance abuse is involved.
- If your client is currently abusing substances, he/she needs to be treated immediately.
- Suggest that your client sees a psychiatrist and oncologist.
- Remember, some substance abuse programs may not accept people who are having chemotherapy treatment (or any chemical treatment).
- The patient, therefore, may need to delay chemotherapy to treat chemical dependency first.
- Serious physical and emotional stress may prevent cancer patients from complying with recommended treatment; thus treatment effectiveness is decreased.
UNDERSTANDING CANCER PATIENTS’ MINDS

The will to live
The will to live is the force within each cancer patient to fight for survival. This force is stronger in some patients than others, determined by one’s character and personality, the quality of one’s current life, and whether the patient has a purpose to live.

In many cases, the strength of a patient’s will to live appears to be an important factor in obtaining positive prognosis, unexpected remission, and overall quality of life.

The most critical ingredient of the cancer patient’s will to live includes:
- Hope
- Faith
- Perseverance
- Optimism
- Courage
- Goals
- Love
- Supportive family and friends
- Purpose
- Fear of dying
- Strong coping skills
- Feeling that it was their destiny to endure and survive

Challenge to the will of life
Just as the will to live can be nurtured by a positive attitude, it can also be determined by fear, anger, loss of self-esteem, and alienation. These feelings are common responses to the diagnosis of cancer. If allowed to go unresolved, they lead to feelings of depression, helplessness, futility, and loss of the will to live.

- Fear
- Anger
- Loss of self-esteem
- Alienation

Example of fear
Cancer patients may experience fear in following aspects.

- Loss of relationship
- Loss of control
- Being a burden
- Pain
- Disfigurement
- Rejection
- Loss of identity
- Invasion of privacy
- Stigma of disease
- Not knowing the truth
- Alienation from important others
- The dying process
- Progression of the disease
Model Vignettes

Robert, a 72-year-old patient, with metastasized lung cancer patient, is a “fighter.” Although he admits that he has “down” days, his overall attitude is positive and optimistic. He constantly expresses his appreciation to his wife, makes other members of his support group laugh with his “cancer jokes,” and is willing to share his fear of death with other group members. He is still fighting 13 years after his first diagnosis, when his oncologist told him that he would live no more than 6 months.

Carol is a 74-year-old patient, whose breast cancer recurred after 10 years. She is extremely angry about the recurrence, feels lonely after being recently widowed and is distant from her adult children. She loses hope and she is unwilling to go back to treatment.

Tips for therapists

✓ A person, such as Robert not only spiritually uplifts himself, but also positively influences other patients like Carol. One advantage of support groups for cancer patients, therefore, is sharing thoughts about hope, optimism, and a new purpose of life.
When a person’s security and routine are threatened, the first thing that happens is a “fight/flight” response. The person either flees into denial, or starts to fight it out. Part of either response is a grieving process – grieving for plans, hopes, and wishes that may not be fulfilled. Cancer patients often experience this grieving process.

Kubler-Ross (1969) developed a 5-stage grief process, most easily remembered as “DABDA.” It helps both cancer patients and their families/caregivers understand their grieving process.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial</td>
<td>Upon Diagnosis, a person’s first response is to say, “No, not me. You must have it wrong.” This is a flight from reality, and a necessary step on the conscious level, while the unconscious mobilizes forces to deal with the consequences of the unwelcome news. This stage usually lasts only a few days. It can return, however, as one feels better and the reality of the disease is not present, or with future diagnosis. Family members also experience denial.</td>
</tr>
<tr>
<td>Anger</td>
<td>Once “the truth” sinks in, the “fight” response is to become angry. “How dare this happen to me!” “What have I done to deserve this?” “Those doctors should have caught this problem months ago. Didn’t I go in for a check up?” Blame is a response to anger.</td>
</tr>
<tr>
<td>Bargaining</td>
<td>As “the truth” continues to widen, permeating into the very meat of existence, a sort of bartering process begins to take place. The patient, or family members, begins a bargaining process with God. “I’ll tell you what... just let me stay well long enough to raise my children, or get that trip in, or enjoy some retirement, and I’ll figure it is my time to go.” There is a feeling that surely, if there is a just God, we are in this together, with equal say.</td>
</tr>
<tr>
<td>Depression</td>
<td>There comes a time when a little piece of “the truth” sneaks in without all the defenses against it. It may happen as one notices weakness, or as one is aware that this may be the last holiday. Or, as the patient notices how precious sunsets, laughter, friends, and family are. And then, they notice why these are so precious: their pleasures are very time limited. That’s a depressing fact. No longer, at least in this moment, is the truth of all of these losses being fought against, or bargained for. Depression will come and go. Different family members will experience it at different times.</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Sometimes, but not always, a state of grace is obtained, and a person and/or a family come to a place of peace about the loss of life. This can happen in moments, or it can become a state of being. It is most likely to occur if the previous stages have been grappled with. This stage can also be confused with denial, for they can look alike.</td>
</tr>
</tbody>
</table>

Source: Kubler-Ross, On death and dying (1996)
Tips for therapists

✓ This material (Kubler-Ross’s 5 stages of grief process) can also be used as a material to educate cancer patents and families about what to expect, and also to normalize such reactive emotions to cancer.
✓ Keep in mind, however, that these stages do not happen in a nice and neat order. It looks linear on paper, but it is not. They come and go, repeat, or skip stages.
✓ How a patient, or a family member, experiences grief has something to do with how other loss and grief were dealt with in his/her past.
✓ It is, therefore, useful to ask the client about other recent and/or previous losses, tragic life events, and family circumstances.
✓ Also, keep in mind that not everybody reaches the “acceptance” stage.
The following are typical DSM-IV-TR diagnoses that cancer patients experience.

<table>
<thead>
<tr>
<th>Code</th>
<th>Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>296.xx</td>
<td>Major Depressive Disorder</td>
</tr>
<tr>
<td>296.2x</td>
<td>Major Depressive Disorder, Single Episode</td>
</tr>
<tr>
<td>296.3x</td>
<td>Major Depressive Disorder, Recurrent</td>
</tr>
<tr>
<td>300.00</td>
<td>Anxiety Disorder NOS</td>
</tr>
<tr>
<td>300.02</td>
<td>Generalized Anxiety Disorder</td>
</tr>
<tr>
<td>300.4</td>
<td>Dysthymic Disorder</td>
</tr>
<tr>
<td>309.0</td>
<td>Adjustment Disorder with Depressed Mood</td>
</tr>
<tr>
<td>309.24</td>
<td>Adjustment Disorder with Anxiety</td>
</tr>
<tr>
<td>309.28</td>
<td>Adjustment Disorder with Mixed Anxiety and Depressed Mood</td>
</tr>
<tr>
<td>309.3</td>
<td>Adjustment Disorder</td>
</tr>
<tr>
<td>309.4</td>
<td>Adjustment Disorder with Mixed Disturbance of Emotions and Conduct</td>
</tr>
<tr>
<td>296.xx</td>
<td>Major Depressive Disorder</td>
</tr>
<tr>
<td>311</td>
<td>Depressive Disorder NOS</td>
</tr>
<tr>
<td>316</td>
<td>Psychological Symptoms Affecting Axis III Disorder</td>
</tr>
<tr>
<td>V62.82</td>
<td>Bereavement</td>
</tr>
</tbody>
</table>

*Source: DSM-IV-TR*
PSYCHOLOGICAL SYMPTOMS AMONG CANCER PATIENTS

Anxiety, anger, and depression are the most commonly experienced psychological symptoms among cancer patients. Here is some information about each symptom and their characteristics.

ANXIETY

- Anxiety is the most common psychological responses by cancer patients.
- Cancer patients often have feelings of fear and apprehension about their own mortality.
- Acute stress responses often happen at the time of initial diagnosis.
- But anxiety occurs at any crisis point along the cancer continuum, especially the night before, on the way to, or in the waiting room of medical appointments (chemotherapy, radiation, CT scan, etc).
- If uncontrolled, anxiety develops and interferes with both the patient’s treatment responses and psychological functioning.

Examples of anxiety responses

- Reactive anxiety Related to the diagnosis and treatment of cancer.
- Generalized anxiety disorder Excessive anxiety and worry, restlessness, fatigue, irritability, tension, and difficulty concentrating.
- Panic Recurrent and unexpected panic attacks, losing control, having a heart attack, and feeling “going crazy.”
- Phobias Marked persistent fear that is excessive and unrealistic. For cancer patients, it can be related to blood and injections.
- Post-traumatic stress Patient has witnessed or experienced event(s) that involved actual or threatened death or serious injury. For cancer patients, past experiences (trauma, such as other serious illnesses of family members or unpleasant hospital experiences) may be triggered by their own cancer diagnoses and treatment (stressful events), and cause intense fear and helplessness.
- Medical illness Anxiety resulting from medical states, such as pain and side effects.

Tips for therapists

- It is important for the therapist to recognize signs and symptoms of anxiety, and differentiate between normal anxiety responses and clinical anxiety.
- Some patients say guided imagery, meditation, and other relaxation techniques help reduce their anxiety.
ANGER

- Anger often occurs after the initial shock of cancer diagnosis.
- As the 5-stage grief process (Kubler-Ross) indicates, feelings of anger, resentment, and rage occupy cancer patients typically when denial is no longer maintained.
- Anger can be demonstrated in both overt and covert manners.

Examples of overt anger demonstration
- Verbal abuse
- Emotional outbursts
- Temper tantrum
- Swearing
- Shouting
- Name calling (especially towards medical staff, friends, and family members)
- Sarcasm
- Criticism
- Hostility
- Irritation
- Defensiveness
- Body language (tightened jaw, clenched fists, and frigidity)

Examples of covert anger demonstration
- Silence
- Withdrawal
- Depression
- Bitterness
- Attempts to control everything
- Refusal to control everything
- Refusal to see visitors
- Refusal to eat, drink, comply with doctor’s appointments and treatment
- Continuing to and/or increasing alcohol, smoking, or using substances
- Acting out
- Being overly nice
- Passive aggression
- Emotional detachment
- Forgetting to do important things (i.e. medical appointment)
- Procrastination

Factors that elicit cancer patients’ anger
- Powerlessness
- Vulnerability
- Fear
- Anxiety
- Isolation, loneliness
- Humiliation, shame
- Feeling of being neglected, forgotten (by family, work, and community)
- Anonymity, abandonment
- Mistreatment, abuse
- Annoying physical stimuli (i.e. light, noise, temperature, humidity)
- Past unresolved anger
- Grief over other losses
- Unfairness of life
- Frustrating people and situations
- Loss of control
- Overwhelming and confused feelings
- Unmet expectations
- Grief over “non-events” (i.e., life plans which did not occur due to cancer)

Due to the above factors of their anger, cancer patients often claim that they become sensitive and reactive to the following situations:

- Good health of others (“Why me?” dilemma)
- Distance of family and friends (“They are avoiding me because of cancer.”)
- Being unfairly treated (i.e. Prolonged waiting times at medical appointments)
- Unfamiliar hospital routines
- Dependence on medical team (loss of control)
- Cognitive impairment (i.e. “chemo brain”)
- Unsolved childhood resentment

**Remember!**

- According to my experience, anger is the #1 topic among cancer patients in support group settings. They suffer from tremendous feelings of anger day and night, throughout the continuum of cancer.
- Anger is also frequently brought up in family support groups. Naturally, patient’s anger affects all family members, and family members experience a dilemma between expressing their own anger and feelings of guilt and trying to hold in these feelings in order to protect and be “nice” to the cancer patient.

**Tips for therapists**

- Anger is demonstrated in a variety of ways; cancer patients may use abusive language or aggressive behavior, express negative feelings about hospital staff, or refuse to participate in their treatment.
- It is important to grasp, therefore, if such demonstrations of anger come from the illness, or other pre-existing causes.
The therapist should expect and carefully observe signs of anger demonstration in early stages (i.e., assessment and intake).

Feelings of anger should be acknowledged and treated appropriately in early stages, because these feelings may cause failure to comply with treatment, which leads the patient to undesirable treatment results.

DEPRESSION
In addition to “normal” affective reactions to their illness, cancer patients’ depressive symptoms are induced by many cancer drugs, the disease process itself, and physical discomfort. Following are some important information about depression among cancer patients that the therapist needs to keep in mind:

- At least 25% of cancer patients suffer from levels of clinical depression (American Cancer Society, 2012) that could be alleviated with proper treatment.
- Cancer patients are also at higher risk for suicide.
- Cancer patients with depression have poorer outcomes from their physical illness than those who do not have depression.
- Patients who are hospitalized for long periods of time are more likely to have depressive symptoms.
- Cancer patients who have a past history of depression are at greater risk of depression.
- Previous suicide attempts greatly increase the risk for a subsequent suicide attempt.
- Cancer patients who have developed a pessimistic outlook on life are more prone to depression. With the added stress from cancer, such pessimism may accelerate their negative worldview.

(American cancer Society, 2012)

Remember!

- Depressive symptoms among patients with cancer metastasis and recurrence (especially after many years) are extremely high. They are more prone to depression than patients with first diagnoses.
Naturally, the higher the cancer stage progresses, the more depressive symptoms are expressed.

The illness itself is just a partial cause of depression among cancer patients. Other psychosocial aspects brought on by cancer, such as change in interpersonal relationships (especially marital and family relationships), financial distress, loss of job, can all be causes of depression.

Remember, cancer treatment may cost a lot, especially if a patient is not insured, if insurance does not cover desirable treatment or regimen, or if a patient tries treatment abroad, they may face incredible financial difficulty including bankruptcy. (It is just unfair…)

Tips for therapists

Know your client’s cancer stage (1 to 4, 4 being the highest), and if her/his cancer is recurring and/or metastasized.

Know your client’s type of cancer. Some are treated with high success rates, while others have high mortality rates.

Due to easy access to online information (in addition to books and information from medical offices), many cancer patients are extremely savvy about their types (and stages) of cancer.

Having much information can be good or bad, sometimes, since cancer patients can feel overwhelmed. Too much information, and too straightforward statistics (especially when their type of cancer has a high mortality rate), can cause more depression, hopelessness, and loneliness.

In group settings, a patient with a “miracle case” (a person who survived high mortality cancer) is highly welcomed, and her testimony boosts up other members’ hope.

As the above data show, it is important for the therapist to know about the cancer patient’s (and his family’s) history of depression. A patient’s past depressive episode, therefore, should be carefully evaluated through the course of therapy treatment.
PSYCHOTHERAPEUTIC INTERVENTIONS

TYPES OF INTERVENTIONS

As discussed in the previous section, cancer patients may experience tremendous psychological distress in addition to physical distress. Such psychological problems may result in poorer treatment outcomes. In other words, if those psychological symptoms are treated, not only will cancer patients’ quality of life increase, but they also can expect more desirable medical treatment outcome.

So, how can psychotherapists contribute to such positive outcomes for cancer patients in their journeys? In the next section, process and core functions of psychotherapy in both individual therapy settings and support group settings will be introduced. The following list shows the possible psychotherapy methods for cancer patients.

Individual psychotherapy

<table>
<thead>
<tr>
<th></th>
<th>Short term: solution focused</th>
<th>Long term: client centered</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Orientation</strong></td>
<td>May not apply</td>
<td></td>
</tr>
<tr>
<td><strong>Screening</strong></td>
<td>May not apply</td>
<td></td>
</tr>
<tr>
<td><strong>Assessment</strong> (Intake, or interview)</td>
<td>Very important The client will complete forms, such as “Request for individual counseling” with statements of confidentiality and policy. Information about the client’s current situation around cancer, stress level, history of other traumatic experiences, and family situation will be gathered. (Note: Sample questions will be introduced following this chart.)</td>
<td></td>
</tr>
<tr>
<td><strong>Goal setting</strong></td>
<td>Very important</td>
<td>Important</td>
</tr>
<tr>
<td><strong>Goals</strong></td>
<td>Focus on specific complaints such as “anxiety reduction before chemotherapy” and “panic attack prevention.”</td>
<td>Could be broad such as “gaining insight,” “redefining meaning of life,” “improve QOL.”</td>
</tr>
<tr>
<td><strong>Treatment plan</strong></td>
<td>Very important (Identify and rank problems, and formulate short-term goals.) Note: Make sure to focus on tangible and specific problem(s). Beginner therapist tends to be “too nice” and only listen to all the patient’s complaints.</td>
<td>Important (Identify problems, and periodically reevaluate treatment plans, goals met or unmet, and progress. Note: Your client may explore from current concerns around cancer to all kinds of her life issues, (for instance, child abuse, dysfunctional marriage, financial burden, and self-esteem.)</td>
</tr>
</tbody>
</table>
### Counseling focus

<table>
<thead>
<tr>
<th>Solution focused</th>
<th>Humanistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-solving</td>
<td>Existential</td>
</tr>
<tr>
<td>Cognitive behavioral</td>
<td>Psychodynamic</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Narrative</td>
</tr>
</tbody>
</table>

### Referral

- Refer to support groups
  (Meeting other cancer patients with similar problems may reduce a client’s loneliness, and the client can learn solution techniques from other patients.)
- Refer to relaxation classes and workshops.
  (Guided imagery, meditation, and yoga)

### Client education

- Educate cancer patients to be proactive.
- Help patients with “questions lists” before their doctor appointments.

---

### Group Psychotherapy

<table>
<thead>
<tr>
<th><strong>Short term: solution focused</strong></th>
<th><strong>Long term: client centered</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Orientation</strong></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td></td>
</tr>
<tr>
<td>Whether the setting is at a hospital, mental clinic, or cancer support organization, it is very important to describe to the client the following: (1) overview of the group, (2) general nature, goals, and objectives of the program, (3) rules of member conduct that can lead to discharge from the group or switch to individual therapy, and (4) client’s obligation and rights. Notes: Although the orientation may be provided before the screening, it is ideal to repeat the rules during and/or after the screening process since clients (potential group members) may not remember everything they are told. Remember, cancer patients are busy with treatment, and are often already experiencing high levels of physical and emotional distress by the time they come to the orientation.</td>
<td></td>
</tr>
<tr>
<td><strong>Screening</strong></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td></td>
</tr>
<tr>
<td>Determining the client’s appropriateness for admission into a group is critical. Rarely, but occasionally, people with Munchausen’s syndrome come to the cancer support group. Other common criteria that have to be screened are borderline personality disorder, substance abuse, and suicidal ideation.</td>
<td></td>
</tr>
</tbody>
</table>

---

1 Psychiatric factitious disorder. A person with Munchausen’s syndrome demonstrates feigned disease, illness, or psychological trauma to draw attention or sympathy to him/herself.
**Assessment (Intake, or interview)**

<table>
<thead>
<tr>
<th>Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessing the client’s current situation around cancer, social support, and stress level should be conducted. Whether the client is currently seeing an individual therapist should also be asked. Information including history of psychological problems, hospitalizations, other traumatic events and how the client coped with them should be gathered. The client will complete forms such as “Request for support group” form with statements of confidentiality and policy.</td>
</tr>
</tbody>
</table>

**Goal setting**

<table>
<thead>
<tr>
<th>Very important</th>
<th>Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yalom’s (1985) factors will be emphasized:Universality (The opportunity for group members to feel that they are not alone.)Altruism (members give support and guidance to one another in the group.)Hope (members have opportunities to see others who have experience the same emotions, coping with similar circumstances, and feel that they can cope with their own situations.)Cohesiveness (members develop bonding as they all experience similar illness.)Imitative behavior (members observe others and learn new ways of coping with negative emotions around cancer.)</td>
<td></td>
</tr>
</tbody>
</table>

**Goals**

<table>
<thead>
<tr>
<th>Very important</th>
<th>May not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short-term group therapy (such as 12-week group, or 16-week group) typically has carefully deliberated specific formats, including discussion topics and timetables for each session, activity plans, from the initial stage to termination stage. Homework (such as journaling and self assessment) is often used.</td>
<td>Ongoing support groups at cancer support organizations, for instance, may not necessarily have treatment plans, since their main goals may be bonding development (avoiding loneliness), hope development (learning positive results from other cancer patients), and information gathering (how to cope with side effects and anxiety, how to communicate with medical teams, and doctor referrals).</td>
</tr>
</tbody>
</table>

**Treatment plan**

<table>
<thead>
<tr>
<th>Solution focused</th>
<th>Humanistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-solving</td>
<td>Existential</td>
</tr>
<tr>
<td>Cognitive behavioral</td>
<td>Psychodynamic</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Problem-solving</td>
</tr>
</tbody>
</table>

**Counseling focus**

**Referral**

| Referral to relaxation classes and workshops. (Guided imagery, meditation, and yoga)Referral to novel medical treatments and specialists. Referral to individual psychotherapy, if a member feels her problems are too personal, she is not comfortable sharing such problems, or she feels she needs more individual attention. |
|---|---|
| Referral to relaxation classes and workshops. (Guided imagery, meditation, and yoga)Referral to novel medical treatments and specialists. Referral to individual psychotherapy, if a member feels her problems are too personal, she is not comfortable sharing such problems, or she feels she needs more individual attention. |
Client education

| Educate cancer patients to be proactive. Help patients with “questions lists” before doctor appointments. Learn from other members how to communicate with, negotiate with, and be proactive with his medical team. |

Individual vs. group therapy
Support group settings are relatively new in cancer patient care (Spira, & Reed, 2003). Traditionally, emphasis has been on improving the doctor-patient relationship and psychotherapy was performed only for patients with the most serious emotional problems. Nowadays, however, support group therapy is well developed and widely used. In general, group therapy is suitable for patients with relatively low severity of psychological symptoms and less unusual or extreme problems, but privacy and confidentiality levels are low. Individual therapy is suitable for high severity of psychological symptoms, preexisting psychological disturbances, or personality disorders. Levels of privacy and confidentiality are high.

Group therapy concerns
Support groups for cancer patients can be either homogenous groups (members of same type and stage of cancer, gender, and age) or heterogeneous groups (mixed members with different types and stage of cancer, gender, and age). While homogenous groups are ideal and easier for the psychotherapist to facilitate, is it often difficult to recruit a sufficient number of patients. Therefore, heterogeneous groups are more widely offered by cancer support organizations and hospitals. However, facilitating heterogeneous group is extremely difficult since members are likely to have different concerns. And yet, members share mutual goals such as enhancing hope and feelings of control, and minimizing loneliness. Even the homogenous group, therefore, definitely can be a “safe harbor” for cancer patients.

Tips for therapists

- Facilitating heterogeneous groups is difficult but rewarding, especially for beginner therapists.
- The therapist (facilitator) must work hard to pull commonalities and interactions among patients.
- Again, looking for commonalities, and thus, developing universality is one of the best strategies.
- The therapist also must be upfront about the differences in issues and interests of each member.
The therapist should respect every member’s right to speak up. For instance, stage four patients’ fears of near death should be discussed. It could, however, intimidate another member who is recently diagnosed with an early stage of cancer that needs minimum surgery. In such a case, the member with an early stage cancer should have time to express her reactive feelings.

It is, therefore, very important for the therapist to pay attention to all members’ reactions to others frequently, and to not miss the signs of discomfort.

ASSESSMENT

Sample questions in assessment process (intake/interview)

- What is your cancer treatment plan?
- What has changes since the diagnosis?
- Has your life been touched by cancer before?
- Has your life been touched by other crises?
- If yes, how did you cope with them?
- What is your current support system?
- What is going well for you right now?
- What is not going well for you right now?
- What seems to help when you get overwhelmed by these challenges?
- How would you describe your current emotional state?
- Do you have a history of depression, anxiety, and substance abuse?
- If yes, are you receiving support for such conditions, and how?
- Have you ever had therapy/counseling before?
- If yes, what was you experience like?
- Have you ever been hospitalized with mental problems? If yes, please describe.
- What other information would you like for me/us to know?

Source: Cancer Support Community manual (2012)

Stress level self-check
This single-scale (scale 0 to 4) questionnaire can be used at the assessment stage, and also periodically during the psychotherapy process (individual or group). The questions include both physical and psychological states because cancer patients’ physical states change constantly (for instance, before, during, and after chemotherapy, radiation, and scans) and psychological states also fluctuate depending on side effects, prognosis, and scan results.
The questionnaire can also be used as homework for the client to be aware of her stress level, and can be asked verbally by psychotherapists during sessions.

The answer options include (0) Not at all, (1) Slightly, (2) Moderately, (3) Seriously, (4) Very seriously.

Today, how concerned are you about…..

- Eating and nutrition
- Coping with your feelings
- Moving around (walking, climbing stairs, lifting, etc)
- Knowing how to communicate best with your doctor
- Sleep problems
- Changes and disruptions in work, school, or home life
- Feeling sad or depressed
- Transportation to treatment and appointments
- Pain and/or physical discomfort
- Body image and feelings about how you look
- Feeling nervous or afraid
- Worrying about the future and what lies ahead
- Preparing for an upcoming treatment decision
- Intimacy, sexual dysfunction and/or fertility
- Considering taking your own life
- Feeling lonely or isolated
- Health insurance or money worries
- Problems in your relationship with your spouse/partner
- Feeling too tired to do the things you need or want to do
- Coping with side effects of treatment (nausea, swelling, hair loss, etc) Worrying about family, children, and/or friends.
- Recent weight change (gain or loss)
- Ability to exercise or be physically active
- Substance use (alcohol, tobacco, and other chemicals) by you or someone in your household
- Finding reliable information about complementary or alternative practices

Source: Cancer Support Community manual (2012)

**TREATMENT PLAN**

Treatment planning is the process by which the therapist and the client identify and rank problems needing resolution. As mentioned in the list of intervention types, the treatment plan is especially important in short-term, goal-oriented formats. Treatment planning includes setting short-term and long-term goals, which are agreed upon both the therapist and the client.
Treatment planning typically starts with an explanation of assessment results by the therapist to the client in an understandable manner. Together, they identify and rank problems (especially in short-term setting) based on each client’s needs. Then treatment methods and resources are selected and used as appropriate for each client.

Samples of short-term and long-term goals are as follows.

**Short-term goals**

- Develop trust relationship between therapist and client
- Describe diagnosis, symptoms, and treatment plan of current cancer.
- Identify feelings associated with cancer.
- Encourage verbalization of such feelings.
- Identify losses and limitations that have been experienced by the client due to his illness.
- Assess present and past coping mechanisms.
- Normalize feelings of patients.
- If anxiety is the problem,
  - Assist patient to identify anxiety-provoking stimuli, and the positive and negative ways to deal with it.
  - Teach cognitive-behavioral reinforcement for adaptive coping strategies.
- If anger is the problem, assist the client to
  - Discern the triggering event
  - Focus on the underlying feelings
  - Identify the patient’s perception of the problem that causes anger
- If depression is the problem,
  - Correct cognitive distortion by discussing irrational thoughts and automatic negative thoughts.
  - Explore the client feelings by maximizing ventilation and dialogue.
  - Refer for psychiatric assessment if depression is moderate to severe.
  - Create no suicide contracts as needed and monitor the client carefully.

**Long-term goals**

- Reduce anxiety, fear, and worry associated with cancer
- Accept cancer, and adapt life to the necessary limitations.
- Accept the role of psychological and behavioral factors in cancer treatment and its outcome, and focus on resolution of such factors.
- Regain a sense of control.
- Become as knowledgeable as possible about one’s own cancer, and about living as normally as possible.
- Live life to the fullest extent possible.
- Increase quality of life.
- Accept emotional support from those who care.
- Work through the grieving process in healthy ways.
- Accept optimal medical treatment and stabilize physical condition.
Tips for therapists

✓ Remember to avoid diagnostic terminologies. Cancer patients are tired of medical terms from their doctors.
✓ Stay calm and quiet when the patient is angry. She may have enough reactive expressions of feelings from her family member and friends.
✓ It is extremely important to acknowledge the patient’s feelings and show empathy in a relaxed manner.
✓ Do not argue with the patient.
✓ Make eye contact, and call the patient by name.

TREATMENT
As mentioned before, short-term therapy (both individual and group setting) focuses most on cognitive behavioral, solution-focus, and problem solving approaches, while long-term therapy (both individual and group setting) combines those approaches with humanistic, existential, and psychodynamic approaches.

Here are some common approaches and treatment techniques.

Cognitive Behavioral Therapy
Cognitive behavioral therapy is active, structured, and time limited. Identification and correction of client’s distorted negative cognitions is attempted. Treatment involves task assignment, activities, daily monitoring of moods, and teaching new behaviors.

Solution-focused therapy
Solution focused therapy argues there is no one single correct or valid way to live one’s life. It is the client’s goals that should be identified and accomplished. Treatment involves exception questions, scaling questions, formula tasks, and miracle questions.

Humanistic/existential therapy
Humanistic/existential therapy focuses on the client’s subjective experience, uniqueness or wholeness as an individual, and his/her current behavior. Assessment techniques and diagnostic labeling is rejected. Treatment includes accepting the client, affirming the client’s worth, empathic understanding, and active listening.

Psychodynamic Therapy
Psychodynamic therapy argues that human behavior is motivated by unconscious processes. Early development has impact on adult functioning. Insight into unconscious process is explored, and insight is believed to leads the person to awareness, understanding, conflict reduction, and interpersonal change.
**Tips for therapists**

- Whatever approach you take, it is important to establish rapport, engage in reflective listening, and ask questions rather than give answers.
- The therapist’s self-disclosure with cancer patients is normally not a good idea, but in a group setting, and if the therapist’s concern is something many other members have, it may help as an ice breaker as a new topic, or to facilitate an especially difficult topic (for instance, hospice care and assisted suicide).
- The therapist’s self disclosure, however, should be made carefully and sensitively, and a specific strategy should be in therapist’s mind (such as encouraging a member who is shy and does not participate much on a topic of her interest.)
- Self-disclosure and expressing distress are different. Therapists should not express their distress especially regarding cancer.
- Be ready for difficult topics. Working with cancer patients can be extremely rewarding as long as therapists are willing to confront issues of death and dying.
- Fear of dealing with such issues and feelings may lead the therapist to shy away from group members’ distress, which in turn may lead members to escape from their own emotions.
- When the therapist can tolerate strong negative emotions, the members will be better able to tolerate their experiences and cope more effectively with them.

**PSYCHOEDUCATION**

As repeatedly mentioned in this workbook, cancer patients may experience tremendous distress physically and psychologically. People who were recently diagnosed are especially overwhelmed with a long list of “things to do.” Helping them proactively communicate with their oncology team and make appropriate decisions about their treatment is an important job for psychotherapists. Following are samples of psychoeducation material the therapist can use with her clients, to help them actively participate in their treatment, make effective decisions, and gain a sense of control.
### Decision-making Tools

These question lists are designed to help cancer patients actively discuss treatment options with their doctors.

<table>
<thead>
<tr>
<th>Medical Background Questions</th>
<th>Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>When was I diagnosed? (A person with newly diagnosed cancer may have different treatment options than a person who has already had certain treatment.)</td>
<td></td>
</tr>
<tr>
<td>What type of cancer do I have? (The type of cancer will determine the type of treatment you need.)</td>
<td></td>
</tr>
<tr>
<td>What is the stage of my cancer? (The Stage of the cancer will also determine the types of treatment available.)</td>
<td></td>
</tr>
<tr>
<td>What is my current health status? (Your overall health status may affect the types of treatment you can tolerate.)</td>
<td></td>
</tr>
<tr>
<td>What should be the goal of my treatment? (The goal of treatment – cure, symptom control, and prolonged remission – may affect the type of treatment that is available to you or that you select.)</td>
<td></td>
</tr>
</tbody>
</table>
As you discuss treatment options with your doctor, take notes under each column below

<table>
<thead>
<tr>
<th>Treatment Options</th>
<th>Potential Side Effects (i.e., hospitalization, hair loss, fatigue, peripheral neuropathy.)</th>
<th>Quality of Life/Treatment Convenience (i.e., required visits to the hospital or clinic to receive treatment, monitoring, blood counts, restricting activities, etc.)</th>
<th>Effectiveness (i.e., what are the chances that this treatment will work for me?)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Can the tumor be surgically removed?)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre- or Post-Surgery Chemotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre- or Post-Surgery Radiation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Novel Therapies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investigational Therapies in Clinical Trials</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Combination Treatments (From above)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best Supportive Care</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
DISCUSSION TOPICS IN PSYCHOTHERAPY

As mentioned earlier, cancer patients’ physical and psychological states change frequently as the treatment progresses, or possibly as the stages of cancer advance. It is useful, therefore, for therapists to expect what issues are likely to be raised by cancer patients in individual and group settings.

In heterogeneous group setting (group of cancer patients with different stages and types of cancer), it is especially important for the therapist (group facilitator) to understand each member’s unique concerns. (Types of support group will be discussed later).

Issues likely to be raised are as follows:

**Diagnosis stage**
- Initial shock
- Distress/confusion over diagnosis, treatment, and prognosis
- Fear of side effects of treatment
- Stress management
- Anxiety reduction
- Decision making process regarding treatment
- Emotional support
- Leave of absence from work

**Treatment stage**
- Recovery from surgery
- Discomfort from chemotherapy and radiotherapy
- Side effects (nausea, fatigue, dry or sore mucus membranes, weight changes, flu-like symptoms)
- Changes in appearance (hair loss)
- Daily functioning
- Coping with treatment
- Adjusting/accepting the reality of cancer
- Emotional support
- Healthy lifestyle (diet, exercise, supplement)

**Recovery stage**
- How to return to normal life
- Changes in self-image
- Changes in relationship
- Re-prioritizing daily activities
- Desire to gain control over their health and recovery
- Changes in behavior regarding their health and prognosis
- Possibility of recurrence and death
- Changes in life value
- Redefining the meaning and purpose of life
Recurrence Stage

- Bad news (metastasis, lack of responsiveness to treatment, announcement of switching hospice care by a group member in case of support group setting)
- Death of a group member (in case of group setting)
- Gradually aggressive treatment or longer hospitalization
- Increased financial burden
- Traveling (possibly abroad) for potential treatment (more financial burdens)
- Missing important present and future family events
- Emotional distress about severity of cancer, treatment, and imminent loss of life.

**Tips for therapists**

- Even for well-experienced psychotherapists, it is not always easy to handle the psychological distress of cancer patients, especially when the therapist is experiencing her own, or a family member’s physical or psychological issues, such as illness or loss.
- It is, therefore, extremely important for the therapist to take care of herself by talking to her supervisor, bringing up concerns in staff meetings, and sparing sometime for self care. I cannot emphasize this more!
- It is important, however, to take time and bear the client’s pain by listening and expressing empathy. In group settings, many other members experience the same or similar feelings at each stage. When one member brings up his concerns (for instance, initial shock of cancer diagnosis), it is a good idea to ask other members how they coped with when they were in similar situations.

**Discussion topics in group settings**
The following list contains typical discussion topics for support group settings. The therapist should monitor the group carefully at both macro and micro levels at the same time, so that every member is given time to speak up, to ensure that discussion does not stay at a superficial level, opinions are not biased, and undesirable topics are appropriately handled.
<table>
<thead>
<tr>
<th>Contents</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Checking in</td>
<td></td>
</tr>
<tr>
<td>▪ Greeting</td>
<td></td>
</tr>
<tr>
<td>▪ General topics (weather, traffic, local</td>
<td>Facilitator makes sure to redirect once the group</td>
</tr>
<tr>
<td>news, weekend plans)</td>
<td>officially starts.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Information gathering &amp; sharing</td>
<td></td>
</tr>
<tr>
<td>▪ Sharing general medical information</td>
<td>In general, the beginning of a group. If eruptions</td>
</tr>
<tr>
<td>(scan results, onset of new treatment,</td>
<td>occur in the middle of the group, these topics</td>
</tr>
<tr>
<td>etc.)</td>
<td>should be redirected to an issue of therapeutic</td>
</tr>
<tr>
<td>▪ Acknowledgement about absent members</td>
<td>value.</td>
</tr>
<tr>
<td>(closed group)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical status &amp; treatment</td>
<td></td>
</tr>
<tr>
<td>▪ Economic problems (insurance, co-payment,</td>
<td>Important and valuable topics for patients.</td>
</tr>
<tr>
<td>needs of extra income, mortgage)</td>
<td>These topics can be a bridge into therapeutic</td>
</tr>
<tr>
<td>▪ Sharing information about cancer</td>
<td>value.</td>
</tr>
<tr>
<td>(side effects, new treatment, experimental</td>
<td></td>
</tr>
<tr>
<td>treatment)</td>
<td></td>
</tr>
<tr>
<td>▪ Hopes for improvement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor-Patient relationship</td>
<td></td>
</tr>
<tr>
<td>▪ Concerns about the patient’s medical team</td>
<td>Therapist encourages open and active communication</td>
</tr>
<tr>
<td>▪ Patient’s expectations</td>
<td>among members on these topics. Role-playing is</td>
</tr>
<tr>
<td>▪ Likes and/or dislikes of medical approach</td>
<td>helpful. Members can share their own coping</td>
</tr>
<tr>
<td>▪ Physician’s reputation and competency</td>
<td>techniques and ideas.</td>
</tr>
<tr>
<td>▪ Physician’s compassion &amp; listening skills</td>
<td></td>
</tr>
<tr>
<td>▪ Communication difficulties</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Family and social network</td>
<td></td>
</tr>
<tr>
<td>▪ Increased stress over economic issues.</td>
<td>Encourage open and honest communication. Members</td>
</tr>
<tr>
<td>▪ Changes in physical intimacy.</td>
<td>share their coping techniques. Members demonstrate</td>
</tr>
<tr>
<td>▪ Fear of future.</td>
<td>understanding.</td>
</tr>
<tr>
<td>▪ Communication or lack of communication</td>
<td></td>
</tr>
<tr>
<td>with family members</td>
<td></td>
</tr>
<tr>
<td>▪ Fear of distressing family members</td>
<td></td>
</tr>
<tr>
<td>▪ Stress of not being understood or</td>
<td></td>
</tr>
<tr>
<td>insufficient emotional and physical</td>
<td></td>
</tr>
<tr>
<td>support</td>
<td></td>
</tr>
<tr>
<td>▪ Relationships with friends, coworkers,</td>
<td></td>
</tr>
<tr>
<td>and community groups (whether or not</td>
<td></td>
</tr>
<tr>
<td>informing about cancer)</td>
<td></td>
</tr>
<tr>
<td>▪ Stigma and “reverse stigma”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Coping skills</strong></td>
<td>Cancer-related distress (psychological and physical stress, hopelessness, negative feelings, loss of control, pain, insomnia, and fatigues.</td>
</tr>
<tr>
<td><strong>Death &amp; dying</strong></td>
<td>Feeling of guilt having cancer&lt;br&gt;Feeling fortunate when another member deteriorates or dies&lt;br&gt;Practical arrangements (financial, legal, hospice, funeral)&lt;br&gt;Decision of treatment termination&lt;br&gt;Discussion of a members’ death&lt;br&gt;Rituals&lt;br&gt;Suicide</td>
</tr>
<tr>
<td><strong>Self image</strong></td>
<td>Changes in body image caused by cancer treatment&lt;br&gt;How one looks and feels&lt;br&gt;Functional roles, activity levels&lt;br&gt;Commitments and fulfillments&lt;br&gt;Self-worth&lt;br&gt;Self-definition</td>
</tr>
<tr>
<td><strong>Life Values</strong></td>
<td>Religious, spiritual, and philosophical beliefs&lt;br&gt;What it means to die&lt;br&gt;Reflection of one’s life&lt;br&gt;Altering one’s life view&lt;br&gt;Recommitting to what is important&lt;br&gt;Sense of being</td>
</tr>
</tbody>
</table>

*Source: Personal notes from cancer support group facilitation (2012)*
INTEGRATING THERAPEUTIC APPROACHES

Other Approaches and Techniques
Psychotherapists play a significant role in cancer patients’ psychological support. Each patient, however, has unique needs in his/her psychosocial care. Patients should be offered, therefore, other options in addition to individual and group psychotherapy to reduce their psychological distress.

Following are examples of approaches that cancer patients find beneficial to reduce both their physical and psychological stresses. Cancer support organizations, such as the Cancer Support Community, offer classes and workshops on those approaches for their members, and they are extremely popular.

- Guided imagery
- Yoga (gentle yoga)
- Meditation
- Alexander technique
- Qigong
- Mindfulness-based stress reduction
- Hypnosis

Tips for therapists

✓ Always make sure that your client has permission from her oncologist to participate in classes that involve physical movement such as yoga, Qigong, and the Alexander technique.
✓ Some cancer patients say they like classes offered at cancer support groups because they do not get curious eyes if they are covering their heads with scarves, or exposing their hairless heads.
PART III:
FAMILIES/CAREGIVERS

UNDERSTANDING FAMILY CAREGIVERS

Being a family member of a cancer patient is as stressful as it is for the cancer patient himself. In addition to caring for their cancer patient, family members, especially spouses, have their own roles to play in their families or even increased responsibilities to cover the cancer patient’s role.

The following story thoroughly exemplifies the emotional experience of cancer patient’s family caregivers. Please read this if you are with not only cancer patients but also their families.

Caregiving: Emotional Roller Coaster

I’m a caregiver to my loved one who has a terminal cancer. That means my life has altered completely. My time is spent proving home care as if I was a nurse. But I don’t have shifts and I don’t get off duty. I live this role 24 hours a day.

I remember the day I heard the news: terminally ill. All I could feel was shock, intrusion, and violation, even hatred. Nothing could have prepared me for hearing that someone I loves was dying. My life is now a strange state of suspension of everything that I used to call normal. Since that time, my emotions have been on a roller coaster. Shock first, then disbelief; I just knew a mistake had been made. When it was inevitable that one hadn't been made, the anger began to surface. First, I was angry at what I perceived as the inadequacy of the physicians, than a God. I’m embarrassed to say this but at my loved one as well; for dying. Part of me wanted to do everything I could to prolong the death, part of me wanted it over quickly, so the suffering could be at a minimum. That brought on fear about my own mortality. Then I felt guilt that I would wish for the relief of suffering. And grief because I was losing someone I loved.

Telling everyone was a nightmare. I learned that everyone reacts differently. I had to break the news depending on how willing or capable others were to hear. Some of the family denied it could be happening. Some pitched in to help. Some were remote and insensitive. And the children had to be told in a way they could handle and understand based on their age. Dealing with the medial profession has been hard. But checklists have helped. We also had to decide where death would occur. Since we chose home, I had to convert part of my house into a hospital room. But even though I had some difficult situations there, I’m glad I did it. I’ll tell you some time how I set up the house, dealt with the medical profession, and made checklists.
Mostly, I just wanted to tell you, I’m grieving. I started grieving as soon as I knew the truth. I have a hard time dealing with the day-to-day changes in the personality of the one I love. I need to tell you about that also. There are so many things left unsaid yet. I need to learn how to finish talking about the things we still need to say. I need to understand my loved one is grieving also.

Some day, I feel I am blessed to have this chance to give this loving care. But it’s extremely easy to fall into feeling self-pity. I just have to keep telling myself that I’m grieving.

These emotions that I feel have taken over my life now are not going to be here forever. The rest of my life will not feel so sad and overwhelming. I’m grieving. I’ve become a griever.

*By Deb Sims, DeeAnn Burnette-Lundquist, & Jim Balzell
Source: Camarillo Hospice Training Manual*
ANTICIPATORY GRIEF OF FAMILY CAREGIVERS

Please refer to the Five-stage grief process developed by Kubler-Ross (1969) introduced in Part II. Family members experience the same or similar grief process about their loved one’s illness. In addition to such psychological burdens, however, family caregivers often struggle with physical and psychological care of the cancer patient, and increased family roles to play. Here are some important aspects of family caregivers’ psychological experiences of which psychotherapists need to be aware.

The family may fear:

- Unknown new role(s)
- “Poor” performance: “Am I a good enough caregiver?”
- Loss of physical relationship
- Outside interference in relationship
- Physical changes in patient
- Uncertainty in making decisions
- The patient will “give up” when/if hospice becomes involved
- The dying process
- Economic loss or financial burden

Family members also often experience:

- Feeling numb: “this can’t be happening to us.” “This is not real.”
- Sadness or depression
- Anger
- Guilt over past actions, words spoken and unspoken, etc.
- Exhaustion, if the person is the primary caregiver or the patient has been “hanging on” for a long time.
- Not sure what to do, especially if the person have never had an experience with someone who is severely ill.
- Remembering other losses in the family
- Clinging to the patient, while trying to let him/her go at the same time.
- The need to let go of forgiveness issues or to make amends or apologize while the patient’s condition deteriorates, or is still alive.

Remember!

- While psychological support for cancer patients has been increasingly available in recent years, support for family caregivers is still limited.
- Psychotherapists need to treat them with maximum empathy because they often feel their needs are not as important as the cancer patient.
FAMILY DYNAMICS AND LIFE-THREATENING ILLNESS

In this section, I examine how a life-threatening illness like cancer influences family dynamics.

A family is made up of individual people who have roles to fulfill so that the family unit can function and grow. A family has probably met problems before, and developed coping mechanisms, and then gotten on with the daily business of life. What happens, however, when a family member develops a cancer? It is a big crisis.

Many family members of cancer patients state that, first of all, there is shock, denial, numbness, and an effort on everyone’s part to reestablish a sense of equilibrium and normalcy. Different family members may react differently; some may withdraw, others may get very busy. One may want to do all kinds of investigation into medical information, and another may blame himself/herself. A young child may lapse into behavior of an earlier age. Everyone is trying to understand, feel better, cope – and get on with life.

Imagine the following case.

**Model Vignette**

Joe, a 45-year-old father of two children, was recently diagnosed with stage 4 lung cancer. As a result, he became withdrawn, irritable and angry. His wife, Gina, believes that her husband’s stress caused his cancer and blames herself for not stopping her husband from working so hard for the last 20 years. Their 13-year-old daughter keeps herself busy with her friends, and her 7-year-old son acts like a baby.

Indeed, family members, especially spouses, are thrown into a whirlpool of distress, and feeling overwhelmed, alone, and hopeless. I have heard family members say, “my kids are not as sad (as I am),” and “my husband (cancer patient) is withdrawn and does not talk to me. I feel abandoned.” These words come from the expectation that everybody copes with cancer in the same way.

Also, family members’ distress does not stay the same. It is fluid, and it changes as the patient’s cancer and/or treatment progresses. Here are several things that may happen:

- The focus of attention may shift almost totally to the person who has cancer. This divides the family.
- Roles within the family may have to be redefined as cancer progresses; someone may no longer be able to earn a living, or prepare the meals, or participate fully as a spouse or child.
- Dreams and ideas are altered. This brings about anger, bitterness, regret, rage,
depression, and sadness.
- Either the patient or the family may distance and withdraw as a way of protecting him or herself from emotional pain.

**Remember!**

- The family is the patient, not just the ill person. The family needs treatment, not just the ill person.
- Physical pain causes emotional pain – causes physical pain – causes emotional…
- The more the family members can define their course of action, the less confusion and anxiety they will feel.
- People need to maintain hope. What is being hoped for may change during the course of the illness, but hope is essential for life.
- People in pain need nurturing.
- When behavioral symptoms arise, it is helpful to view them as the first stage of a “cure.” It is family member’s attempt to ‘right’ itself, to establish a new equilibrium.
- The family is not always in pain. The cycle goes:

  ![Crisis Cope Establish a new equilibrium Normal time](image)

- The family has a history, and the present circumstances play upon that history. There may be unfinished business between the person with cancer and a family member about injustices.
- Individuals from different ethnic backgrounds have different norms for family behavior.
- Families will behave differently during hospitalization than when at home.
- Most people know best how to support life – we are all novices at how to support the cessation of life.
PSYCHOEDUCATION TOOLS FOR FAMILY

As we saw in Amy’s case, some cancer patients express their anger by being withdrawn, sarcastic, and intimidating. They may become sensitive to the comments and questions from family members even they mean to be nice to the patient.

Psychotherapists can help family caregivers with some simple ideas of how to communicate with cancer patients. The following list includes such examples.

<table>
<thead>
<tr>
<th>When you think you want to say:</th>
<th>Try this instead:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dear, you are going to be just fine.</td>
<td>Dear, is there something that worries you?</td>
</tr>
<tr>
<td>Don’t talk like that! You can beat this!</td>
<td>It must be hard to come to terms with all this.</td>
</tr>
<tr>
<td>I can't see how anyone can help.</td>
<td>We will be there for you, always.</td>
</tr>
<tr>
<td>I just can’t talk about this.</td>
<td>I am feeling a little overwhelmed right now. Can we take this up later tonight?</td>
</tr>
<tr>
<td>What do the doctors know? You might live forever.</td>
<td>Do you think the doctors are right? How does it seem to you?</td>
</tr>
<tr>
<td>Please don’t give up. I need you here.</td>
<td>I need you here. I will miss you terribly. But we will get through somehow.</td>
</tr>
<tr>
<td>There has to be something more to do.</td>
<td>Let’s be sure we get the best medical treatment, but let’s be together when we have done all we can.</td>
</tr>
<tr>
<td>Don’t be glum. You will get well.</td>
<td>It must be hard. Can I just sit with you for a while?</td>
</tr>
</tbody>
</table>

Source: Handbook for Mortals p.92
CAREGIVER BURNOUT

Cancer patients’ family caregivers often manifest signs of caregiver burnout. Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude – from positive and caring to negative and unconcerned (WebMD, 2012). Burnout can occur when caregivers don’t get the help they need, or if they try to do more than they are able – either physically or financially. Caregivers who are “burned out” may experience fatigue, stress, anxiety, and depression. Many caregivers also feel guilty if they spend time on themselves rather than on their ill loved ones (National Family Caregivers Association, 2012). Here are some symptoms and causes of caregiver burnout.

What are the symptoms of caregiver burnout?
The symptoms of caregiver burnout are similar to the symptoms of stress and depression. They include:

- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Feeling blue, hopeless, and helpless
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Getting sick more often
- Feeling of wanting to hurt oneself or the person for whom the caregiver is caring
- Emotional and physical exhaustion
- Irritability

What causes caregiver burnout?
Caregivers often are so busy caring for others that they tend to neglect their own emotional, physical, and spiritual health. The demands on a caregiver’s body, mind, and emotion can easily seem overwhelming, leading to fatigue and hopelessness, and ultimately, burnout. Other factors that can lead to caregiver’s burnout include:

- Role Confusion: Many people are confused when thrust into the role of caregivers. It can be difficult for a person to separate her role as caregiver from her role as spouse, lover, child, friend, etc.
- Unrealistic expectations: Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be unrealistic for patients suffering from a progressive disease, such as some types of cancer.
- Lack of control: Many caregivers become frustrated by a lack of money, resources, and skills to effectively plan, manage, and organize their loved ones’ care.
- Unreasonable demands: Some caregivers place unreasonable burdens upon themselves, in part because they see providing care as their exclusive responsibility.
- Other factors: Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively. They may even become sick themselves.

Source: Camarillo Hospice Training Manual, 2012
**Tips for therapists**

Psychotherapists can help a family caregiver prevent herself from burnout by giving the following advice. You can mention these points in both individual and group settings.

- Accept your feeling. Having negative feelings such as anger at the cancer patient is normal. It does not mean that you are a bad person or a bad caregiver.
- Recognize and accept your potential for caregiver burnout.
- Set aside time for yourself. Taking care of yourself is not a luxury, but an absolute necessity for caregivers.
- Educate yourself. The more you know about your loved one’s cancer, the more effective you can care for him.
- Set realistic goals, and know your limits.
- Learn to turn to others for help with some tasks.
- Talk to other family members. Involve children in caregiving.
- Have a healthy diet.
- Get plenty of exercise and sleep.
Unfortunately, some cancer patients are very close to their mortality. Your client’s loved one may move on to hospice care, or even die during the process of psychotherapy. Your client focus may shift from caregiver burnout to loss and bereavement issues. Psychological treatment of this transition period is very important. Here are some useful information that psychotherapist should know about grief reactions of family caregivers who lost their loved ones to cancer.

Normal expected grief reactions
Because grief can be so painful and seem overwhelming, it frightens bereaved family members. Many of them worry if their grieving is the “right” way, and wonder if their feelings are normal. Most people who suffer a loss experience some of following feelings:

- Feel tightness in the throat, heaviness in the chest, or shortness of breath.
- Have an empty feeling in their stomach and lose their appetite.
- Feel restless and look for activity, but find it difficult to concentrate.
- Feel as though the loss isn’t real: as if it didn’t actually happen.
- Have feelings of panic, the desire to run away, or self-destructive thoughts.
- Sense the loved one’s presence, such as finding themselves expecting the person to walk in the door at the usual time, hearing her/his voice, or seeing their face.
- Wander aimlessly, or don’t finish things they’ve started.
- Have difficulty sleeping, and dream of their loved one frequently.
- Experience an intense preoccupation with the life of the deceased.
- Feel guilty or angry over things that happened or didn’t happen in the relationship with the deceased.
- Feel intensely angry with the loved one for leaving them.
- Experience a loss of warmth in relationships with others and have a tendency to respond with irritability and anger.
- Feel as though they need to take care of other people who seem uncomfortable around them by politely not talking about the feeling of loss.
- Not to tell and retell, and remember, things about the loved one and the experience of their death.
- Feel their moods change over the slightest things.
- Cry at unexpected times.

Personal notes from workshops and classes (2011)

Tips for therapists

- These are all natural and normal grief responses. Educate your client and normalize their feelings.
- Tell your client that it is important to cry and talk with other family members and friends when needed.
DEATH AND THE FAMILY SYSTEM

According to TLC Group (2012), almost all literature in the field of Death and Dying and Grief Resolution focus on the reaction of the individual to death; only a few look at the impact of deaths on family dynamics.

When his wife is on her deathbed, a father may not be comfortable sharing his emotions with his adult children. Another parent might maximize discussion about her husband’s death from cancer with her young children, and develop her own rituals to remember him. Everyone has different and unique ways of grieving, but how each family member handles their emotions after a loss has a huge significance for other members of the family (especially children) in the future.

Rules
“Rules,” in this context, are set ways of coping mechanisms, which have been inherited from previous generations and will most likely be passed on to future ones. There are healthy and unhealthy rules.

<table>
<thead>
<tr>
<th>Healthy rules</th>
<th>Unhealthy rules</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ It’s okay to talk openly about feelings, be sad, or cry in front of other family members.</td>
<td>▪ Be strong and never cry in front of each other.</td>
</tr>
<tr>
<td>▪ It’s okay to talk about the deceased at family gatherings.</td>
<td>▪ Crying and other emotional displays are signs of weakness.</td>
</tr>
<tr>
<td>▪ It’s okay to let the children see adults display their emotions.</td>
<td>▪ Never talk about deceased family members who are not flattering to the family’s image.</td>
</tr>
<tr>
<td>▪ It’s okay to use times of crisis to forgive old hurts and put aside differences.</td>
<td>▪ Someone is always to blame and there is enough guilt to go around.</td>
</tr>
</tbody>
</table>
Tasks of resolution
For a family to remain healthy, or break the bonds of unhealthy, inherited rules, certain tasks must be accomplished. Also, it is essential that all family members attempt to accomplish, and help other family members accomplish, these tasks concurrently. Psychotherapists can help the bereaved families in individual, family, and group therapy settings.

Accept the death
This may sound obvious, but many people still talk in the present tense about or to the deceased, including him/her in every family decision. Unfortunately, geographical distances and separation within the extended family can make this task more difficult because many members may not even see the deceased or be a part of the dying process.

Experience the pain
All family members should be allowed and encouraged to experience the pain of the loss. Family sessions can be held to give everyone an opportunity to say, in front of children and adults alike, what the loss means to them.

Assign new roles
The family now has to adapt to life without the deceased. As mentioned earlier, this often means a reassignment of roles: Who is going to be the communication center? Nurturer? Comedian? Although this rarely happens formally, if the family is made aware of the process, misunderstandings can be avoided and the surviving family members can begin to accept each other, and their newly defined roles, gracefully.

Feel comfortable with the new family
If the family adjustment to the death of a loved one is complete – in the word of Elizabeth Kubler-Ross (1997), “remember without pain,” – that is one big goal accomplished for that family. This would include being able to talk about the deceased honestly and openly at family functions; to remember the good times and the bad times; and the lessons learned from the person.

It also would include the mending of any fences temporarily disturbed by the individual grief process and an understanding that “the family” still exists but in different form. All family members should see this as an opportunity for the “re-emergence” of the family unit.

Source: TLC Group (2012)
Unhealthy reactions
If a family is very dysfunctional, much of the above will be impossible. If a family stays in denial, anger, or guilt, one or more members will exhibit destructive behaviors, such as the following:

- Substance abuse
- Eating disorders
- Child neglect
- Violent outbursts
- Suicidal ideations
- Frenzied activity

The psychotherapist’s role is critical, therefore, to prevent such unhealthy behaviors.

Tips for therapists

- Pay close attention if your client’s loved one is near-death or dies.
- If you are the facilitator of a support group for family members, set extra time for her to talk about her feelings, and ask other members nicely to allow her do so.
- Someone’s death, especially after you have known the family caregiver, or even the person who died, is extremely hard for the psychotherapist, especially novice therapists.
- Make sure to share your emotions in supervision meetings, ask for extra time from your supervisor if necessary, or ask for other psychotherapists’ support.
- If you are willing to attend the funeral, or “the celebration of life,” ask your supervisor or colleagues. If you are working in a cancer patient support organization setting, it is most likely that the organization has guidelines for such a situation.
- Remember to separate your work and privacy. DON’T TAKE HOME your emotions of grief and loss. It may negatively affect your own family dynamics!
Psychotherapy for grieving children is another specialty realm and there is no way I can discuss it in the remaining few pages. If your bereaved client has young children in her family, if your client is a child, or if there is any child affected by the loss of a family member, it is critical to be aware of what to expect in children’s bereavement.

I will conclude this section, therefore, by briefly introducing issues of bereaving children, and cite useful information from the Camarillo Hospice training manual about children’s emotional responses to death by age. This material can also be given to your adult client who has children affected by loss.

**Issues of bereaving children**

- Living in the shadow of the deceased.
- Taking on chores, responsibilities, identity of the deceased
- Become INVISIBLE.
- Loss of emotional support
- Protection games, keeping secrets of the death
- Being isolated
- Not being included in family concerns and decisions
- Fear of being afraid and weak
- Silence (family rules: don’t speak, don’t rock the boat, etc.)
- Search for a new identity

**Tips for therapists**

Advice your adult client to treat her child(ren) in the following ways

- Answer the questions that you are asked.
- The way you behave is more crucial than what you say.
- Be open and honest.
- Include children in rituals or plans of “leave-taking.”
- Be open with your emotions.
- Reassurance is important.
CHILDREN’S & ADOLESCENTS’ EMOTIONAL RESPONSE TO DEATH

Children under 7 years:
(Theses ages are rough estimates; some children develop faster or slower than others.)

- The problem death presents is separation and the fear of separation, especially from the mother or primary caregiver. This fear of separation, especially after the death of a sibling, may be expressed by clinging close, or perhaps a regression of behavior appropriate to much younger ages when the mother was more immediately involved with their physical activities like eating, toileting, or dressing. It can also express itself as withdrawal and a determination not to need the parents.

- At this age, children have a real feeling of power in the world. The sun rises so they can have a day and goes down that they can have a night. Words can also have a magic power, so to call someone a name, or to damn them, or wished them death has the same force as reality. If, therefore, a child has wished them dead (as most of us have, to our siblings) and they die, the child may very well feel as if he/she has cause the death.

- Adults have a good deal of child left in them when grief is strong. Very few people who have not, at some point, thought their death as punishment, and some parents can feel strongly that their words or wishes caused the death of the child.

Children 7 to 12:

- The problem with death is aggression. Death is personified as something that comes to get you. Our culture has many such personifications: Darth Vader, the grim reaper, and the bogeyman. Death may very well be connected with the aggressive forces the child of this age is attempting to control within himself/herself as society is putting pressure on him/her to act in socially acceptable ways. If death came and got my brother or sister, it could very well be coming to get me.

- Those who have read Tom Sawyer know that the best way to ward off such strong aggressive death is to utter magic incantations, or to do ritual things like putting special objects in special places. We will sometimes find children acting in ways to ward off the Grim Reaper.

- The child in adults is pretty strong as they grieve, and adults may find these thoughts in their own minds.

Children about 12 or 15:

- These children respond to death much the same as adults. The problem death presents is especially strong to some adolescents in a philosophical or religious sense. Death tends to produce serious questions about the justice of God, or the ultimate meaning of life. Perspective to such questions, from the adolescent point of view, can be found in their music and literature, which expresses a kind on nihilism. On the other hand, the same kind of encounter with death may well lead to a life-long religious or political commitment.

- Often, adolescents have difficulty expressing emotions connected with death. The encounter may be frightening so they simply turn off the experience so as not to feel it.

- Another consideration is that this age group has many strong and new feelings inside them and they have trouble sorting them out, so a calm exterior can be a way of
“acting cool” for some pretty hard turmoil inside.

- There has been some scholarly writing about prolonged psychological problems in children when they have not adequately resolved their grief. It is important to remember when we hear such things that we understand that most children are basically healthy but if they continue to present themselves as younger, manifesting a child’s behavior within 18 months after significant death, it is possible that there are some serious death-related problems at work.

- Changes can be observed are:
  - Sleeping habits
  - Eating habits
  - Associations
  - Dropping grades
  - Talk of suicide

- When these changes are occurring, the problem is usually not the child’s alone, so the whole family involvement with a professional is suggested.

*Source: Camarillo Hospice training manual*

---

**Tips for therapists**

- Treating grieving children can be very difficult for novice therapists, especially if she has a child of her client’s age.
- It is extremely important, therefore, to constantly seek for the supervisor’s advice or colleagues’ feedback.
- In support group settings, it is ideal to form groups by the age groups (approximately) since their life environments can be widely different (i.e. 6 year-old pre-school boy and 13 year-old middle school girl). It may be, however, difficult to recruit enough members of their ages.
- Family support groups with different ages may work if older children are willing to be mentors to younger children. Children can certainly develop Yalom’s universality and altruism.
PART V: RESOURCES

SELECTED READINGS


CONTACTS AND RESOURCES

Cancer Support Organizations
American Cancer Society
   http://www.cancer.org/
Cancer Hope Network
   http://cancerhopenetwork.org/index.php?page=home
Cancer News
   http://www.cancernews.com/support.html
Cancer Support Community
   http://www.cancersupportcommunity.org/
Cancer Treatment Center of America
   http://www.cancercenter.com/
Caring Bridge
   http://www.caringbridge.org/
Chemo Angels
   http://www.chemoangels.net/
CureSearch for Children’s Cancer
   http://www.curesearch.org/
Imerman Angels
   http://www.imermanangels.org/
Los Angeles Police Cancer Support Group
   http://lapcsg.org/
National Cancer Institute
   http://www.cancer.gov/
OncoChat
   http://www.oncochat.org/
The Wellness Community
   http://www.twcvv.org/
UCSF Medical Center, online Peer Support
   https://www.ucsfhealth.org/online_peer_support/?gclid=CMa31IbK8LACFQkaQgodlkHlvQ

Hospices
Buena Vista Hospice Care
   http://www.buenavistahospicecare.com/
Camarillo Hospice
   http://www.camarillohospice.org/
Hospice Care of the Valley
   http://www.valleyhospicecare.com/index.html
Hospice of the Conejo
   http://www.hospiceoftheconejo.org/
Los Angeles Hospice
   http://www.losangeleshospice.com/Pages/Mission.aspx
National Hospice and Palliative Care Organization
   http://www.nhpco.org/templates/1/homepage.cfm
Silverado
Skirball Hospice, The Los Angeles Jewish Home
http://www.jha.org/about/skirball.asp

TLC Home Hospice
http://www.tlchomehospice.com/index.html

**Caregiver Support**
Family Caregiver Support Group, City of Los Angeles Department of Aging
http://aging.lacity.org/caregivers/family.cfm

Los Angeles Area Agency on Aging, Community and Senior Services
http://css.lacounty.gov/Data/Sites/1/aspx/FCG/Caregiver.html

Los Angeles caregiver Resources Center
http://lacrc.usc.edu/ShowPage.php?PageID=1

National Family Caregivers Association
http://www.nfca.cares.org

**Others**
Adult Protective Services (APS), State of California
http://www.cdss.ca.gov/agedblinddisabled/PG1298.htm

California department of Aging
http://www.aging.ca.gov/

Department of Health & Human Services, Administration of Aging
http://www.aoa.gov/AoARoot/Index.aspx

Los Angeles County Community and Senior Services Area Agency on Aging
http://css.lacounty.gov/welcome.aspx

Ventura County Area Agency on Aging
http://portal.countyofventura.org/portal