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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

THE EFFECT OF PROFESSIONALLY-FACILITATED GROUP SUPPORT ON
PSYCHOLOGICAL WELL-BEING AMONG CLIENTS WITH CANCER

By

Joann C. Harper, MS, RN

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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In partial fulfillment of the
requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

February, 2003

Dissertation Committee

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Abstract

The Effect of Professionally-Facilitated Group Support on Psychological Well-Being Among Clients with Cancer

Many persons suffer from cancer, some of whom seek psychological relief through group support. Despite the widely held belief that group support helps, its efficacy has not been consistently evident in the scientific literature. The purpose of this study was to compare the effect of professionally-facilitated group support on the psychological well-being of clients with cancer between persons who participated in professionally-facilitated group support with those who did not.

A comparison design measured effect by the Psychological General Well-Being (PGWB) index. Each study enrollee was diagnosed with a new or recurrent cancer within 18 months of study entry. ANCOVA was used to consider the effects of stage of disease, age and pretest. Participants were briefly interviewed three times during the study period to monitor attendance, to record participation in complementary therapies and to capture intervening events, which could affect results.

Study findings were not significant measured by the PGWB ($F [4,47]=.097$, $p=.757$, $p \leq .05$). Age was inadequately associated ($r=.061$, $p \leq .05$) with the dependent variable and stage of disease and pretest were only weakly correlated ($r=.362$, $p \leq .05$ and $r=.423$, $p \leq .05$). A disproportionate number of study participants did not attend group support ($n=43$) versus those who did ($n=9$). Of those who did, only three fulfilled the threshold for attendance. Recruitment sites may have been a factor in the study's enrollee composition for the two groups used for comparison.

Other findings indicated that while select individuals increased their PGWB score after group support attendance, many others who did not attend group support had no change or improved scores. Individuals may vary in their psychological morbidity over time.

Further research is indicated: (1) replication of the study with equal sample sizes may yield different results; (2) adding psychological morbidity as a comprehensive screening indicator in the design of studies may define the target population; and (3) group support studies should explore the psychological distress perceived by persons with cancer concurrent with the timing of diagnosis and treatment. Findings may focus attention on what may be unique about group support in a population with cancer and propel future studies.

Dedication

I dedicate this work in memory of my parents, Katherine and Michael Scavone, two extraordinary persons. By their endearing example of life and love, by their model of how to survive adversity without bitterness, but with understanding, they have endowed me with the fortitude to complete what I undertake, and launched for me an enduring goal to be a better human being. In so many ways, they were always, ultimately, the driving energy for this endeavor.

Acknowledgments

Many persons and ideas come before this effort. Psycho-oncology is not new at the forefront of research. Yet, its many dimensions continue to elude us in our designs to improve care. Studies tell us interventions may affect many who suffer, but many persons already live well with cancer.

Because group support is an available service that is accessed by some persons with cancer, and because its efficacy has not been scientifically demonstrated consistently, it is an adjunct to care that deserves attention. The study undertaken reviewed the effect of group support by examining its effects on psychological well-being. This work has several iterations to go to contribute significantly to the works of others. However, it may renew interest about a long-standing, heart-felt service like group support, about which we may have forgotten needs a closer look.

The study results beg the question: Who are those that benefit from group support? Life and its growing complexity can be a barrier to restoring psychological well-being. For persons with chronic illness like cancer it is seemingly a tougher road, yet many endure this illness without the psychological morbidity we might have suspected. As Jimmie Holland, MD and many others have alluded, researchers continue to learn from the “true experts”, patients with cancer whose courage in the face of illness continues to teach us.

In this endeavor there are many to thank and still many more who deserve recognition. First, are those that contributed and continue to support this and many other endeavors; they enhance my daily life, they are my source of love and comfort: my husband, Michael and my daughters, Elizabeth and Alexandria. Then there are those who supported this academic effort with their time, wisdom and experience. I thank my Dissertation Committee: Jane Georges, Ph.D., RN, Chair, Patricia Roth, Ed.D, RN, Ann Mayo, DNSc., RN and Mary Jo Clark, Ph.D., RN, who served as chairperson early on in this undertaking. Another, Evelyn Anderson, Ph.D., devoted her time and energy selflessly, and in doing so, was an inspiration to me. Finally, I am deeply indebted to Dr. Harold Dupuy. Decades ago he designed the Psychological General Well Being schedule used for this study. He offered immeasurable assistance to my understanding of its origin, its purpose and provided confirming documentation for its utility.

Finally, there are those who were vital to the study without whom this effort would not have been possible. They are the most inspirational of all. They are the many who although weary from illness, still gave their precious time to this study. They are the participants of this study, those who were diagnosed with cancer, still struggling with its sequelae, agreed to another procedure, the study. I am enormously grateful to each of them.

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Chapter 1

Review of the Problem

When all age groups are considered, cancer is the second leading cause of death in the United States (U.S.) and ranks first among women ages 40 through 79 (Landis, Murray, Bolden, & Wingo, 1999). Over the past three decades, although mortality rates for cardiovascular disease have decreased dramatically, adult cancer mortality rates have declined only 10 to 15 percent. These trends may mean that in the next five to ten years cancer will be the leading cause of death in the U.S. (Schottenfeld & Fraumeni, 1996).

The number one cancer goal of Healthy People 2010 is to reduce the incidence of cancer as well as the illness, disability, and death caused by cancer (U.S. Department of Health and Human Services [DHHS], 2000). Along with the reduction of cancer incidence by 25 % and mortality by 50%, the American Cancer Society's vision for 2015 is to improve the quality of life (QOL) for cancer survivors (American Cancer Society, 1999).

Persons diagnosed with cancer represent an important segment of the population with serious illness because of their potential for physical, psychological and social disability. Cancer can have a myriad of effects on health including psychosocial status. Many interventions designed to address the psychosocial status of cancer populations are intended to improve their QOL (Bradburn, Maher, Young, J., & Young, T., 1992).

Although many services are accessed by clients with cancer seeking emotional or psychic relief (Benjamin, 1995), the one given the earliest and most persistent attention in the literature is group support. By the measurements used in several studies, investigators suggest group support may alter psychological well-being (Anderson, 1992).

Psychological well-being or one's mental attitude may be one factor in the perception of quality of life. It may also influence the disease process according to select studies and anecdotal case descriptions; however, it is a belief inadequately reflected in scientific evidence.

Despite common beliefs spurred by popular and scientific publications, the scientific literature reflects ambiguous and equivocal evidence that group support in any setting is consistently and conclusively effective. Group support for persons with cancer remains equivocal as a positive influence on its participants. The effects of social support are considered in the literature, mostly associated with the unifying term of psychosocial support, but these effects are not clearly differentiated from one's psychological status. Although psychological status may be a likely indicator for the influence of group support, a theoretical focus for group support as a basis to determine its influence is limited. These factors create a critical void, which further establishes the need to examine group support.

Aims of Current Research

A better understanding of how group support may affect its participants is needed. Psychological well-being may be one dimension pivotal among multiple dimensions to reveal the evidence required to advocate for group support. Despite the many variables studied about group support, a major contributing factor given inadequate attention in the

literature, may emanate from an intrapsychic state and the perceived degree of psychological distress. Through group support, improvement in psychological well-being may be enhanced, a clearer measurement of group support. Thus, the selection of psychological well-being as a primary outcome of group support warranted attention.

Although many researchers have studied group support, the body of research could be enhanced by: (1) knowing more clearly how group support may affect individuals; and, (2) expanding our knowledge of other possible contributing factors to its outcome. The principal aim of this study was to examine the effect of professionally-facilitated group support on the psychological well-being of its participants by comparing two naturally occurring groups, those who attended group support and those who did not. Study enrollees were persons who had been diagnosed with cancer within the last 18 months, but who had not attended any group support sessions for cancer in the last two years. Enrollees were monitored for their determination to start attending group support sessions during the study period or not. Study participants who attended group support, were limited to group support with specific characteristics and agreed to attend sessions through The Wellness Community (TWC) for 12 weeks. The aims of the research were as follows:

1. Compare psychological general well-being between two groups to measure the effect of group support by using the Psychological General Well Being (PGWB) instrument completed at pretest and posttest intervals analyzed with inferential measurement.
2. Measure the effect of extraneous variables: predisposition, age, and stage of disease by using an ANCOVA design.
3. Analyze the level of attendance at group support that may have affected results.

Other associations that may affect group support attendees were also important to the study's aims. These data were presented using two approaches. One approach used descriptive statistics to help explicate data where inferential statistics could not be used. The second approach used techniques of qualitative analysis to synthesize data. These aims were the following:

1. Analyze the qualifications of group leaders to adequately confirm that facilitator characteristics were consistent with TWC criteria, such as professional education, credentials and specialized training for facilitation.
2. Examine the use of complementary or alternative therapies by study participants (activities such as group support coupled with hypnosis, one-on-one counseling, and combination therapies with music, relaxation and stress reduction) that may have affected results.
3. Provide a context for the data by eliciting responses about life events that occurred during the study period affecting the lives of participants, which might have in turn affected study results, called "intervening events".

Finally, include data analysis that although not part of the initial plan, may add to the study's findings and may provide additional explanations. These data are called supplemental data.

Research Questions

The study was intended to reveal valuable information from which to provide a basis for understanding the effect of group support on psychological general well-being. Extraneous factors identified by the literature review were included, which regularly arise in the population under study. The research questions were the following:

1. Does psychological status (PGWB) improve for persons with cancer who attend professionally-facilitated group support, as defined?
2. Do factors such as age, pretest and stage of disease play a significant role in predicting the effectiveness of group support as measured by the PGWB?
3. If group support is an important action for clients with cancer to undertake, must they participate with a threshold or level of attendance in order to benefit (improved PGWB scores)?
4. Does engagement in complementary therapies reveal a potential association between the scores on the PGWB scores and participants' of group support?
5. Is there a context revealed by the description of intervening events perceived and conveyed by study enrollees during the study period that may have altered PGWB scores?

Operational Definitions

The following section provides the operational definitions for psychological well-being, age, stage of disease, professionally-facilitated support groups, clients with cancer, complementary therapies and intervening events.

Psychological well-being. Psychological well-being was the degree of a client's positive affect or subjective outlook as measured by the Psychological General Well-Being (PGWB) index tool. While there are many psychological states that could be elaborated, six states were identified in the development of the PGWB index. These are: anxiety, (b) depressed mood, (c) positive well-being, (d) self-control, (e) general health, and (f) vitality (Dupuy, 1972, 1978, 1984).

Age. Age is the number in years recorded on the demographic data form completed by study enrollees. The data demographic form requests “your age today in years”.

Stage of disease. Stage of disease is an enrollee’s severity of cancer illness ranging from Stage I through Stage IV that has been recorded in the enrollee’s medical record or has been confirmed by the enrollee’s attending oncologist. A more detailed description of how staging was determined is in Chapter 3.

Professionally-facilitated support group. Professionally-facilitated group support conducted at The Wellness Community (TWC) is by licensed psychotherapists (psychologists, social workers, family therapists, and occasionally by registered nurses), who have also completed the agency’s training for facilitation, about three months. The specific term used at TWC for group support is “participant groups”. For this study, participant group carried the same meaning as group support. Participant group may also refer to study enrollees who elected to attend group support sessions.

Group sessions focused on principal topics relevant to persons with cancer, namely: loss of hope, loss of control, and death and dying. TWC emphasizes “community” in its approach to its program and promotes group support as: “they are not alone in their fight-whether for physical, emotional or spiritual recovery. Together, they regain a sense of control over their lives, and ultimately discover that hope is a valuable tool irrespective of stage of disease” (TWC printed materials). The sessions are deliberately unstructured, but are managed within the guidelines of TWC to promote discussion of topics that emanate from participants. Discussion is prompted from within-group sharing of feelings and spontaneous interaction among the group members.

Problem-solving is prompted by the facilitator from the participant discussion within the group session.

In addition, the facilitator's role in group sessions at TWC is to provide a safe atmosphere to share emotionally-laden information and feelings. Other facilitator functions are to manage the interaction so that one participant does not dominate the session, that each person has an opportunity to share, and to assess the needs of participants in order to further guide the session. On rare occasions, a participant may be advised to seek one-on-one counseling (J. Kraemer, personal communication, September 6, 2001).

Group sessions were from 1.5 to 2.0 hours, but usually 2.0 hours, and sessions met once a week. Groups were no more than 17 participants with an average of about 6 to 12 participants attending per session (attendance varies with different group sessions and different TWC sites). In summary, group support for this study was defined as an assembly of persons with cancer, who met routinely as a group, directed by a TWC professionally-prepared facilitator, who attended to the needs of persons, expressed during the group's interactive dialogue. These characteristics were distinguished from and in contrast to those with prepared education sessions and combined therapeutic approaches (such as group support coupled with hypnosis, one-on-one counseling, and combination therapies with music, relaxation and stress reduction).

Clients or persons with cancer. Persons or clients with cancer were adults, age 21 and older, who had a new or recurrent diagnosis of cancer within the last 18 months, and who never attended or who had not attended professionally-facilitated support groups for persons with cancer within the last two years.

Complementary or alternative therapies. First, clarification may be helpful. Some authorities define complementary therapies as approaches to cancer designed to enhance coping and adaptation (relaxation, 1:1 counseling, meditation, etc.). These are distinguished from alternative therapies aimed at slowing, halting, or reversing tumor growth or spread of cancer--biochemical or physical interventions often outside of conventional treatment (Doan, 1998). However, it was assumed the public at large was not well-versed on how these terms may be differentiated by the medical community. For this study, the use of complementary or alternative terms may be used interchangeably by study participants and means those therapies that study participants access such as relaxation, music, imagery and others to help them cope with a cancer diagnosis and its treatment.

Intervening event. Intervening events are inevitable life occurrences, which happen concurrently with the study period, which were reported by enrollees at closure of the study in the final telephone contact. These experiences may alter the study's outcome by how these occurrences may affect enrollees' perceptions of their lives during the study period.

Assumptions

The study assumed that the diagnosis of cancer and its consequent sequelae are likely to alter one's psychological well-being. The study further assumed that persons who attended group support do so to neutralize the cancer experience, reduce anxiety or promote improvement in their psychological status. Cancer site was not predicted to be an influence, but it was included in the cancer demographics of the population. The information was not analyzed for its effect on the dependent variable (DV). It is an

assumption that pre and posttest scores on the PGWB incorporated the net effect of the varied circumstances encountered by enrollees during the study period. Factors that may be extraordinary are documented as intervening events, self-determined by enrollees.

Once participants were enrolled in the study, a critical assumption was that an equivalent proportion of the population under study would perceive group support as one alternative to relieve tension or anxiety, or provide psychic relief. The two naturally occurring groups were not equivalent with respect to their decision to attend group support.

Overview of Study

Two naturally occurring groups were compared in this study in order to better clarify the relationship between group-support and its attendees through measurement of psychological general well-being. Psychological well-being was measured as one effect of group support, using the PWGB Index, a psychological well-being instrument, while controlling for the design and content of group support by using one type of group support. Age, stage of disease and pretest results were covariates to promote the equivalency of participation and comparison groups, while also measuring these as potential influences on group support. The study also monitored attendance and participation in complementary therapies, potential factors that may alter the outcome of group support. In contrast to many studies, improvement, as well as deterioration of the scores on the PGWB Index were recorded to better assess the outcome. Finally, rarely described but factors which may modify or alter group support were included. Importantly, events, called “intervening events” were recorded and described because these may alter or contribute to the study’s outcome. The study contended that

psychological well-being is a representative measurement of the effects of group support. Psychological well-being could be a distinct factor in the positive effects of group support and ultimately in quality of life determinations.

Significance

Cancer and its Impact

Beyond the mortality and morbidity costs of cancer and other losses associated with forgone wages and salaries are the significant psychosocial costs. These are not reflected in direct or indirect economic costs. Victims of cancer may endure disfigurement, disability, pain, grief, and impending death, the effects of which extends to their significant others. Some of the more dramatic and insidious results of the diagnosis and treatment are social isolation, unwanted job changes, changes in living habits, the loss of a number of life's opportunities, and often accomplishments, and activities that cannot be sustained (Brown, Hodgson, & Rice, 1996).

Quality of life may be reduced beyond the restorative capability of rehabilitation (Brown, Hodgson, & Rice, 1996). Progress in reducing both morbidity and mortality rates continue; however, improvements in person's lives through activities such as psychosocial support need to be enhanced. The psychological toll is not a direct part of the economic equation. Psychosocial support may be a cost effective means to improving psychological status. It may in some circumstances be the only improvement to be realized, particularly when some cancers are refractory to treatment. Reduction of psychological anxiety may be extraordinarily beneficial and the least costly improvement to address. Although the intent of this study was not to measure QOL, but psychological

well-being, a discussion about QOL and its relationship to the study is relevant because improvement in psychological well-being may be a benefit to one's QOL (Haas, 1999).

Quality of Life

Quality of life has a distinctive importance for each individual, but interest from national socioeconomic and political healthcare proponents is mounting to include quality of life as an essential health care measurement. Quality of life is one of many expectations for outcomes in healthcare initiatives, and it has been adopted by the U.S. government and the research community as an outcome worthy of measurement (Briss et al., 2000; Carande-Kulis et al., 2000; Green & Kreuter, 2000; Truman et al., 2000; Zaza et al., 2000). The way in which an abstract conceptual construct such as quality of life is operationalized will determine its value and contribution as an outcome measure, but QOL continues to be an elusive concept to operationalize. In the context of health status, QOL is often viewed within the scope of wellness, health promotion and disease prevention, which contributes to the challenge of its measurement. (Erickson, Wilson, Shannon, & National Center for Health Statistics, 1995).

QOL and HRQL. There continues to be a lack of clear differentiation between generic quality of life (QOL) and health related quality of life (HRQL). According to Olweny (1993), "quality of life" in clinical medicine represents the functional effects of an illness and its consequent therapy upon the patient, as perceived by the patient. Patrick and Erickson (1988) depicted health related quality of life "as the level of well-being and satisfaction associated with events or conditions in a person's life as influenced by disease, accidents or treatments" (p.11).

Patrick and Erickson, (1993) proposed the following definition: “Health related quality of life is the value assigned to duration of life as modified by impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy” (p.22). In a critical appraisal of quality of life measurements by Gill and Feinstein (1994), no article distinguished overall quality of life from health related quality of life; and, investigators conceptually defined quality of life in only 11 of the 75 articles. Therefore, QOL and its meaning in a population with chronic illness has not been defined, nor its relationship to an ill population well understood.

The measurement of psychological status within the framework of QOL. Quality of life is an abstract phenomenon, with its measurement inconsistently determined by a broad cadre of diverse clinicians, investigators and disciplines (Ebrahim, 1995; Ferrans & Powers, 1985; Ferrans & Ferrell, 1990; Haas, 1999; Rogerson, 1995; Testa & Nackley, 1994). However, common themes to characteristically describe QOL are based on multi-dimensions as these are determined and perceived by the individual. It is subject to change over time because QOL determination is subject to intervening events. Therefore, one’s QOL will change over the period of one’s life and how an individual perceives life has a defining role in its determination. (Ferrans & Powers, 1985; Ferrans & Ferrell, 1990; Gill & Feinstein, 1994; Naughton, Shumaker, Anderson, & Czajkowski, 1996; Olweny, 1993; Padilla, Grant, Ferrell, & Presant, 1996; Schipper, Clinch, & Olweny, 1996).

Tools to measure either overall QOL or HRQL use different questions for each domain, and may have different theoretical themes driving the instrumentation and investigation, but a similar gestalt emerges (Ferrans & Powers, 1985; Ferrans & Ferrell,

1990; Gill & Feinstein, 1994; Naughton, Shumaker, Anderson, & Czajkowski, 1996; Olweny, 1993; Padilla et al., 1996; Schipper et al., 1996; Ware, 1996). Most models created to measure health related quality of life (HRQL) include: (a) physical status with or without symptom distress, (b) psychological states, (c) social dimensions: interaction- from inner (personal) to outer (community) contacts, (d) performance, which may be part of the physical measure, or may be defined as functional: the ability to do physical and occupational tasks, and (e) less frequently, a spiritual or existential component (Naughton et al., 1996). Examples of individual scales in one instrument providing total scores for relevant HRQL dimensions include the Cancer Evaluation Rehabilitation System (CARES), the Functional Assessment of Cancer Therapy (FACT), and the Functional Living Index-Cancer (FLIC). If one instrument does not identify all desirable measurements, then a HRQL battery using separate instruments is often used (Moinpour, Savage, Hayden, Sawyers, & Upchurch, 1995).

If one accepts that the generic themes described are inherent in the definitions of QOL, perception is a key to one's interpretation of QOL. According to Joyce (1988) and Selby (1988), the "patient's" own assessment of quality of life, satisfaction or changes, is the only valid basis for its determination. QOL is often defined from, and measured by, individuals' perception of their psychological and physical states. How psychological status is perceived then may affect how one feels about their QOL.

Haas (1999) reported that researchers often measure one component of QOL without specifying whether they are focusing on the subjective or objective nature of QOL. She posits that QOL "is primarily a subjective sense of well-being encompassing physical, psychological, social and spiritual dimensions" (p. 219). Figure 1 depicts her

conceptual definition of QOL. Within this conceptual definition, this study explores the effect of group support on the subjective sense of psychological well-being by measuring group support through the PGWB index.

Figure 1. Well-being and functional status as subjective and objective components of quality of life.

From: "Clarification and Integration of Similar Quality of Life Concepts" by B. Haas, 1999, *IMAGE: Journal of Nursing Scholarship*, 31 p.219. Copyright, 1999, Reprinted with permission.

The purpose of this study was not to measure QOL, but an important precept was promulgated—psychological status is a constituent, worthy of consideration within the framework of QOL. And, according to Haas (1999), psychological status is one dimension of QOL measurement. The construct embodied in health-related QOL and its strong relationship with wellness, predisposes psychological status as a significant component and an important measurement. Notably, psychological status may hold a distinct meaning for chronically ill populations, such as those living with cancer. For this study, psychological well-being was an outcome measure because it may alone determine the positive effects of group support. The measurement of psychological well-being may help us discover that a prevailing force in QOL determinations is psychological status and may better direct our focus on the benefit of group support.

Mediators: Wellness and Illness in Persons with Cancer

One difficulty of linking psychological well-being within a QOL framework and QOL with any of its multiple dimensions, is the prevailing theme of how to interpret a QOL dimension given the perceptual and operational challenges of defining wellness and illness. If one perspective is that wellness and illness represent opposite sides of the continuum spectrum, how do we conceive the measurement of one with chronic illness, such as cancer, along this continuum? One's sense of wellness and illness regardless of the clinical interpretation may not translate to well-being. QOL and the measurement of psychological well-being are influenced by many factors that shape an individual's perception, their physical status, the socioeconomic environment within which they live, and as is the case of persons with cancer, specific cancer-related factors. The following acknowledges the multiple influences by which one considers their state of wellness or

illness. These perceptual influences are implicit in what then may mediate the measurement outcome of psychological well-being.

Published national objectives reinforce wellness, moving beyond the reduction of mortality to improving quality of life (Clark, 1999; DHHS, 1990; DHHS, 2000). In the context of wellness, health outcomes have any number of goals and endpoints (Hawe, Noort, King, & Jordens, 1997). Wellness action or health promotion is shaped by the ideologies of society and the practices that are adopted by health care professionals (Adams & Armstrong, 1996; Benson & Latter, 1998; Maben & Clark, 1995). One's paradigm for wellness is created by these ideologies and practices, coupled with the intrapersonal characteristics of persons interacting with their environment. Values for health and well-being are dependent on many factors--values are shaped by each individual's evolution, which also influences and is influenced by, society. The perception of wellness is inextricably linked with these values. Wellness and well-being are not synonymous and each may be conceptually perceived differently by the same individual.

Wellness. A cogent definition of wellness is unclear for a healthy population, and it is even less accessible in a chronically ill population, such as those living life with cancer. Wellness was a theme in this study because of its major contribution to the perception of one's well-being state, often, in part, a culmination of the effects of secular and personal expectation. Despite the lack of explicit definitions, the dimensions of a disease process and its treatments have implications for wellness and may mediate a study's outcome. Further research may help identify a clearer relationship between an

activity's effects and improvement in wellness and one's sense of well-being who is chronically ill.

Rose (1989) asserted that health promotion and risk prevention for persons diagnosed with cancer have several purposes: (a) to enhance a sense of well-being and control over one's health, (b) to eliminate behaviors which may contribute to future health problems, and (c) to promote the early detection of recurrent disease. According to Rose, the primary purpose of health promotion and risk prevention is to modify one's self-perception of health. Thus, a generic theme of wellness may guide therapies designed for persons with cancer. The literature centers on achieving wellness by behavior modification through motivational and attitudinal change (Ajzen, 1985; Froman, 1997; Kuhl, 1985; Lev, 1997; Maiman & Becker, 1974; Pender, 1996; Rosenstock, 1974a; Rosenstock, 1974b). However, the evidence of successful approaches predicated on these motivational and attitudinal changes are minimal. Thus far, there is no scientific or behavioral basis established for use of psychosocial support as a means to achieve wellness in persons with cancer. The wellness concept is obscured by a lack of an accepted definition for all populations, "well" and ill. Yet, its popularity in clinical and in secular discussions perpetuates a universal health goal that is touted and should be recognized for this study. Clinical and secular discussions shape perceptions of what is wellness. Given the inconsistent linkages between wellness and well-being, the terms are not interchangeable. Psychological status presumably affects well-being.

Wellness in illness. In persons diagnosed with cancer, wellness is a perception that evolves with varying degrees of illness. Significantly, QOL and specifically psychological status, has renewed importance to those who have had their health

compromised by infirmity. However, in illness its determination is more complex, and its measurement more central to the context of how one is able to live life.

Relief from pain, functional capacity, physical endurance and many other dimensions are part of the cancer experience. These dimensions also have extraneous forces that may mediate the outcome of support interactions. For example, the disease process, the cancer site, the institutional setting and its resources, and the choice and administration of treatment all have an interactive effect on any complement to care. Importantly, researchers suggested age, the site of cancer, the stage of cancer, comorbidities and a number of other variables may influence the effects of group support (Anderson, 1992; Cassileth et al., 1984; Kurtz, M. E., Kurtz, J. C., Stommel, Given, C., & Given, B., 1999). Further, clients with cancer often seek emotional and physical relief through complementary therapies such as music, aromatherapy, stress reduction and others. Although the literature describing the effects of these therapies is minimal, they have the potential to mediate the effects of group support.

Psychological Well-Being

The conceptual determination of psychological well-being can be confusing given its frequent association with quality of life concepts such as satisfaction, morale and happiness (Bradburn, 1969; O'Rourke, 1985). Even multi-scaled instruments do not clearly differentiate quality of life from wellness and wellness from general well-being (O'Rourke, 1985). According to Costa, McCrae, and Zonderman (1987), "for normal individuals, states of mind are typically viewed primarily as emotional reactions to circumstances and events, and psychological well-being is seen as an index of the objective quality of life" (p. 299). According to Dupuy (1972), the measurement of

mental health and mental illness is to assess psychological functioning from its positive to negative aspects. Psychological functioning is inherent on the conditions that bear on the well-being and the quality of life of persons (Dupuy, 1972).

Psychological well being reflected in the psychological general well-being index (PGWB) encompasses a construct broad enough to consider mental distress, mental health and positive well-being (Dupuy, 1972, 1978, 1984; O'Rourke, 1985). Cassileth et al (1984) used the PGWB index (transformed into the Mental Health Index) in their comparison of six diagnostic groups, comprised of persons who were physically ill including those with cancer. They concluded there was a direct relationship between declining physical status and mental-health scores. Equally important, was the predisposition (personality strengths) of study participants in determining their scores, suggesting pretest scores was an important variable to help evaluate predisposition on positive psychological well-being and the adaptation to disease.

Psychological Well-Being and Group Support

Expected positive effects from psychosocial support, derived from research efforts, incorporate the increased capacity to cope with adversity and reduce distress (Anderson, 1992; Bloom, 1982; Bloom & Spiegel, 1984; Folkman & Greer, 2000). These effects would presumably improve psychological well-being. Several instruments could be used to measure these effects or serve as proxies for changes in psychological status. Instruments that measure possible contributions to psychological status could also be used to assess the degree of negative affect such as distress, anxiety, depression and anger. These would not be direct measurements of psychological well-being, but could be components that may have an inverse or negative correlation. A direct measurement of

psychological well-being however, simplifies the overall expected influence of group support.

Several studies reported obscured the relationship between professionally-facilitated group support and its outcome. Rather than measuring psychological well-being, several researchers chose to measure possible mechanisms by which a psychological effect may occur. For instance, mechanisms studied such as mood disturbance, self-esteem, ego-strength and coping may actually represent mediators of psychological well-being (Anderson, 1992; Fawzy, Cousins, Fawzy et al., 1990; Bloom, 1982; Bloom & Spiegel, 1984; Edgar, Rosberger, & Nowlis, 1992; Folkman & Greer, 2000; Schnoll, Harlow, Brandt, & Stolback, 1998; Worden & Sobel, 1978). As important as these discoveries may be, they are not a *direct* measurement of psychological well-being. The lack of a direct measurement may blur the positive relationship between the effects of group support and psychological well-being. In this study, psychological well-being was measured as direct evidence of the positive effect of group support.

Another reason for choosing psychological general well-being was the outcome of a preliminary inquiry. Focus groups representing participants of group support were conducted with their input subsequently analyzed using qualitative methods (Harper, 2000 [Focus group results of participants and non-participants of group support] Unpublished raw data). Each characteristic labeled from focus group analysis, such as self-importance, normalization and self-efficacy, is potentially identifiable with mechanisms that promote psychological well-being. If characteristics such as these are enhanced, then these and other experiences may positively contribute to psychological well-being. It was synthesized that one significant effect of professionally-facilitated

group support may be adequately demonstrated by the measurement of psychological well-being.

Conceptual Representation of Psychological General Well-Being

The term “Psychological” reflects an intra-personal state about how people feel (affect). It is a self-representation based on the assumption that individuals differentiate their feelings in qualitative ways (pain, joy, anger, happiness), and that these feelings also have a subjective magnitude or intensity for each person. Measurement components are based on the assumption that there is a bipolar range of feelings from distress to euphoria that most people have experienced and can identify for themselves. These states (or sub-states) can be differentiated by personal introspection (emotional experiences), and the individual process of ordering these feelings or interpreting their quality (positive or negative) based on their intensity, duration and frequency. “General” indicates that the affective state is to be determined from a number of different subjective states. “Well-being” represents the net impact of the many psychological forces that may bear on an individual, measurable from a continuum of negative to positive subjective feelings to culminate in a net effect (Bradburn, 1969; Dupuy, 1978, 1984; Ware, Johnston, Davies-Avery, & Brook, 1987).

Psychological well-being, like QOL, is a personal evaluative state. Any number of external and internal influences may help form or transform an individual’s perception of psychological status. For this study, psychological well-being was defined as the degree of a client’s positive or negative affect or subjective outlook as measured by the Psychological General Well-Being Index. Specifically, other investigators have not

defined psychological status in the context of clients with cancer except implicitly or indirectly by the tools employed for measurement in many of the studies reviewed.

While the mechanisms and mediators for change, the intrapsychic processes in psychological status, are not directly measured in this study, the expected outcome of improvement in psychological well-being is. In a classic study, Bradburn (1969) explained the structure of psychological well-being as a measurement of the degree of happiness--based on his and others conclusions that mental health is really about a subjective sense of well-being, the degree of happiness. The following is his position on a structure developed to measure psychological well-being:

By naming our forest "psychological well-being," we have not meant to imply that concepts such as self-actualization, self-esteem, ego-strength, or autonomy, which others used to describe the forest, are irrelevant to our study, but only that they can be better viewed as species of trees that are part of the forest, rather than the forest itself". (p.224)

Significance to Nursing Research

Researchers have measured the effects of group support often by using instruments that are mostly used or aligned with QOL measures (Anderson, 1992; Linn, Linn, & Harris, 1982; Helgeson, Cohen, Schulz, & Yasko, 1999, 2000), or intrapsychic mechanisms (Anderson, 1992; Bloom, 1982; Bloom & Spiegel, 1984; Edgar, Rosberger, & Nowlis, 1992; Fawzy, Cousins, Fawzy et al., 1990; Folkman & Greer, 2000; Schnoll, Harlow, Brandt, & Stolback, 1998; Worden & Sobel, 1978). Although improvement of QOL or health related quality of life presumably is an endpoint, it is also recognized as a complex construct, not well defined. As a result, studies about the effects of group

support may continue to have equivocal outcomes. Nursing research may be expanded by a better understanding of the effects of group support by a more specific and focused measurement. The use of an instrument to measure psychological well-being directly is not prevalent in the research conducted by nursing or other disciplines.

An important philosophical stance established by nursing conceptualizes its practice by the care of the holistic being, which may be diverted by the challenges of scientific method. Attention in the literature is given to pathways for change, intrapsychic mechanisms, perhaps at the expense of measuring critical dimensions from an index (PGWB) that may give us more information about group support's effectiveness. From the research reviewed, it may be premature to evaluate group support by dissecting its effects into component parts, such as intrapsychic mechanisms, before we know what dimension of the whole human being is likely to be affected.

The body of nursing research may be enhanced in primary ways. One, by introducing or re-introducing psychological well-being as a dimension we can and should measure directly. Two, the study indicated to establish group support as a positive influence, more study is needed. Finally, the study may motivate nurses and other health care professionals, who refer clients to group support, to seek a better understanding of its effects and the appropriateness of their referral.

Summary

Society's interpretation of wellness is not crystallized, complicated by the lack of a definition for wellness in an ill population. Health-related quality of life adds the dimension of how the disease may influence measurement, but QOL and HRQL have not been clearly differentiated in the literature. Yet, measuring one effect of group support

may serve as evidence at a time when quality of life considerations by clinicians, policy makers, and funding agencies may be more responsive to its value. QOL is mostly accepted as one's perception, a construct in reality, less shaped by theory and more shaped by each individual, with life history and circumstances cumulatively resulting in an ever-evolving personal definition. Finally, if one accepts psychological well-being as a significant component of QOL, then it followed that an action which may affect psychological status is worthy of attention.

From the literature synthesized, the multiple dimensions of measurements and the multiple instruments employed to examine group support may confound the results of group support. Outcomes of studies with varied treatments representing one intervention are mixed with positive and negative results without a discovery about what part of the treatment intervention contributed to what result. Although many interventions aimed at improving one or many dimensions of the quality of life, group support for persons with cancer is one pursuit given persistent attention in the literature. However, its effectiveness is unclear. Measurement of effectiveness may be simplified by linking group support with an outcome such as psychological well-being, a credible expectation of group support.

Informal support from fellow patients, family members and the health care team influence the adaptation of the diagnosis and treatment of cancer. The presumed role of support groups, more formally organized through a variety of institutions and efforts, are prevalent in both the scientific and popular literature (Benjamin, 1995; Samarel & Fawcett, 1992; Telch & Telch, 1986). Despite this perception, and the current literature about the role of formal support groups, few studies yielded the conclusive evidence that

group support consistently promotes improvement in the lives of its participants. Yet, support groups are widely accepted and from the lens of participants, may be invaluable as each person confronts the cancer process. Group support may modify one's response to cancer and its related sequelae by the influences it may have on psychological well-being. Psychological well-being is a significant measurement with which to measure the effects of group support.

This undertaking filled a void in the literature by attempting to demonstrate that group support was a positive influence on the psychological well-being of persons diagnosed with cancer. In doing so, it was another step to clarify professionally-facilitated group support as one that may improve a significant component of quality of life in an ill population, psychological well-being.

Chapter 2

Review of the Literature

The literature review begins with a brief discussion of wellness and cancer influences on wellness, followed by an overview of the measurement of group support. This review helps establish why improvements from interventions with clients with cancer have been difficult to demonstrate. Psychosocial interventions with an emphasis on group support are then addressed, categorized by major themes. The review concludes with the significance of psychological well-being as a measurement, with the final pages discussing the critique of the literature.

Wellness, Cancer and Interventions

Measures of health related quality of life, despite the obstacles for measurement, imply wellness as a standard component. Whether certain mental health variables like optimism and perceived symptoms independently influence wellness, or if these variables are more likely affected by age, gender, and the presence of co-morbidities are not well understood. What equally eludes us is the lack of knowledge about the order of events or a specific cluster that might predict mental or physical health. Even in non-cancer populations, wellness determinants vary (Ferrini, Edelstein, & Barrett-Connor, 1994; Resnick, 2000).

Watt, Verma and Flynn (1998) examined the association between wellness and improvements in quality of life to assess the strength of the scientific evidence. Their

objective was: “to answer the question, are wellness programs worthwhile?” (Watt, Verma, & Flynn, p. 225) Studies between 1980 and 1996 which aimed at wellness programs that measured outcomes were analyzed. Based on the desired improved global measures of health, such as perceived well-being, illness experience, and functional status, they reviewed the “wellness” literature using key terms such as wellness, health promotion, chronic disease, psychoneuroimmunology, different therapeutic techniques (such as relaxation, music therapy, meditation), and several other terms. Of 1082 articles, only 11 met their criteria. Articles were ranked according to subject population, the number of subjects followed to the end of study with continued follow-up, methods based on randomized controlled trials, and significance and confidence intervals, along with other factors. The evidence was unconvincing that wellness programs enhanced a patient’s quality of life.

Investigators have demonstrated that the determination of an intervention for a cancer population, for whom age, gender, site of cancer and degree of wellness may also contribute to its determination, is particularly elusive (Given, Given, Azzouz, Stommel, & Kozachik, 2000; Gordon et al, 1980; Kurtz, Kurtz, Stommel, Given, & Given, 1999; Stafford & Cyr, 1997). Wellness and its determinants in a cancer population may confound intervention results because cancer affects persons’ wellness in multiple ways. Yet, group support presumably represents a health care initiative to help achieve wellness. A population with cancer for whom multiple variables contribute to their response to the cancer experience may be better served by examining the effects of group support by a more direct measurement, psychological well-being.

Cancer and Wellness

Cancer is a disease with multiple etiologies and disparate outcomes (Anderson, 1992). The variables of cancer site, changes in symptom experience, treatment-induced fatigue, and treatment interruption complicates isolating individual influences for their specific effects on wellness (Given et al., 2000). Gordon et al. (1980) found that each cancer site provoked separate clinical issues, different body image concerns, and various reactions to medical treatment. Negative affect scores were also different. The authors concluded that cancer should be viewed as a group of different diseases with each one requiring a different type of adjustment and intervention. Given, Given and Stommel (1994) proposed that influences such as age, site of cancer, and interval of time out of treatment contributed to symptom experience, which then determined perceived physical and mental health status. Other researchers found that patients with carcinomas of the prostate, colon and particularly the lung independently predicted poorer health, with lung patients reporting greater loss of physical functioning (Given et al., 2000; Gordon et al., 1980; Kurtz, Kurtz, Stommel, Given, & Given, 1999; Stafford & Cyr, 1997).

In another study, age, comorbidity, symptom severity and cancer site were significant predictors of physical functioning. During the year after diagnosis, older age and female gender were related to lower levels of functioning (Given et al., 2000). And, mental health scores were predicted by symptom severity. Given et al. (2000) concluded: "Symptoms emanate from the physiologic impacts and the psychological responses of patients to their cancer and its treatment" (p. 490).

Vinokur, Threatt, Vinokur-Kaplan, and Satariano (1990) suggested there may be temporal circumstances such as the time of diagnosis or age which may influence

depression and physical impairment. They found in their longitudinal analysis of recovering breast cancer patients at four and ten months that physical impairment at four months was a significant predictor of deteriorating mental health at ten months. Younger patients also experienced greater deterioration than did older patients. In a related finding, Lev, Paul and Owen (1999) measured self-care efficacy and quality of life, and found the greatest decreases in scores, using the Strategies Used By Patients to Promote Health (SUPPH), occurred between baseline and four months after diagnosis.

By contrast, in a population of female geriatric patients with cancer, Kurtz et al. (1999) found age, comorbidity, symptom severity and cancer site were significant predictors of physical functioning, but only symptom severity predicted mental health scores. Hunt, Bond, and Pater (1990) also found younger patients reported higher levels of stress in response to a cancer diagnosis. Cassileth et al. (1984) reported poorer mental-health scores for patients around the time of diagnosis, but reported a very positive correlation between the improvement of mental health and advanced age. Using the mental health index (derived from the PGWB schedule), a more remarkable finding by Cassileth et al. was that patients did not differ in their psychological status by diagnosis or by comparison with the general public when six different chronic illnesses, including cancer in 758 patients, were reviewed (excluding those with end-stage diseases). They reported that persons diagnosed with particular chronic diseases did not exhibit any particular stereotyped behaviors or characteristic behavior clusters commonly associated with these diseases.

Many other factors contribute to psychological status, which confound wellness determinates in a cancer population. Akechi, Okamura, Yamawaki and Uchitomi (1998)

pursued predictors of mental adjustment (*fighting spirit and helplessness/hopelessness*) to cancer on the basis that cancer patients' mental adjustment is one of the important factors which correlate with quality of life and degree of psychological distress (Folkman & Greer, 2000; Greer & Watson, 1987). Akechi et al. (1998) defined mental adjustment as "the cognitive and behavioral responses made by an individual to the diagnosis of cancer" (p.2381). Performance status was the only predictor of fighting spirit among the medical variables, and along with several patient characteristics, social support was correlated with fighting spirit. Although performance status was unclearly defined, it was a construct of physical capacity. Interestingly, the patient's physician played the strongest role in patients' mental adjustment scores.

A similar finding was published (Rijken, Komproe, Ros, Winnubst, & van Heesch, 1995) comparing three groups of women: cancer patients, women suffering from chronic illnesses, and healthy women. Perceived health was a greater determinant of global well-being for patients with cancer. Perceived physical health had significant importance in determining global affective well-being (happiness) over other variables.

Marks, Richardson, Graham, and Levine (1986) examined health locus of control and found, especially in cancer patients who perceived their illness as severe, beliefs about health self-control and expectations about treatment related to depression. The population of newly diagnosed cancer patients who saw the self as controlling one's health as opposed to the physician or by chance, had negative correlations with depression. The authors postulated that on initial diagnosis, prior experiences and perceptions of health generalize to determine the first reaction to a cancer diagnosis. However, control beliefs were not studied, which may vary throughout the course of

treatment, particularly if controlling one's health does not lead to recovery or symptom relief. Frank-Stromborg, Pender, Walker, and Sechrist (1990), who studied ambulatory cancer patients for healthy promotion styles, found some variance explained by the cognitive/perceptual variables of the definition of health, perceived health status and perceived control of health. The reaction to the diagnosis of cancer as an illness-specific variable was a significant contributor to the prediction of health-enhancing behaviors.

In summary, physical and mental health states, and the perception of these, may contribute to a person's sense of wellness. To the degree that wellness may have a relationship with well-being in persons with cancer, what constitutes wellness and well-being is unclear. Such things as diagnosis, treatment, symptom experience, and age may transform the status of wellness and its perception among persons with cancer, which contribute to the complexity of a well-being determination. These factors also impose an equal challenge on determining what may alter the psychological status of persons with cancer. How to achieve relative wellness in a cancer population remains a dilemma too confounding to address in its totality. While this reality may overwhelm science, it should not prevent investigators from looking for enhancements that may make positive differences in how persons with cancer perceive how their lives are lived.

Overview of Group Support Measurement

Psychosocial interventions are designed to reduce or minimize the distress that occurs with the diagnosis of cancer and its subsequent course (Edgar, Rosberger, & Nowlis, 1992). When focus groups were conducted, the analysis indicated psychological status may be improved by group support. Yet, the outcome variables often chosen in other studies reflected how distress may be mediated, rather than directly relating how an

intervention may directly affect psychological well-being. For example, psychosocial interventions, usually support techniques, have been related to ego-strength (Edgar, Rosberger, & Nowlis 1992; Worden & Sobel, 1978), coping, and adjustment responses (Bloom, 1982; Folkman & Greer, 2000; Spiegel, Bloom, & Yalom, 1981; Worden & Sobel, 1978), self-concept (Ferlic, Goldman, & Kennedy, 1979), anxiety, hostility and depression (Gordon et al., 1980), fighting spirit (Greer, Morris, Pettingale, 1979) and mood states (Fawzy, Cousins, Fawzy, et al., 1990; Cella et al., 1987; Telch & Telch, 1986; Worden & Sobel, 1978).

Researchers have developed a number of multi-scale instruments in an effort to be comprehensive. Many researchers inferred by their outcome measures, such as adjustment, coping, self-concept, and self-esteem among others, that psychological well-being may be improved by group support. They, did not however, explicitly identify psychological well-being as a dependent variable, but many of the variables measured could be considered contributions to psychological well-being. The approach in this study was to match professionally-facilitated group support (group support), with psychological well-being, a likely dimension affected.

Another major thrust in psychosocial oncology research is the interaction of psychosocial support and physiological variables (Gellert, Maxwell, & Siegel, 1993; Greer, Morris, & Pettingale, 1979; Redd et al., 1991; Spiegel, Bloom, Kraemer, & Gottheil, 1989). In contrast, this research suggested that the value of group support is improvement in psychological well-being. Psychological well-being was measured as a whole, rather than the components of its make-up, and regardless of the intrapsychic explanation to achieve it, which may vary with each individual.

Although group support as a therapeutic adjunct for populations with cancer is prevalent in the literature, the evidence for its effectiveness is inconclusive. The variables identified for studies undertaken often confound analysis. In part, this ambiguity may be a result of the lack of conceptual clarity, and subsequently, the tools utilized for measurement. Mediators are often identified which cause confusion between the processes influencing the dependent variable, the intervening variables and the desired endpoint of an intervention.

Despite the confluence of many factors, it appears that investigators identified the value of group support as a psychological intervention early on, with improvement in psychological well-being at least, the conceptual outcome. Outcome measures such as coping better, improved self-esteem, survival, decreased depression, and better mood states are likely components of psychological well-being, or implicitly represent contributions to it. In the research reviewed, psychological well-being was not operationalized with these measurements. These measures may have reflected researchers' intent, but as distinct endpoints of a psychosocial intervention, require more pursuit. If coping, self-esteem, and mood are associated with a theoretical framework for the self and evidence of improvement of self, these are silent assumptions, perhaps implicit in the intent of studies. To proceed with psychological well-being as an outcome measurement was and continues to be an explicit and rational approach of the effects of group support.

Most interventions with group support have included additional components such as education, therapies such as relaxation and imagery, individual psychotherapy and stress management in combination with group or individual support. The difficulty is

these treatment variables are often grouped as a single modality, so the efficacy of group support alone is confounded.

The discussion that follows categorizes an array of interventions inclusive of group support under the heading of psychosocial interventions. This is because rarely has group support alone been studied. When it has been studied, few interventions have been studied with characteristics that limit group support to an interactive dialogue among its participants, guided by trained professional facilitators, the prevailing characteristics of group support for this study.

Psychosocial Interventions for a Cancer Population

Studies directed exclusively to the psychological effects of group support on populations with cancer are limited. Instead, the literature spans different elements of psychological dimensions that may be useful to understanding psychosocial interventions, such as improvements in self-esteem, self-control, coping, and adjustment, and how these may transform psychological states. These may be helpful in understanding how group support might influence psychological status.

Major themes from psychosocial interventions are the association of and interaction between psychological and sociological effects from interventions. One difficulty is that authors seldom differentiated social support from psychological support; some who did include Bloom (1982), Bloom and Spiegel (1984) and McLean (1995). A few studies elaborated on social network and were designed to correlate directly or indirectly with changes in psychological distress (Bloom, 1982; Bloom & Spiegel, 1984). These studies defined social support as an independent variable within the context of

family and friends as networks. One may conclude it may not be useful to distinguish between psychological and sociological-based interventions.

The literature review continues with those interventions from which the outcomes could more directly infer psychological effects. These studies are differentiated from those that demonstrated physiological effects (survival). Following this discussion, are those studies categorized under structural considerations, because these studies reflected treatment variation in the kind, frequency, and context of group support, which contributed to results. Group support alone, without other therapeutic techniques, such as planned education sessions, stress reduction, one-on-one counseling and music therapy, among others has not been isolated in many of the studies. Research found about these interventions was minimal, but a discussion is included because of the potential influences on group support. Finally, psychological well-being is presented along with a critique of the literature that explains why psychological well-being was a representative, applicable and appropriate dimension with which to measure the effectiveness of group support. To conclude, the literature is subdivided into studies that: (a) show an association between psychological and sociological effects, (b) explain or associate group support with psychological variables or effects, (c) have been found to have effects on survival, and (d) consider the effects of the structural context of group support—such as content, the level and dynamics of the participation, and how the sessions were facilitated.

The Association Between Psychological and Social Effects

The fact that adjustment to a diagnosis such as metastatic carcinoma intensifies almost all psychological aspects of a person's life has been studied and reported (Spiegel,

1979). Researchers have reviewed social support and the mechanisms of adjustment and coping. As part of a larger investigation, in a two-step design Bloom (1982) first assessed the independent effect of social support on adjustment, and subsequently examined the relationship between social support, coping and adjustment by measurement of psychological distress, self-concept, and sense of power. The study group consisted of 133 women with breast cancer (mean age 51 years) sequentially accessed over a 2.5 year period. The women were interviewed postsurgery, but none had metastatic disease at the time of the interview. A battery of self-administered tests were completed to obtain demographic and background information on each study participant.

Bloom defined psychosocial adjustment as the "...feelings and symptoms indicative of positive mental health..." (p. 1329). Coping responses may be intrapsychic or behavioral, but they reflect an individual's attempt to manage demands that challenge available resources. In a path analysis, social support was analyzed for its effect on adjustment, and then one's coping response was proposed to mediate the relationship between social support and adjustment. Social support was the strongest predictor of coping response and had indirect effects on the three dependent measures: psychological distress, self-concept, and sense of power. When psychological distress was the only indicator of adjustment, coping response was the only significant contribution to the equation. Because marital status was not a predictor of adjustment, the study affirmed the investigator contention that perception of support rather than the existence of social ties was critical.

In a study that followed, Bloom and Spiegel (1984) conducted an investigation with women, all with documented metastatic carcinoma of the breast. There were 86

participants (mean age 54 years) who completed questionnaires about social demographic variables, amount of pain, coping response, sense of power, self-concept, family support, social activity, outlook and social functioning. They proposed a causal model suggesting that self-concept, sense of power, and outlook on life directly affected social functioning; these were causally a result of two indicators of social support, emotional support and social network. Emotional support refers to "...a perception that one is cared for, loved, is esteemed, regardless of achievement..." (p. 831). Network is the opportunity for social exchange and the degree of support, "or a network of social ties to which the individual is connected..." (p.832).

Researchers investigated how the many dimensions of the social support construct related to psychological well-being. The study goals were to explain a decrease in perception of social functioning by examining role change and activity decrease. Cancer can change the reality and perception of expected roles, and this change in turn may cause behavioral disorganization and psychological distress. As the constriction of social network and emotional support occurs, one perceives oneself as functioning less well. The results indicated emotional support by one's family related significantly to only one measure, outlook on life. Family support was not related to social functioning. Self-concept had a significant effect on social functioning, but not on sense of power. One's coping response did have direct effects on social functioning.

According to the authors, social support is vital to one's adaptation (versus maladaptation) during a medical crisis, and merits further study. Psychological withdrawal from friends or family can further depersonalize and isolate an individual "...becoming to the individual a metaphorical statement of feeling already dead" (Bloom

& Spiegel, 1984, p.836). Members of one's social network may withdraw from the victim due to the stigma attached to a cancer diagnosis often caused by their own fears and associations with cancer. Reduced role functioning, induced by fatigue and circumstances is, however, an alternative explanation for "network constriction".

These investigators attributed some of their results to the multidimensionality of the social support construct itself and the difficulty in isolating influences. For example, they conceptualized social support as emotional support and social activity, with each of these two dimensions having different effects. Emotional support was predicted to affect psychological functioning. Social activity was predicted to affect social functioning.

The results described above indicate the complexity of the interrelationship between psychological and social functioning. Further, it was predicted that the greater the perception of emotional support, the greater the sense of psychological functioning. "Psychological functioning" was measured by self-concept, sense of power and outlook on life in order to predict the relationship between emotional support and psychological functioning. In this study, psychological functioning was represented by indirect measures of or mechanisms that could be mediators of psychological well-being. Explicit measurements of psychological well-being were not performed (Bloom & Spiegel, 1984).

Group Support and Psychological Variables

Despite the seeming frequency and availability of support groups as a psychosocial intervention, only a few studies of their effects were found. Positive effects of group support began appearing in the literature with some frequency in the early 1980s. Early researchers, sometimes in response to concerns by health care professionals,

set out to reject the belief that group support could demoralize persons by association with persons with the same disease.

Spiegel, Bloom and Yalom (1981) predicted women with metastatic breast cancer would benefit “psychologically” from the group support experience. They based their premise on sympathetic and direct confrontation with life and death issues resulted in mastery rather than demoralization in the group setting. Eighty-six women with metastatic breast cancer were randomly assigned to treatment, group support ($n=50$) and control groups ($n=36$). Group support consisted of discussions among members about their concerns, death and dying, communication with physicians, and teaching others what they had learned about life. The group, facilitated by trained leaders, met once a week for 90 minutes.

The period of measurement was for one year, although some participants continued to meet after the study concluded. Outcome measures were Health Locus of Control, Profile of Mood States (POMS), self-esteem by the Janis-Field scale, maladaptive coping response, an inventory for phobias, and a denial measure. Because of subject loss due to severe illness and death, only 52% of the participants completed all tests.

The interval between test periods was approximately 100 days. Although results fluctuated at the 100, 200 and 300 day intervals, at one year, the treatment group had significantly better mood states (exceptions were anger-hostility and depression scales, which were not significant), less maladaptive coping response, and fewer phobias (measures on health locus of control, denial, and self-esteem were not significant). Especially noteworthy was the lack of psychological deterioration in the treatment group

at a time when they experienced serious physical deterioration. The investigators surmised the group members felt a sense of belonging. Cancer diagnosis was not a separating factor, but a unifying bond.

Ferlic, Goldman, and Kennedy (1979) conducted a study to examine the effects of a structured interdisciplinary group-counseling program on 30 newly diagnosed adult patients with cancer. The program, based on a crisis intervention model, had three primary components: patient education, team presentation and supportive group therapy. Each group consisted of about eight patients who met 1.5 hours three times a week for six weeks. Patients were compared with a control group ($n=30$). All patients were in advanced stages of cancer. Differences between groups were based on adjustment to hospitalization, patient-staff communication patterns, patients' knowledge of cancer, patients' psychological adjustment to their illness, and patients' self-concept. The instruments used were an investigator-derived patient perception questionnaire (a self-concept questionnaire measuring hospital adjustment, communication, and knowledge) and the Differential Personality Questionnaire (another self-concept inventory measuring personality traits). Changes in mean scores in the treatment group indicated positive results for all measures except for personality measurement. Psychological adjustment was not an explicit measurement.

Although the group-counseling program resulted in a significant increase in self-concept ($p < .001$), the result did not hold in follow-up testing at 6 months. If crisis-intervention was the goal to address the difficult time around diagnosis, this result might be acceptable, but even if the patient population is in advanced stages of cancer with

short survival times, the lingering effects of an intervention beyond six months are desirable.

Fawzy, Cousins, Fawzy et al. (1990) evaluated the effects of a 6-week structured “psychiatric group intervention” (p.720) on psychological distress and coping (and ultimately on survival) in a group of patients diagnosed with malignant melanoma (intervention age group mean, 45.5 years, control age group mean, 37.64 years). A randomized controlled experimental design was used. Experimental and control groups consisted of 38 and 28 participants. Both groups underwent standard surgical and medical treatment.

The intervention consisted of health education (health care promotion and maintenance with a focus on cancer prevention), enhancement of problem-solving skills (targeted especially at the problems patients with cancer often encounter: uncertainty, disability) stress management (relaxation techniques), and psychological support (involvement and talks with staff; within-group support provided by study participants).

Assessment was performed before the intervention, at six weeks or immediately following the intervention, and at six months. The Profile of Mood States (POMS) and the Dealing With Illness Coping Inventory were completed for data comparison at the planned time intervals. Patients at baseline as a whole exhibited psychological distress, despite good prognosis (94% at Stage I disease).

After six weeks, the only significant difference ($p \leq .026$) in the POMS scale between the two groups was on the vigor scale (lack of vigor), with the intervention group reporting higher levels of vigor. Similar findings have been found elsewhere (Cella et al., 1987). The Dealing With Illness-Coping Inventory demonstrated that the

intervention groups used significantly more coping strategies. At six months, however, both the POMS and the Dealing With Illness-Coping Inventory demonstrated significant differences between the two groups. The intervention group demonstrated less depression, fatigue and bewilderment on the POMS scores and significantly more vigor-activity ($p \leq .001$). These differences were more pronounced at six months than at the 6-week measurement. After six months, the intervention group continued to use significantly more coping methods than the control group.

Helgeson and Cohen (1996) examined social support interventions for patients with cancer in a critical review of several articles comparing descriptive, correlational and intervention research. The emotional, informational and instrumental social support (provision of goods, money, transportation or assistance with chores) literature reviewed addressed the association of these elements to the psychological adjustment to cancer. They defined psychological adjustment as the adaptation to disease without continued elevations of psychological distress. Limitations mentioned were the lack of treatment and control groups, the lack of random assignment of patients to conditions, and in some cases, the small sample sizes. They concluded that group discussion (peer support and peer-dyad) and its relationship with cancer adjustment are inconsistent with the correlational research. According to them, studies suggested emotional support was the most important, and descriptive studies reported it is the kind of support cancer patients say they desire, and is what group discussion should foster. There is, however, a lack of evidence for the positive effects of group discussion. They suggested that educational interventions (structured information) appeared just as effective as group discussion.

They attributed their findings to these possible limitations: (1) the framework and the composition of support groups, even those led by a trained facilitator, may be inconsistent; (2) the mechanisms by which the intervention is expected to achieve its results (e.g., enhancement of self-esteem, reduction of denial or better coping styles) are not measured explicitly; and, (3) the dynamics of group interaction may create topic discussions uncomfortable for the participant, and may reduce self-esteem by the lack of control or by association with a stigmatized group. "Talking to group members who are doing well (upward comparisons) may be inspiring, but talking to group members who are not doing well (downward comparisons) may be fear arousing" (Helgeson and Cohen, 1996, p.144). Thus, participation in a group may reduce optimism about the future.

One study by Linn, Linn, and Harris (1982) is particularly important because it reflected one-on-one-counseling (in contrast to professionally-facilitated group support) with an all male population, a departure from the disproportionate representation of women in studies. Patients were assessed for the effect of psychosocial counseling on the outcomes of quality of life, functional status and survival in end stage cancer disease. Patients were randomized to experimental ($n=62$) and control groups ($n=58$). Several cancer sites were represented, but about half the study population had primary lung cancer.

One trained counselor met with each participant several times a week (hours not reported), and treatment continued until death. The counselor's focus was to develop patient trust and to use interactions to support study participants by: reducing denial, but maintaining hope, listening to patients to develop a sense of the meaning of one's life (often a life review), and to provide a basis for increased self-esteem and life satisfaction.

Patients were assessed pre-intervention, and at one, three, six, nine and 12 months thereafter.

Quality of life was defined by depression (POMS), self esteem (Sherwood's 14-item scale), life satisfaction (Cantrill's 9-item scale), alienation (Strole's 9-item scale) and locus of control (Rotter's 11-item scale). Functional status was measured using the Rapid Disability Rating Scale, a 16-item activities of daily living instrument. The measure of survival was the number of days at study entry until death and from the time of diagnosis until death. The experimental and control groups were essentially equivalent on personal, functional, and all other measurements at the start of the study.

Data were analyzed by using univariate and covariate statistics. No differences between groups was found at one month, but at three months some of the strongest differences were demonstrated for all test points in the study. For example, depression was significantly decreased for the treatment group as compared to the control group, but not thereafter. Life satisfaction and self-esteem significantly increased for the treatment group compared to the control group at three months, and at every interval thereafter. Alienation and locus of control demonstrated the most variation, and the least significant effects between the two groups. Depression vacillated with almost each measurement period. Functional status remained good for both groups.

Survival time did not vary between the two groups. When lung cancer patients were evaluated separately, no differences were found between lung and other cancer sites. Because of subject attrition, mostly due to death, trends were re-analyzed, and no changes in the pattern of results were found, although, those surviving 12 months who received treatment throughout the entire period, did better overall. The investigators

concluded that the therapy intervention did improve the quality of life for study participants, despite their terminal prognosis.

Anderson (1992) published one of the few comprehensive research reviews found for psychological interventions for cancer patients to enhance the quality of life. The interventions discussed included those with the following expected outcomes: reducing emotional distress, enhancing coping, improving adjustments, and improving survival. A positive aspect of the review was in the way the findings were organized. Based on this investigators's assessment, there was support for the correlation between the magnitude of disease/treatment and the psychological and behavioral endpoints across sites of disease. Because of the evidence for the role of disease/treatment in moderating psychosocial outcomes, the psychosocial intervention literature was organized by study population differences in cancer disease, treatment states and prognosis. Risk categories were created of low morbidity (localized disease, recovery unimpaired, emotions stabilize in about one year posttreatment), moderate morbidity (regional disease and treatment, such as Hodgkins's disease, surgical treatment with cancer- and/or radiotherapy), and high morbidity (systemic or rapidly progressing disease where survival to the next year is unlikely).

Studies included a diverse range of psychosocial interventions, with limited interventions for pain management (self-hypnosis). The interventions included coping, skills training, peer counseling (1:1 periodic telephone contact by other persons diagnosed with cancer), crisis-oriented intervention (mostly to manage response to initial diagnosis), psychotherapy, specialized home care, health education/information only, group support, and combined group support and information. Those studies categorized

under high morbidity risk most often included a focus on death and dying in the intervention, and living in the context of a terminal illness (Anderson, 1992).

Studies representing the low morbidity risk group (Edgar, Rosberger, & Nowlis, 1992; Fawzy, I., Cousins, N., Fawzy, N. et al., 1990; Gordon et al., 1980 and others as cited by Anderson, 1992; Houts, Whitney, Mortel, & Bartholomew, 1986; Capone, Good, Westie, & Jacobson, 1980) had varied outcome measurements, but included self-esteem, POMS, sexual response (with mastectomy and gynecologic cancer groups), coping skills (particularly timing of the intervention), immune function and varied measures of distress, such as anxiety and depression. Overall, only modest improvements were reported, yielding mixed results. Support for limited gains were by the consolidation of effects across time, with increased improvement for longer posttreatment assessments (three to 12 months). Anderson concluded that the data confirmed the hypothesis that low clinical morbidity is consistent with low psychosocial risk.

Outcome measurements for the moderate morbidity risk group were similar to the low morbidity risk group, but also included self-reports of satisfaction with care and the quality of life, experimenter-derived measures of distress, social adjustment, and self-efficacy scales, among others. Many study participants were still receiving some form of chemo- or radio-therapy treatment (Telch & Telch, 1986). Study participants were more representative than the low risk group on site of cancer, gender, age and socioeconomic variables that are prevalent in cancer incidence. Outcome measures reflected more improvement compared to the low risk group, but pretest scores were generally higher than in the low risk group. Anderson (1992) contended these higher scores were a result

of the higher risk profile compared to the low risk group and the greater degree of distress at study entry.

In the high morbidity risk group outcome measurements were similar to both the low and moderate morbidity groups, except in one study all measures were experimenter-derived: hospital adjustment, communication with others, disease information, death perception and self-concept. Despite the disability and the increasing discomfort of patients, many of whom were dying, positive outcomes were achieved on several measures (POMS, self-esteem, self-concept, and maladaptive coping response). Participants mostly represented adults with advanced disease along typical cancer sites, and study participants were often at least 50% male. Subject mortality required additional statistical measures (slope analysis) (Anderson, 1992; Ferlic, Goldman, & Kennedy, 1979; Linn, Linn, & Harris, 1982; Spiegel, Bloom, & Yalom, 1981).

A diversity of professionals, with different levels of training and professional credentials, were used for the interventions. Treatment sessions varied from a brief time (9 hours of therapy) to at least 75 hours, and sometimes until death. Content varied and was inconsistent from one study to another as both approaches, and the measures used for the interventions, were sometimes distinctly different. Yet, at least conceptually, there were commonalities among measures. Most instruments used related to measures of psychological status (self-esteem, self-efficacy, self-concept), reduced psychological distress (coping, locus of control, anger, depression), or represented the mechanisms by which psychological well-being may be altered (such as, body image, sexual adjustment, et al.).

Group support alone, without any other intervening or modifying variables, was not examined. For example, if support was an intervention in a group format, the structure of the study's intervention(s) included other variables such as: (a) content focus: cancer information, overcoming the fear of cancer, overcoming the fear of death, sexual adjustment and crisis-intervention; (b) other therapies: self-hypnosis for pain, relaxation training, behavior therapy (temperature, electromyography and cognitive-behavior therapy, with imagery), adaptive coping and psychotherapy; and (c) different formats: group versus individual sessions or a combination of both. Further, out of the 18 studies discussed in some detail (six equally distributed among high, moderate and low morbidity risk), none were reported that examined professionally-facilitated group support in this context: where the sessions were relatively unstructured, conducted by professionally-trained facilitators, and the dialogue was guided by and dependent upon the contribution of peers within the group.

Given the description and outcome of the studies, the following cited by Anderson (1992) is pertinent: By definition, the intent of psychological intervention research is clinical improvement in distressing psychological states.... Considering the range of assessment measures, it appears that psychological interventions for cancer patients have been expected to provide "all things (outcomes) to all people".... (p.566) It is further suggested that such a wide array and range of measures ("a wide net") may be due to some pressure in the scientific world to explain mechanisms through which outcomes may be achieved.

Anderson's (1992) review in addition to other studies may also account for the reason interventions have had mixed results. Interventions had multiple independent

variables not clearly differentiated from one another such as content, format and a combination of therapies (i.e. coping skills with relaxation therapy, one study with eight components, crisis intervention with patient education, and supportive therapy with many other combinations). These were often grouped to represent one intervention with several outcome measures. In those studies with significant results, it was unclear exactly what part of the intervention (coping skills, relaxation therapy, stress management, group support, individual psychotherapy, et al.) could be attributed to which outcome.

Psychosocial Interventions: Effects on Survival

According to Cassileth (1999), the idea that mental activity, attitude, and positive emotional patterns can alter the course of disease has been entertained by many, but is not supported by current research. But, conflicting evidence has been published earlier (Fawzy et al., 1993; Sommer, 1996; Spiegel, Bloom, Kraemer, & Gottheil, 1989). Emotional support and the socialization effects of support groups have been found to physiologically improve health status. Sommer asserted: "The significance of social isolation as a risk factor for health is now accepted to be on a par with smoking and high serum cholesterol" (p. 1237).

Fawzy et al. (1993) in a follow-up to their original study (Fawzy, Cousins, Fawzy et al., 1990), evaluated 68 patients with melanoma for recurrence and survival, who had undergone the 6-week psychiatric intervention several years earlier. They used the Cox proportion hazards regression model to quantify the relationship between treatment and outcomes, based on POMS and an investigator-derived coping inventory scales.

Psychological assessments were completed at baseline, at the completion of the intervention (six weeks) and at six months, and then these were performed again at one

year, three years and five years after the intervention. The follow-up study does not report all assessments, but reports on affective state, coping, and immune factors as the early predictors of recurrence and survival experience at the five-to six-year period. The two main outcome variables were the time from surgery to recurrence and the time from surgery to death. A useful tool, Breslow depth of lesion (the lesion measured in millimeters from top to bottom, with 1.5 millimeters considered a high-risk lesion) supported the evaluation as one prognostic and recurrence indicator. The investigators found this measurement and the intervention were significantly associated with recurrence and survival.

After adjustment for Breslow depth, higher baseline distress (POMS) scores and higher baseline coping scores (specifically active-behavioral) were related to lower recurrence and death rates. Interestingly, lower baseline distress scores were associated with recurrence and death. The investigators speculated that this might be the result of the minimization of the importance and threat of the diagnosis, which might lead to denial of the cancer threat and prevent mobilization of essential coping behaviors. Those with active-behavioral coping abilities had the best health outcomes regardless of the intervention. However, participants in the structured, 6-week psychiatric intervention had a statistically significant ($p=.03$) better survival rate than the control subjects at five to six years' follow-up (Fawzy et al., 1993).

A study by Spiegel et al. (1989) also demonstrated psychosocial effects on medical outcome in a longitudinal study of patients with metastatic breast cancer. Working from the premise that psychological and symptomatic relief could occur with psychosocial group therapy, the investigators additionally evaluated the effects of group

therapy on disease progression and mortality. The treatment was a one-year intervention consisting of weekly supportive group therapy with self-hypnosis for pain. Both groups, treatment ($n=50$) and control ($n=36$), had routine oncology care. Cox's proportional hazards model was used to examine treatment effects. This model was used to isolate the influences of treatment over the effects of prognostic variables before randomization, although all patients had metastatic disease. Using the O'Brien's logit rank procedure, each medical treatment variable was controlled in order to test the significance of the intervention.

At study entry, the two groups (70 of the 86 records available) were similar except for some difference in staging at initial diagnosis, but these initial staging differences in this study were unrelated to survival. Treatment and control groups did not diverge until about 8 months after the year intervention ended. At a ten-year follow-up, three of the patients were still alive. From the review of death records, the mean survival was 36.6 months for the intervention group from the onset of the intervention and 18.9 months for the control group, a significant 18-month difference ($p<.0001$).

In contrast to the results by Spiegel et al. (1989), Gellert, Maxwell, and Siegel, (1993) individually matched 102 non-participants with 34 participants to prognostic factors in a retrospective study of survival of breast cancer patients receiving adjunctive psychosocial support. Three women with breast cancer, who never participated in a support program, were matched to each group participant regarding race, age, histology, surgery, sequence of malignancy, and date of diagnosis, without knowledge of survival status. The purpose was to minimize the selection bias by controlling for the effects of prognostic factors. Each matched set was assessed by an algorithm method for

comparison of survival scores. In contrast to the results by Spiegel et al. (1989), when analysis tested for differences in treatment and prognostic expectations between the two groups, no significant differences were found.

The support program consisted of 90 minute weekly sessions where cancer patients received individual counseling, patient peer support, family therapy, and direction in relaxation with positive mental imagery. The program incorporated these interventions with relaxation and meditation to help patients accept their disease, and to build hope, while encouraging patients to exert control in their lives. With a ten-year follow-up applied to this intervention (this was a cohort under prior study; dates of monitoring were from date of diagnosis, 1971 through 1980 until 1991), the mean survival for the program group was 96.0 months compared to 85.1 months for the non-program group. At a confidence interval of 95%, the results were not significant ($p = .1$).

According to the investigators, several factors could have influenced the results. It is possible that the non-participants possessed a stronger social support network, and had a stronger motivation for coping than the participants. This may have produced a beneficial effect for survival, although this bias could be in either direction. Group support participants may have had greater needs for emotional support, which attracted them to the intervention, creating a self-selection bias. A lower baseline for coping and a high degree of distress at study entry could alter survival results. It may be the support intervention correlated rather than caused the improvement in survival experience reported by Spiegel et al. (1989). Yet, Spiegel et al. used a randomized design. Another plausible explanation, although not discussed, is that the content, structure, or delivery of

the support groups in studies reported may not be equivalent, contributing to inconsistent results.

Structural Considerations of Group Support Interventions

Support groups have also been studied under what were identified as structural considerations. One differentiation was made by whether these were professionally led or community-based. This is not a true differentiation because many community-based support groups are led by group-trained professionals. A comparison of support groups by their source such as community-based organizations versus their counterparts in hospitals or nationally-sponsored programs may be equally challenging. McLean (1995) noted that the features, origins and structures of programs differ in ownership, hierarchical organization and funding arrangements, rather than innately from their program characteristics, access, use of professionals or their effectiveness. Other researchers have examined differences in program content, design, techniques and format of group support that may result in different outcomes (Helgeson, Cohen, Schulz, & Yasko, J., 1999; Stevens & Duttlinger, 1998 Telch & Telch, 1986). These variables, along with the participatory dynamics of support groups, may be just as important as the intervention itself and are discussed in the next section.

Group support and participation by attendees. Stevens and Duttlinger (1998) reported that the level of support-group participation affected the perceptions of participants about group support. Established members, who attended meetings regularly rated group as more supportive. The adjustment of breast cancer patients varied with their level of participation. More established members than new members reported coping skills and sense of community as the most helpful, while new members cited medical

information and symptom discussion as the most helpful. Although non-members reported the lowest overall pain, they appeared less well-adjusted, manifesting the highest levels of anxiety, stress and perceptions of non-support. The authors suggested their findings be used to shape support groups to the varied coping styles and values assigned by participants to groups. In addition to attendance, meaningful involvement should be measured to determine participation levels with some control over content and format, guided by support group leaders.

Content of group support. Helgeson and Cohen (1996) looked at the association between social support and psychological adjustment to cancer. They summarized that the literature was not methodologically sound enough to be conclusive. Group educational sessions appeared to be just as effective as group discussion, which suggested the content of group sessions may be a determinant of efficacy.

From all the studies Helgeson and Cohen (1996) presented, there were four that differentiated the effects of peer group discussion from education-focused interventions. Three of these studies randomized patients to conditions, and demonstrated that the educational intervention assisted patients in adjustment by reducing anxiety, psychological distress, mood deterioration and promoting better coping with daily activities. The fourth study did not have positive outcomes for either group discussion or education-focused intervention. Limitations included a small non-random sample size to detect effects.

Helgeson and Cohen (1996) concluded that education-focused interventions appeared to be as effective, if not more so, than group discussion interventions. They cited studies with group discussion and group education, both with no-treatment controls,

revealed more efficacy for education-focused groups—with the only evidence for group discussion's efficacy coming from a 12-month intervention (Spiegel et al., 1989).

Contrary to these conclusions, Meyer and Mark (1995) found no significant differences between treatment categories in a meta-analysis of randomized experiments. They examined categories of psychological interventions with adult cancer patients in which information and education were distinct categories. Even in well-planned group sessions, content may be difficult to control for experimental conditions.

Telch and Telch (1986) (one of the four studies discussed by Helgeson and Cohen, 1996), randomized 41 cancer patients with a marked degree of psychosocial distress (determined by an investigator-derived structured interview) to three groups. One group received group coping skills instruction ($n=13$), a second group received supportive group therapy ($n=14$), and the third group served as the control ($n=14$). Outcome measures were the POMS, the Cancer Inventory of Problem Situations and an experimenter-derived self-efficacy scale.

The group that received coping skills demonstrated better results than either of the other two groups. On the POMS and perceived self-efficacy scales used, the coping skills group demonstrated significant improvement in POMS total and in all six subscales (lower posttest scores) and in the self-efficacy scores (higher posttest scores). Importantly, in the pretest the coping skills group had higher mean levels of distress and lower coping efficacy levels. Presumably, this was accounted for in the measurement analysis by using the pretest score as a covariate in the adjustment for the between group differences.

Through five different instructional modules, coping skills were emphasized by teaching and promoting rehearsal of cognitive, behavioral and affective strategies to group participants. Support therapy consisted of unstructured sessions led by a facilitator. The facilitator allowed participants to discuss their feelings and concerns, pointing out common themes: helplessness, sense of loss of control, while encouraging participation from all group members. Whether coping skills were excluded explicitly is unclear. A presupposition could be, that due to the interactive discussion of the sessions, coping skills may have been conveyed implicitly. Patients who received supportive group therapy exhibited little improvement, but the “untreated patients evidenced a significant deterioration in psychological adjustment” (p. 802).

Clearly, the approach between support group discussion and coping instruction is different, and according to Telch and Telch (1986), the outcome of the intervention is also different. More study is needed to understand how the dynamics of the session, and how the characteristics of the individuals that comprise a support group may influence results. These findings among the others described by Helgeson and Cohen (1996) provided the impetus for the studies presented below (Helgeson et al., 1999, 2000).

In data published by Helgeson et al. (1999), peer discussion conditions had no positive impact, and in some cases, showed negative effects. They studied a group of women ($N=312$) with Stage I and Stage II breast cancer, ages 27 to 75 years. Women were randomly assigned to a total of 28 groups, each consisting of 8 to 12 women: seven education groups, seven peer-discussion groups, seven combined groups, and seven control groups.

The education intervention aimed at providing information about breast cancer, its treatment and managing its effects on overall recovery. Peer-discussion, guided by trained facilitators, aimed at emotional support and focused on sharing feelings, so experiences could be normalized and feelings validated. The combined intervention was sequenced. It began with education and ended with peer discussion. Instruments included the Medical Outcomes Study (short form, 36 items), the Positive and Negative Affect Scale, the Impact of Event Scale and others to assess physical functioning and to assess a number of pathways the interventions may influence adjustment.

Patients in educational groups exhibited greater personal control, less vicarious control and fewer intrusive thoughts. The education intervention increased psychological and physical functioning, immediately and six months after the intervention. The increased functioning, according to the investigators, was related to enhancing self-esteem, instilling a positive body image, and reducing intrusive thoughts about the illness.

Immediately after the intervention, peer discussion groups had negative effects on vitality and physical functioning and no statistically significant positive effects. After six months, peer discussion groups had a slightly higher negative effect than groups without the intervention. Persons in the peer discussion group had greater intrusive thoughts and avoidant thoughts than those not in peer discussion groups. The peer group intervention may also have had the unintended effects of increasing anxiety or negative downward comparisons (feeling fearful when someone is worse off).

The results discussed above (Helgeson et al., 1999) became the impetus for another study by Helgeson et al. (2000), who examined how the variation in individual

differences may moderate the effects of information-based education and emotion-focused peer discussion groups on mental and physical functioning. In other words, what kinds of persons might benefit from which kind of intervention? They drew on the data of their earlier study using a population of 231 women with breast cancer (participants' ages 27 to 75 years, with Stage I, Stage II or Stage III disease), with the same random assignment for a total of 28 groups.

The data in this study was used to determine if information assessed at baseline predicted differences in those who might benefit from two interventions: education or peer discussion. There were eight scales including the Rosenberg (self-esteem), the Cancer Rehabilitation Evaluation Systems (CARES), the Medical Outcomes Study (SF-36) to measure personal resources and separate mental and physical health component scores, pre- and post intervention. The content of each group intervention has already been described in the discussion of the earlier study.

Neither education, nor income nor stage of disease was associated with individual differences or outcome variables. Baseline depression, measured by the Center for Epidemiological Studies Depression Scale, did not moderate the effects of the intervention. The investigators reported that a subgroup of women who had reported more negative interactions with their partners benefited from peer-discussion group. They also suggested that people who have effective support from their “naturally occurring network” might not benefit from a peer-discussion group. Women who were satisfied with the level of emotional support from their partner deteriorated over time in physical functioning when assigned to a peer-discussion group. Without more information and study, it would be difficult to accept peer-discussion participation as a sole explanation.

However, as the authors elaborated, it is possible that participation in peer-group discussions alters the perception of one's naturally occurring network, which may change the efficacy of peer group support in either direction.

The way each individual contributes to the interaction and composition of the group may also confound the results. For example, if only subgroups of low-support women were referred to peer discussion intervention, the qualitative aspect of the interaction might change and change the results too. Both the effectiveness of peer support group, and the identification of a subgroup that may benefit, were inconclusive.

The investigators reported that the educational group intervention met the largest portion of women's needs. Yet, the results as reported by the authors only held for the physical health component score, not the mental health component score. In this report, women who had the most difficulties (an interrelated core of problems: lack of partner support, lack of physician support and lack of personal resources) at the start of the study, were the most likely to benefit. Six months after the intervention, both the education and the peer-support groups had no significant lingering effects, with only moderating effects. Peer support benefited persons with lower negative interactions with their partner, and those persons with the lowest perceived control received the largest benefit from the education intervention.

The authors suggested that peer group discussions may have altered these women's perceptions of their network relations. Because women were in a mixed group of high versus low-support rated females, the dynamics of this difference may have contributed to results. The low-support rated women may be unable to create an atmosphere of mutual aid for high-support rated women. On the other hand, high-support

rated women in the group may inadvertently emphasize by comparison the lower support perceived by low-support rated women. In future studies, differentiation of which subgroups might benefit from group support may be helpful.

Specific commentary about the three publications discussed above (Helgeson & Cohen, 1996; Helgeson et al., 1999, 2000) is pertinent. Many of the participant groups reported in all studies were patients with breast cancer. The review summarized by Helgeson and Cohen (1996) indicated, that out of the total number of groups identified by site of cancer, 11 of the 18 study groups were women with breast and gynecological cancers. Where the cancer site was labeled “variety”, the gender of the participants cannot be determined. The fact that these studies are all biased toward a female sample population is not discussed. Although it was minimally discussed that it was difficult to create groups of a purely education focus versus peer group support, this fact is important. Dialogue in this venue often contributes to a melding of the personal, the emotional and the educational interests of the group. In sessions that have been observed, the response to specific questions about cancer disease, prognosis and physical appearance inevitably become part of the discussion.

With the exception of one study cited (Telch & Telch, 1986), there was no change in cancer adjustment in the discussion group, but deterioration of mood from pretest levels in the control group. The possibility that group discussion prevented deterioration is a significant finding.

Helgeson and Cohen’s (1996) goals were to determine the conditions of social environment and the relationship on clients’ adjustment to cancer by the association of social support (emotional, informational and instrumental) on psychological adjustment.

Psychological adjustment, according to Helgeson and Cohen, refers to “adaptation to disease *without continued elevations of psychological distress* [italics added]...” (p.136). Finally, the authors did not ever report the presence or level of other support that may be rendered by other interventions (music therapy, relaxation therapy, meditation) in which participants may have been engaged and which may have influenced all results. Other studies reflect a similar lack of reporting about extraneous variables (Hunt, Bond, & Pater, 1990).

Other approaches to group support. The effects of other structural considerations in support groups have also been reported. Samarel and Fawcett (1992) developed a pilot program for breast cancer support groups modeled after successful childbirth and diabetes education groups that use coaches during group sessions. Coaches act as caring partners to facilitate adaptation to the diagnosis and treatment of cancer. Using the Roy Adaptation Model of Nursing, a pilot program of eight weekly two-hour sessions was developed. The content addressed dealing with stress, problem-solving and effective communication. Traditionally, the coaches’ role in childbirth is to lead, guide, support, and foster confidence in the expectant mother. Although childbirth, diabetes and cancer are fundamentally different, they share similarities of symptom and emotional distress, all of which affect people’s feelings about themselves and their relationships with others.

Coaches in the pilot program were “significant others” of women diagnosed with breast cancer. The role of the coach was to attend all group support sessions, participate with the patient in stress management and communication, provide psychological support, and encourage the patient to follow the medical regimen. The investigators reviewed content and participant attendance and found the strategies used to present

stress management and communication skills were valid. Participants reported that the information and support received was very helpful. There was no control group for comparison.

Weinstein, Rothman and Sutton (1998) hypothesized that interventions are more useful when persons can be identified at various stages in their unique health-decision continuum. Stage theory applied to health protective behaviors may have relevancy to support groups. According to these authors, wellness interventions for an ill population should be aligned with a person's unique treatment, emotional stage, and decision-making stage, with some caveats. These caveats are: an awareness that each stage does not dictate the same barriers for each individual, that individuals vacillate between stages, and that one or more stages may be skipped (not every stage must be experienced for positive health behaviors to be demonstrated). These stages help pinpoint which intervention to apply at any given time.

These authors asserted that the linear model of sequenced behavior action, in order to effect health behavior change, may be substituted by matching the intervention specifically with each individual and his stage. Although this staging approach may be totally impractical for a large scale health campaign, it may have advantages in smaller populations, such as clients with cancer who seek assistance or relief in settings where there are small groups. In an earlier paper, Spiegel (1979) theorized that a crisis resulting from a medical disease may be a time when old coping strategies are more easily suspended, as both the patient and his family are looking for new ways of coping. Shaping or matching support groups to individuals who have been pre-assessed to

determine their stage in the adaptation to the cancer process instead of their disease stage may merit further investigation.

Heiney and Wells (1989) asserted organizing new support groups or revitalizing existing groups are likely to be more successful when a structured format is used, which included advance preparation for meeting announcements, reminders and media releases. Strategies described for managing the group process, such as a group contract, outlining acceptable group behavior however, may be inconsistent with the long-term experience of successful adult peer group support for persons with cancer. One of the reasons individuals may seek group support is because their naturally occurring social network has inhibited an absolute freedom to express their emotions. Although it is important to have a few simple ground rules, excessive structuring may inhibit the interaction that makes peer support work. A well-trained facilitator usually can overcome individual or group behaviors that are counterproductive to the interaction goals.

Other Modalities

There are other alternatives to support persons with cancer, which are presented here. These alternatives will not be compared with group support as defined. Worthy of mention is that a number of professionals may differentiate interventions by the way they have been proposed to aid persons with cancer. In the strictest sense, complementary approaches are designed to enhance coping and adaptation, typically to supplement conventional cancer treatment, such as relaxation, meditation, nutrition and others. Alternative treatments, either with or in lieu of conventional treatment, are aimed at affecting tumor growth (Doan, 1998). There is obvious overlap in these definitions, and how a therapy is promoted to aid the fight with cancer is likely to determine its definition.

Their use by clients with cancer is still relevant because clients seeking support may use a variety of approaches simultaneously, which may act to mediate or modify the outcome of studies.

Physical Function and Exercise

According to Dimeo, Fetscher, Lange, Mertelsmann and Keul (1997), loss of physical performance is a universal problem of cancer patients undergoing chemotherapy. In a randomized study of 33 hospitalized patients undergoing high-dose chemotherapy, they found that aerobic exercise can partially prevent loss. Smith (1996) reviewed the impact of physical exercise as a nursing intervention to enhance quality of life in oncology populations and concluded physical exercise can positively influence all dimensions of life. Longman, Braden, and Mishel (1997), in their evaluation of side-effects burden in 53 women with breast cancer, found fatigue was the most frequent and problematic side effect. They used Braden's self-help model (Braden, 1990) to demonstrate that side effects burden can interfere with self-care and the quality of life. However, in the study conducted, self-care was not significantly influenced by the side-effects burden experienced (Longman et al.).

Complementary or Alternative Therapies

Complementary or alternative therapies such as aromatherapy, meditation, and therapeutic massage have become popular as adjuncts to supportive care services aimed at improving quality of life. Not only can these therapies contribute to symptom relief in some patients, their use reinforces self-care (Cassileth, 1999). Smith, Holcombe and Stullenbarger (1994) conducted a meta-analysis of intervention effectiveness for symptom management. From 428 published and unpublished nursing reports from 1981

to 1990, 28 were selected that met their predetermined criteria for randomized experimental and control group studies.

Several studies lacked age, gender, sociocultural and disease staging information. Many of the studies demonstrated intervention effectiveness for symptoms such as nausea and vomiting, pain, anxiety, infection, and alopecia. There was variation in treatment effects across studies. Massage and music therapy demonstrated strong effects for pain relief, while relaxation with imagery therapy demonstrated the lowest and the least effects on pain (one study, $n=11$) and nausea and vomiting relief (3 studies, $n=40$ to 60). Surprisingly, group support studies were not reflected in their meta-analysis.

Cancer services may be organized around modalities of treatment and other issues such as convenience and accessibility. McIlmurray & Holdcroft (1993) described a district cancer service in the United Kingdom that developed a delivery of supportive care that would include relaxation therapy. The authors based their interest on one important part of supportive services--adequacy of emotional support. Their purpose was to help determine the likely demand for supportive care and, in particular, establish relaxation therapy as one essential mode of supportive care. They compared social activities and activities such as painting, swimming, woodwork and others with the use of and participation in relaxation therapy (massage, meditation and suggestive techniques).

Clients recorded their experience, and the authors monitored clients' participation. The authors reported relaxation therapy as the most important element of the service. Although they reported that, while 67% of clients benefited from the therapy, these were assessments based on clients' reports. The investigators had inadequate quantitative and

qualitative data to evaluate specific issues they were concerned about, such as morale, loss of control, and loneliness amongst the client group.

Yoga and other forms of relaxation such as transcendental meditation (TM) may be useful as adjuncts to therapy, but studies using these techniques exclusively for persons with cancer have not appeared in the literature. Although unrelated to group support, the only study found was published by Johnson (1987), who demonstrated profound results in the reduction of medical care utilization in an insurance population of 2000 participants. The practice of TM was reported by participants and was presumed rather than validated by the investigators. The population was considered “normed” based on actuarial experience. A self-selection bias was also pronounced.

The Significance of Psychological Well-Being as a Measurement

Psychological well-being has two primary phenomena: (a) affective well-being which consists of happiness and satisfaction (as opposed to distress, depression, and anxiety), and (b) cognitive well-being, which reflects the level and ability for thought and concentration (Patrick & Erickson, 1988). Dependent variables such as self-concept, sense of power, psychological distress, ego-strength and coping response have been used as indicators of adjustment for individuals in response to psychosocial interventions (Bloom, 1982; Bloom & Spiegel, 1984; Edgar, Rosberger, & Nowlis, 1992; Folkman & Greer, 2000; Schnoll, Harlow, Brandt, & Stolback, 1998; Worden & Sobel, 1978). These are all de facto measurements for psychological well-being. The literature described below, however, discusses how a few investigators have elaborated on the potential relationship between the status of psychological well-being and the adaptation to cancer.

Coping and Psychological Well-Being

Coping capacity has been well documented by Folkman & Greer (2000) as an influence on the outcome of a situation. Psychological well-being is supported by coping processes. Appraisal and coping are at the heart of the model Folkman and Greer (2000) explicated. Appraisal of circumstances is a result of an individual's evaluation of the personal significance of a given event—her perception. Coping refers to the thoughts and behaviors a person uses to regulate distress—her personal resources. Coping influences the outcome of a situation. The appraisal process influences subsequent coping.

Folkman and Greer (2000) outlined four important stages in their conceptual model of stress and coping: “appraisal, coping, event outcome, and emotion outcome” (p. 12). The appraisal of an event such as an initial cancer diagnosis or news of recurrent disease is most often, according to Folkman and Greer, dependent on personal characteristics such as temperament, personality and history. These characteristics are influenced by beliefs, values and commitments, which then define an event as a challenge, a harm, or a threat.

Coping is based on cognitive and emotional re-framing processes that lead to problem resolving goals. An event is re-appraised, and distress is relieved through maintenance of positive well-being (meaning-based coping). A positive emotional outcome consequently sustains the coping process. Defining an event as a challenge, such as receiving a cancer diagnosis is important because it should trigger a “fighting spirit” response. If one responds to illness with “fighting spirit”, then behaviors such as participating in one's care and mastery of the challenge is more likely (Folkman & Greer, 2000).

The authors suggested that, while personal characteristics determined by entrenched personality traits and shaped by individual history can be more refractory to an intervention, there are ways to create positive challenges. Meeting a challenge or a goal is one of the critical steps in promoting psychological well-being. An environment that allows persons to achieve their goals is a critical contribution to psychological well-being. Group support may provide an environment that facilitates the achievement of goals; if psychological well-being can influence appraisal of an event or situation, coping capacity may also be influenced.

A study by Schnoll, Harlow, Brandt and Stolback (1998) assessed two factor structures of the mental adjustment to cancer (MAC) scale. Coping style scale was assessed by reviewing the relationship between psychological distress and QOL subscales. They found coping styles were highly related to psychological distress and QOL between Stage II and Stage IV breast cancer patients ($N= 100$). However, there were no differences across disease stages for direct psychological distress and QOL scores on both subscales. Instead, coping style and its relationship to distress and QOL were highly correlated when these factors were not considered as a single construct. Age, education and marital status were not factors; although this finding contradicts earlier reports that younger age is correlated with more stress (Cassileth et al., 1984; Hunt et al., 1990).

The investigators suggested that the results may indicate that coping may mediate the relationship between disease stage and the psychological outcomes (distress and select QOL subscales). The two groups (Stage II disease vs. Stage IV) had different clinical scenarios. The use of unique coping styles by the two different groups resulted in

no significant differences of the disease stage on psychological well-being and QOL subscales. Appraisal of the disease threat by patients may explain this difference, according to the authors. Positive reappraisal was related to less distress and greater QOL on specific subscales.

The effects of appraisal on psychological status described by Schnoll et al. (1998) is similar to what was described by Folkman and Greer (2000). If an intervention such as group support promotes psychological well-being, the mechanisms for intrapsychic influences that contribute to psychological well-being such as coping or appraisal may not be explicated as causal mechanisms. Yet, an intervention may still result in a positive outcome—improvement in psychological well-being.

Ego Strength and Psychological Well-Being

Worden and Sobel (1978) studied ego strength in order to better predict its effect on psychosocial interventions. Their premise was that greater ego strength, regardless of other factors such as stage of disease, would lower vulnerability and mood disturbance. Subjects were 163 newly diagnosed cancer patients with five different tumor sites (breast, $n=40$; colon, $n=32$; lung, $n=40$; malignant melanoma, $n=30$; and Hodgkins disease, $n=21$).

Patients were assessed at five intervals over a six-month period. Instruments used were the POMS, an experimenter-derived index of vulnerability, Inventory of Current Concerns (ICC) and two scales to evaluate coping. Barron's Es scale was used to measure ego-strength. Although ego strength related significantly to lower vulnerability, less mood disturbance, fewer concerns and better problem resolution, the low correlation coefficients ($r=.03$ to $.39$) between low and high risk groups precluded any suggestion

that ego-strength predicted psychosocial adaptation to cancer. The authors concluded, “we would like to suggest that ego strength be considered a ‘process’ mediating structure” (p.590).

Edgar, Rosberger, and Nowlis (1992) found ego strength had a strong inverse relationship with the dependent variables of anxiety, depression, intrusion and personal control when it was assessed as an independent variable using MANOVAs. Patients ($N=205$) received a one-on-one coping skills-based psychosocial intervention for five one-hour sessions. Although part of the study was designed to test timing of treatment and its effects, the interrelationship between independent and dependent variables, and covariates were equally important. Anxiety and depression were highly correlated and these measures were also highly correlated with the intrusion scale measures. The ego strength scale was used to evaluate the patients’ capacity to cope, which, as reported, had an inverse relationship with the dependent measures, especially depression. Ego strength may have a definitive role in the evaluation of psychological status.

Critique of the Literature

Group support continues to be part of supportive therapy for persons with cancer. There are conflicting findings of its effectiveness to improve critical dimensions of one’s life, such as psychological well-being. Studies which have demonstrated effectiveness address mechanisms by which psychological well-being may be improved such as reducing emotional distress, enhancing coping, and improving adjustment. These studies used a number of instruments that indirectly measure psychological status (POMS, BDI, CIPS, Anxiety Scale, Karnofsky Performance Scale, several experimenter-derived scales, and many others), or the processes by which psychological status may be improved

(coping, ego-strength, social adjustment, investigator-derived measurements of self-esteem, self-efficacy, distress, among others).

There is evidence that the magnitude of the psychosocial intervention, what Anderson called “dose” (Anderson, 1992, p.563), and the content of treatment may influence results (Telch & Telch, 1986). Studies varied in the duration of the intervention with a few lasting 12 months (Spiegel & Bloom, 1983; Spiegel, 1989), and some limited to nine hours (as cited in Anderson, 1992). Content varied from information with emotional support, education only (Helgeson et al., 1999, 2000), and psychotherapy with self-hypnosis for pain (Spiegel & Bloom, 1983; Spiegel et al., 1989). Rarely, despite the magnitude of the intervention, was the mean participation time or attendance reported.

Further, age, gender, other demographic factors and stage of disease are clearly extraneous variables that should be controlled in studies to help predict the generalizability of study results to similar populations. Age was negatively correlated with distress with younger patients more at risk for their emotional response to diagnosis and treatment (Cassileth et al., 1984; Vinokur et al., 1990). No conclusions can be made about the response to psychosocial interventions between men and women because so few men are participants in studies (Linn, Linn, & Harris, 1982). Likewise, neither race nor ethnicity was routinely reported in the research reviewed. When these were, race was reported more frequently than ethnicity, with “White” or “Caucasian” a distinct and more prevalent demographic representation in studies. These obvious and significant shortcomings in the research to help us better understand demographic and socio-cultural differences, and how outcomes in studies may be affected are rarely acknowledged with the emphasis these deserve.

Some studies did not report stage of disease. Other studies did not correlate their results with stage of disease. To speculate, there is likely to be a different psychological reaction between a Stage I diagnosis and Stage IV diagnosis. There may be a rapid emotional rebound in low psychosocial morbidity (local disease that is controlled), as compared to the psychological distress of devastating illness, with recurrent profound distress with new metastasis (Anderson, 1992; Cassileth et al., 1985; Greer, Morris, & Pettingale, 1979). The content of the intervention may also need to be necessarily different. Recovery may be unimpaired with a needed focus to normalize one's life by living without cancer in Stage I; in contrast to the support needed for palliative care, and reconciling life to prepare for death in Stage IV. Stage of disease may account for differential outcomes in those studies without controls for the influence of stage.

There was inconsistent reporting of the lack of deterioration of the psychological status among treatment groups when compared with the control groups. In a very sick population, such as persons with cancer who are often experiencing debilitating disease accompanied by pain and body disfigurement, the lack of deterioration along psychosocial measures is an important outcome. This may be particularly true for those in a high morbidity risk group for psychological deterioration because of progressive disease, a poor prognosis, and short survival time. There is some evidence that low or moderate risk groups for adjustment difficulty may improve without intervention, where the no-treatment groups, considered in the high risk morbidity group, may deteriorate (Anderson, 1992; Bloom & Spiegel, 1983; Spiegel, Bloom, & Yalom, 1981).

In the studies described, self-selection may continue to be an unavoidable obstacle for "scientific validity" as Watt et al. (1998) contended, but an unavoidable one. An ill

population may have requirements that are more urgent, with an investigator's decision to forego specific customary study controls that demand strict adherence to scientific rigor. Urgency needs, ethical considerations and the reality that most interventions are dependent on willing individuals who will engage in and provide an effort for the intervention goals, create the living context within which persons make their decisions to participate. Importantly, group support participation, in conjunction with complementary therapy participation, was rarely reported in the studies reviewed, which may contribute or mediate support group effects.

Finally, it may be that a number of factors have arisen to promote diverse assessment points of group support, which confound rather than clarify the results. First, different perspectives for study add to complexity: intrapsychic characteristics of individuals (self-esteem and adjustment), behavior change (control and coping strategies), biologic responses (survival), levels of distress (mood and depression states), and social network. The potential for these to interact on one or several domains of interest, conceptually and statistically, adds to the number of confounds. Second, the measurements chosen may have been guided by a scientific paradigm that emphasizes documenting the mechanism of intervention efficacy. Third, the uniqueness of individuals coupled with the complexities of the psyche hardly supports a single intrapsychic mechanism to measure the effects of group support. Measuring psychological well-being incorporates a number of mechanisms, which may contribute to psychological status changes, avoiding the potential compromise to the outcomes of other studies by a too myopic representation of group support.

Anderson (1992) suggested that the outcome net has been cast widely “(and perhaps wildly)” (p.566). Casting a wide net in research may be unavoidable and prudent when the most likely effects on health are not known (Ware, 1981). These considerations represent opportunities to examine group support and its effects more closely. The effects of group support may be more predictable than the literature reflected. Efforts to define a path(s) or mechanism(s) for group support effects may have superseded an obvious outcome measure. From the studies already performed, inductive analyses suggested that the dependent variables measured in studies, despite their variability across studies, contribute to psychological well being. So, why not measure it directly?

Chapter 3

Methodology

This chapter outlines the design of the study. Planned data collection elements, the steps to collect data and the instruments employed are discussed. Data collection is followed by how the data analysis was done: the use of ANCOVA as the inferential test statistic, the descriptive and qualitative techniques used for observations made and the analysis of the event question. Finally, how ethical considerations were addressed are presented. However, before design elements are discussed, a brief overview of a pilot study conducted is presented.

Pilot Study

Focus groups comprised a pilot study. The results became the impetus for the focus of the current study. The results, derived by qualitative methods, helped paved the way to choosing a quantitative approach. Importantly, the results predisposed the measurement of psychological status as the dependent variable, a more direct and less ambiguous variable with which to measure the effects of group support. In the pilot study, four focus groups were conducted at a community-based setting, two participant groups of professionally-facilitated group support (group support) and two non-participant groups (comprised of individuals who did not attend in group support). Proceedings from the two participant groups were analyzed using qualitative methods to

determine individuals' perceptions of group support at this community-based organization. The two non-participant groups were queried for their perceptions about group support and their interest in participating in like-sessions in the future. Although the non-participant groups expressed almost unanimous enthusiasm for attending group support sessions, only the results of the two participant groups are relevant to report here. The results of the two participant focus groups indicated participants believe their lives are positively affected by group support. Many participants interpreted their group support experience in the context of achieving wellness, despite the cancer diagnosis, rather than in the context of illness. The themes identified centered about characteristics that were psychologically-based. From data analysis, these were labeled as normalization of the cancer experience, renewal of self-importance, and self-efficacy (Harper, 2000 [Focus group results of participants and non-participants of group support] Unpublished raw data).

Consistent with the review of the research, which demonstrated that several intrapsychic mechanisms may be responsible for the outcomes of studies, the pilot study indicated that the processes by which group support may have positive effects, vary. Therefore, studies may need to direct attention to measuring net effects, rather than to isolate each mechanism for cause and effect. Each individual may derive a different benefit through a different mechanism causing equivocal outcomes when researchers measured narrowly defined variables. As in the pilot study, research revealed psychological characteristics prevailed as a leading outcome of group support.

Design of the Current Study

The approach to measure the effects of group support was based on the literature review described in Chapter 2, the research void identified after analysis, and the added corroboration provided by the results of focus groups conducted with participants of group support. The use of the instrument, Psychological General Well Being schedule (PGWB) was chosen because it (a) is a composite index for changes in psychological status, (b) is a reliable and valid instrument for use in detecting the physical effects of illness on psychological well-being, (c) has a minimum burden on participants, an ill population; and, (d) importantly, measures one dimension that may minimize equivocal outcomes frequently reflected in the research, when multi-scaled instruments or indirect measures such as intrapsychic mechanisms are used to evaluate group support. Finally, the statistical measure, ANCOVA was chosen to control for the potential extraneous variables identified from the research, such as age, stage of disease, and predisposition (pretest) results.

Changes in psychological well-being were compared between participants and non-participants of professionally-facilitated group support for clients with a diagnosis of cancer. This was a quantitative, longitudinal pretest/posttest study. Two additional components were documented to enhance the understanding of data. Both were an attempt to link data to a context. First, if complementary therapies were accessed during the study period, the kind and frequency were documented. Second, using a qualitative approach, responses to an event question were elicited. These two steps were incorporated so that factors which may change the course of a study participant's experience during the study period, could be recorded and described.

All enrollees in the study were a naturally occurring convenience sample of persons with cancer who met criteria. After enrollment in the study, each enrollee made their personal decision to attend professionally-facilitated support groups (the participant group) or not attend group support, the comparison group (Polit & Hungler, 1997). Data was collected by an index called the Psychological General Well-Being Schedule (PGWB), completed by study participants at study entry and at closure of the study. Study participants also completed an investigator-designed demographic form. During the study, enrollees responded to short telephone interviews that verified their support group status (yes/no), monitored attendance and monitored their participation in complementary therapies. At study closure, telephone contact also prompted respondents to describe any “intervening events” that may have occurred during the study period.

Hypotheses

The assertion of this study was: if clients with cancer attended a professionally-facilitated support group, then their psychological well-being scores would be higher than those clients with cancer who did not attend. The null hypothesis was that there would be no significant differences between the two groups. Hypotheses of the study were:

1. Psychological well-being, as defined by the Psychological General Well-Being Index (PGWB), would be improved after participation in group support, as operationally defined, as compared to a group who did not participate.
2. Extraneous variables would promote different effects on the dependent variable, defined as covariates. Covariates were identified as age, predisposition and stage of disease. The following were hypothesized: (a) Older age would positively correlate with PGWB index scores; (b) Higher scores on the PGWB index at pretest would positively

correlate with the PGWB index at posttest. The degree of psychological distress at study entry, the pretest result, would correlate with the degree of distress at study exit, the posttest result; and (c) Increasing disease severity defined by stage of cancer disease would negatively correlate with PGWB scores.

3. There would be a positive relationship between participants' level of attendance at group support (dose), and their score on the PGWB index.

Other data were examined with descriptive and qualitative techniques without a predicted direction to provide information about the following:

1. Are facilitator qualifications and training consistent with TWC criteria adequate to confirm the uniformity of professional education, credentialing and training for facilitation anticipated at TWC sites?
2. Does engagement in complementary therapies reveal a potential association between the scores on the PGWB scores and participants' of group support?
3. Is there a context revealed by the description of intervening events experienced and perceived by study enrollees during the study period that may have altered PGWB scores? Intervening life events perceived as significantly negative by the study participants may alter study results in a negative direction, with the converse also being true. Events are described as negative or positive based on the perceptions of study enrollees and their interpretations of a positive or negative effect. These data then were visually compared to respective PGWB scores.

Summary of Data Collection Elements

Tables 1 and 2 list each variable or study interest and how these were analyzed and reported. First, the principal study design, the quantitative approach is discussed.

Table 1 lists the variables measured by the inferential statistic, ANCOVA. The study was designed to control for age, stage of disease, and predisposition levels (pretest) on the dependent variable, psychological general well-being.

Table 1

Summary of Data Collection for Each Variable in the ANCOVA Design.

Variable	Operational Definition	Measurement Statistic	Instrument for Measure
Age	Age in years of study participant at the time of demographic tool completion	Descriptive and Inferential, a covariate: ANCOVA	Demographic Data Tool
Predisposition	Completion of the PGWB index at the start of study and before group sessions are attended	Descriptive and Inferential, a covariate: ANCOVA	PGWB Index
Stage of Disease	The stage of cancer disease confirmed by physician, or physician representative or medical record documented as Stage I, II, III or IV.	Descriptive and Inferential, a covariate: ANCOVA	Demographic Data Tool
Psychological Well-being	The PGWB Index completed at approximately 12 weeks. The difference between pretest and posttest scores.	Descriptive and Inferential, the dependent variable, ANCOVA	PGWB Index

Table 2 lists additional study interests; some of these are described using central tendency, without an inferential statistic as part of the design. Another prediction was that the frequency of attendance (dose) would have a relationship with the dependent variable. These data were not reported with an inferential test because of inadequate data, the outcome of which would not be valuable. Attendance is a ratio variable, but due to sample size (9) and participation levels, its effect could not be validated without skewed results. Attendance was monitored, evaluated, and reported using descriptive forms. The use of complementary therapies among study participants were described. The uniformity

of facilitator qualifications were described to confirm evidence that facilitators were consistent with TWC criteria. Both were described to provide additional context for the data analysis. Demographic and other specific data components of the study population were analyzed using descriptive statistics.

A factor called an “intervening event(s)” was predicted to affect the dependent variable measurement and was captured at the end of the data collection period, analyzed using qualitative techniques. The qualitative approach, discussed under the data analysis section, reflected an extension of data collection from which the quantitative data could be interpreted. By doing so, an important element of context, by which data could be examined, was incorporated. Table 2 summarizes these data elements:

Table 2

Summary of Data Collection Elements for Descriptive Analysis

Variable	Operational Definition	Measurement	Instrument for Measurement
Attendance	The number of times group support sessions are attended, monitored by the investigator three times during the study period	Ratio; Descriptive	Monitoring Record
Level and type of participation in complementary therapies	Information submitted from each study participant in response to the question	Descriptive	Demographic Data Tool and Monitoring Record
Facilitators	Information completed by each facilitator in response to questions about their education and group support experience	Descriptive	Facilitator Questionnaire

Variable	Operational Definition	Measurement	Instrument for Measurement
Intervening event(s)	According to the participant an event(s) in the last 12 weeks that would change the way a study participant may feel	Qualitative Content analysis	Monitoring Record: Interview question
Demographic factors such as gender, education, income	Information submitted from each study participant in response to the question	Descriptive: Nominal, Ordinal, and Interval/Ratio	Demographic Data Tool

Setting

Almost all enrollees were recruited at oncology provider centers located in Southern California. After agreement to the study, enrollees were monitored for their decision to attend or not attend group support. Although the investigator did not lead, direct or otherwise participate in how group support sessions were conducted, study enrollees who elected to attend group support were asked to attend through one of several Wellness Community (TWC) sites. This study design feature was to minimize the variance that may be caused by different approaches to group support such as content, and facilitator education and training. Telephone interviews were conducted by the investigator midway and at closure of the study according to a pre-determined agreement for contact. All enrollees, who completed posttests, mailed their results in the prepaid return envelope provided.

Sample

The target population was a purposive non-probability sample of persons diagnosed with cancer, some of whom elected to participate in a professionally-facilitated

support group (participants), who were compared to those persons who did not (non-participants). Non-participants are persons who did not attend group support, but were willing to participate in the study, the comparison group. All study enrollees were 21 years of age, who had been diagnosed with a new or recurrent diagnosis of cancer within the last 18 months and had not attended group support in the last two years.

Instruments

Instruments used for this study, the Demographic Data Tool, the Psychological General Well-Being Index (Index), the Facilitator Questionnaire, and the Monitoring Record (attendance, alternative therapies, intervening event) are described below.

Demographic Data Tool

All enrollees in the study completed an investigator-derived demographic form (see Appendix B). Information elements included: (a) age, (b) gender, (c) marital status, (d) income, (e) employment: full-time, part-time, retired, (f) race/ethnicity, a fill-in response (g) education, (h) month of diagnosis and other information about diagnosis, such as site of cancer, recurrence of disease and staging of disease (i) cancer treatment regimes (chemotherapy, radiotherapy, including surgical procedures, if any), (j) living arrangements (living alone, with relatives, or with significant other(s), (k) engagement in any non medical or “other” therapies, such as massage, yoga, music and relaxation; and (l) engagement in support groups for any other reason. These information elements were collected because of their importance in profiling this study population for comparison with others now and in the future.

Participation in other activities considered as complementary modalities, such as massage, yoga, music and relaxation therapy could mediate or modify score results.

Because the sample population was an ill population, ethical considerations prevailed, an exclusion to complementary activities was not appropriate, particularly when exploratory data were not evident in the research to guide study. Controls for the participation of informal and formal activities, the range of diverse activities and the lack of evidence about how and if each activity may affect the study precluded providing the rationale for an exclusion for a sick population. However, these data were important to document as exogenous variables in order to relate data to results and direct investigations in the future. Therefore, it was important to establish these data as part of the study's population history.

Psychological General Well-being Index

The Psychological General Well-Being (PGWB) index, developed by Dr. Harold Dupuy, provided a quantitative measure of general psychological well-being that may be affected by physical health. The Index was part of the National Health Examination Survey conducted by the National Center for Health Statistics with a probability sample ($N=6913$) of adults (3,171 men and 3,742 women) aged 25 to 74 years (Elinson & Mattson, 1984). It has been tested and retested by several investigators (Dupuy, 1978; Fazio, 1977; Ware et al., 1979). It has since been tested as one part of many multi-scaled instruments, with populations from ages 14 to 90 years.

The PGWB was originally constructed as the General Well-Being Scale (GWB) and then renamed. Fifteen of the 22-item GWB was retained for use in the Rand Mental Health Inventory and a ten-item version was also developed called the Psychological Mental Health Index (McDowell & Newell, 1996; Veit & Ware, 1983). It is a general measure of intrapsychic well-being and is not condition-or disease-specific. Validity

studies have been limited to negative life events, events likely to diminish psychological well-being. However, the Index measures the degree of positive as well as negative well-being, or what is called positive affective and negative affective states (Dupuy, 1978; Elison & Mattson, 1984; Ware, 1979). Generally, it has been used to compare groups to determine the effects of an intervention on one's sense of subjective well-being. It has been used to compare differences between patients treated in the emergency room and those treated by appointment, between rural and urban dwellers, and for different sociodemographic groups (Elison & Mattson, 1984).

The PGWB has been applied in pretest and posttest designs to test the effects of mental health treatment, vitamin supplementation, a mother's reaction to sudden infant death syndrome and many other conditions (Dupuy, 1984). Evidence of PGWB's application to a specific cancer population was not found, but it has been used as a proxy with and for well-being and health-related quality of life measurements in a number of studies in the U.S. and in Europe (Croog et al., 1986; Naughton et al., 1996; O'Rourke, 1985; Testa, 1987).

Test characteristics. The PGWB index covers six intrapersonal subscales: freedom from bodily distress or concern (General Health), intrinsic life satisfaction (Positive Well-Being), sense of vitality (Vitality), cheerfulness versus distress (Depressed Mood), relaxation and freedom from tension or anxiety (Anxiety), and self-control (emotional, behavioral, and mental) (Dupuy, 1978; Dupuy, 1984; Elison & Mattson, 1984). The Index consists of 22 items and can be self-administered or completed by interview. Each item can be scored from 0 to 5 or from 1 to 6. Lower values indicate negative responses. The Index can be scored by each dimension's subscale and a total

score can be calculated (0 to 110 or 22 to 132). A few researchers have used the 1 to 6 rating scale; however, the original instrument design was and in most studies continues to be 0 to 5. In this study a 0 to 5 scale was used. The mean value of the total score in a non-patient population is 105 according to Naughton et al., (1996). Dr. Dupuy (2001) reported that a mean of 105 would be based on a 1 to 6 scoring, and a mean score of 80.4 would be based on a 0 to 5 scale with a 0 to 110 range (H. Dupuy, personal communication, October, 11, 2001).

Cutoff points for the PGWB have been proposed and have been applied in studies representing three levels: scores of 0 to 60 to reflect “severe distress”, 61 to 72 “moderate distress and 73 to 110 to represent “positive well being” (Dupuy, 1978; McDowell & Newell, 1996; O’Rourke, 1985) The time to complete the measure varies from 8 to 15 minutes, a short and desirable time frame for an ill population (Elison & Mattson, 1984). Despite the use of subscales in data analysis by some researchers, this study used total scores, a composite of all subscores to evaluate the results. However, subscales were analyzed by review of correlative data applied using this study’s population as a comparison with the results of larger and different populations. Total scores were used in the development and testing of the instrument.

Reliability and validity. PGWB was used as part of the General Well-Being Schedule (GWB), and the PGWB has also been correlated with several standardized mental health indices including the Beck Depression Inventory (BDI, $r = -.68$), the Zung Depression Inventory (ZUNG, $r = -.75$), the Minnesota Multiphasic Personality Inventory (MMPI, $r = -.55$), the Personal Feelings Inventory-depression ($r = -.78$) and the Centers for Epidemiologic Studies Depression scales (CES-D, $r = -.72$), and the Affectometer, a

scale of general happiness, or sense of well-being ($r = .74$) (Dupuy, 1984; Naughton, et al., 1996).

Most of the data collected to initially test reliability and validity of the Index came from four samples: the National Health and Nutrition Examination Survey (HANES) sample ($N=6,913$) the Rand Health Insurance Study ($N=1,209$), mental health clients at intake ($N=529$), and a group of university students ($N=195$). Additionally, there were community samples: two without known mental health clients ($N=341$) and two community samples of mental health clients ($N=529$), each grouping from the same catchment area (Dupuy, 1978; Fazio, 1977; Ware, 1979).

Correlations were obtained from the General Well Being (GWB) schedule, ($r = .64$) and several mental health scales as described previously. As a well-being scale, it negatively correlates with the depression scales documented. Discriminant validity coefficients ($r_{phi} = .565$ to $.667$) indicate the Index differentiates between mental health clients and community residents (Index means between the two groups are statistically significant ($p = .01$)) (Dupuy, 1984).

The PGWB has a high internal consistency with alpha coefficients of at least .90 when all four samples described above were tested. Subscale coefficients are .88 (Anxiety), .84 (Depressed Mood), .83 (Positive Well-Being), .72 (Self-Control), .73 (General Health), and .81 (Vitality). (Dupuy, 1977, 1984).

To evaluate test-retest stability subsets of the four samples described, a combined sample was used ($N=323$), with retest periods at 1 to 2 weeks and 2 to 4 months. Mental health clients were tested at 1 week and again up to 6 months. Test-retest reliability coefficients have a median value of .66, with the coefficients ranging from .502 to .861,

with the lower coefficients at six months. Unless coefficients are very high such as .85 and above, test-retest stability can be difficult to interpret. These data suggest the tool is sensitive to even small changes of intrapsychic well-being that an intervention may induce (Dupuy, 1984). (see Appendixes C and D for the PGWB Index and the permission for its use).

Facilitator Questionnaire

The Facilitator Questionnaire was an investigator-designed form to capture elements about the qualifications of the persons leading group support sessions for which study participants attended. The role of facilitators was to establish a basis by which their qualifications could be verified to confirm the control for the diverse range of credentials and qualifications of group support leaders observed in other studies. TWC sites all require post graduate education with credentials or licenses to conduct therapeutic sessions in addition to other specialized training. The criteria and rubrics by which leaders facilitate support groups are provided by TWC in order to maintain structural integrity and consistency within TWC's guiding framework. The investigator's intent was to collect data that would reflect the evidence of the uniformity of the standard of education, training and credentials. It was first presented to a group of facilitators for validation. After one question was re-worded for clarity, it was finalized for the study. Questions included facilitator formal education, credentials, certificates or licenses held and any special training or certifications obtained from the TWC or other sources to prepare for facilitation of group support (see Appendix E).

Monitoring Record

The Monitoring Record had a two-fold purpose, although its use was solely for the investigator use to record. One purpose was to document pertinent information about the covariates for the ANCOVA design. Another purpose was to document the data queries by the investigator to participants in order to collect the information about attendance and use of complementary therapy midway through the study and at study completion (about 12 week after treatment). Finally, the record was also used at the end of the study to document the response by all study enrollees about a life event (“intervening event”) that may have occurred in the last three months, a potential effect on the outcome of group support (see Appendix F).

Population Sample

Recruitment

Once the study was approved by the investigator’s dissertation committee and the University of San Diego’s Committee for the Protection of Human Subjects, the first wave of recruitment began (see Appendix G). The first efforts were through TWC and the American Cancer Society (ACS), after permission to recruit enrollees was received. Posters, brochures and mail-out flyers were approved by both organizations. Enlarged posters announced the study along with a trifold brochure. Announcements and brief study explanations were on display at these sites. Thereafter, other TWC sites and other health care sites were pursued for their permission to recruit study enrollees. There were multiple efforts to seek other recruitment sites and opportunities (see Appendixes H, I, J, and K). Although the TWC and the American Cancer Society were the expected sites for most recruitment, these sites were not primary sources. The primary sources for

participants and non-participants were physician oncology offices and clinics. The following describes the recruitment effort. Table 3 summarizes total enrollment by site.

Recruitment efforts and enrollment accrual was from February through August, 2002. There were a total of four TWC sites that permitted recruitment for the study, one in San Diego and three in Los Angeles. There were two ACS chapters that agreed to support, but not sponsor the study, one in Los Angeles and one in San Diego. Altogether, sites comprised 250 geographic miles, which spanned an area 60 miles north of Los Angeles, 120 miles south and 60 miles northeast of Los Angeles, in addition to selected sites in San Diego County. The ASC agreed to mail the study brochure out, if and when, telephone inquiries were received from the public at large. A pre-printed disclaimer also accompanied the brochure, which advised recipients that the ACS was not a sponsor of the study. Ten enrollees were recruited through TWC and only when the researcher had direct access to potential enrollees; no known enrollees were recruited through the ACS.

Five major hospitals, three in Los Angeles and two in San Diego permitted recruitment for the study at their sites; three study participants enrolled in the study from these sites. Brief presentations about the study were delivered to scheduled Oncology Nurse Meetings. At one point, an independent breast cancer facilitator supported the study and 100 study information brochures were sent to prospective interested parties. No known enrollees were recruited by these efforts.

The majority of study participants ($n=46$) were enrolled through oncology offices at five sites localized in San Diego. After permission to recruit from each site was granted, scheduled times each week were spent speaking with persons in oncology offices about the study; these were balanced between mornings and afternoons. About 45

minutes was spent with each person discussing the study, many of whom agreed to the study immediately. From oncology provider sites, three persons who initially agreed to the study, changed their minds and did not complete enrollment material. Interestingly, recruitment through these efforts most often enrolled persons who were willing to participate in the study, but not attend group support. This experience created a disproportionate number of study participants in the comparison group.

Despite minimal enrollment for the study from TWC sites, 23 TWC-affiliated facilitators completed informed consents and questionnaires. Facilitators were not a population sample in the study, but data were collected as confirming evidence of the uniformity of qualifications, as these related to and were consistent with TWC criteria. Uniformity of qualifications among facilitators was a control in the study. These qualifications were analyzed and are presented in Chapter 4.

Table 3

Enrollees from Recruitment Sites

Recruitment Sites	No. of Enrollees
TWC, Pasadena	2
TWC, San Diego	9
TWC, Thousand Oaks	0
TWC, South Bay	0
Los Angeles-based hospital	1
Los Angeles-based hospital	2
San Diego-based hospital	0
San Diego-based hospital	0

Recruitment Sites	No. of Enrollees
ACS, Los Angeles and San Diego Chapters	0
San Diego-based Oncology Center	21
San Diego based Oncology Provider	21
San Diego based Oncology Provider	1
San Diego-based Oncology Provider	2
Total	59

Sampling

The criteria for sample inclusion were adults age 21 and older, who had a new or recurrent diagnosis of cancer within the last 18 months, and who had never attended or who had not attended professionally-facilitated support groups for persons with cancer within the last two years. All enrollees met criteria.

All study participants were given detailed information about the study by the investigator through group or one-on-one meetings, or in a few cases, extended telephone conversations. Study candidates were screened for study criteria compliance and their initial agreement to:

1. Complete the demographic data tool.
2. Complete the PGWB index on two occasions.
3. Respond to contact by the investigator at the beginning of the study, midway through the study (at six weeks) and at the conclusion of the study so the investigator may monitor attendance and obtain the outlined data elements.

4. In the case of group support attendees, attend group support sessions on a regular basis (nine or 75% of 12 sessions).

Sample Size

Using an ANCOVA design with an alpha of .05, the number of study participants required was 45 per group for a medium size effect of .30 SD and a power of .80. This was determined by a statistical power analysis in consultation with a statistician.

However, after six months of aggressive recruitment efforts and after the threshold for the comparison group were met, the number of study participants required for the entire study was re-evaluated.

The accrual of enrollees was based on multiple recruitment efforts at different sites at various points along the entire timeline of the study. Therefore, the outcome of the total recruitment effort could not be adequately assessed for some time after the study began. Importantly, some organizations committed to support the study, changed their structure and modified the circumstances under which their clients could be approached for the study on two different occasions, a significant contribution to disproportionate study group enrollment. When the sum of the recruitment effort leading to unequal sample sizes could be adequately assessed, it was not until early enrollees had in some cases completed all phases of the study.

The dynamic environment within which recruitment results emerge, coupled with recruitment within non-sponsoring agencies creates a challenging environment for research conditions. Two other factors weighed in substantially to recruitment outcome, yet continuation with the study's design. The bias by which individuals decided not to attend group support created an unanticipated disparity, which was not revealed until

some considerable time after the study was started. Although recruitment sites could influence the bias by which enrollees made their decision to participate in the study, oncology centers are obvious and reasonable sites from which to enroll persons with cancer. Nothing in the literature reviewed enlightened the researcher for this distinct, if not probable outcome. To continue recruitment to achieve group support participants would exacerbate the disproportionate sample sizes between the two groups.

Finally, and most importantly, there were other study related decisions for judicious consideration. After review of the study's intent, data could be revealing regardless of the compromise to inferential statistical testing. Additionally, a prevailing interest for the continuation of the study was also the ethical relationship with enrollees, which begins with the informed consent that outlines the obligations of parties, and an implicit commitment to diligently carry out the study. This commitment embodies the respectful attention for the time and resources expended by enrollees. Since the study's data was useful, the design was not abandoned.

Ethical Considerations

Recruitment began after the Committee on Protection of Human Subjects granted approval for the research proposal. Participants were treated as autonomous agents, individuals capable of deliberation, who could act on those deliberations on their own behalf. There were no individuals identified with diminished autonomy or diminished capacity to provide informed consent. Participation was absolutely voluntary. Participants made their own decisions to attend group support or participate in the comparison group for the study. The investigator did not guide enrollee decisions.

Potential Risks

The risk of harm was assessed to be minimal. Study participants were informed of the following possible risks: (a) completion of the forms and the PGWB index could be tiring, (b) completion of forms could cause distress; and (c) due to self-disclosure of information, participants may share information with the investigator they had not anticipated disclosing, causing anxiety. To minimize these risks, the investigator coded every instrument and sanitized each record. The record was identified through a code file. The code file and any records produced that identified study participants were maintained in a locked cabinet, accessible only by the investigator. Study participants completed instruments at their leisure and were given a return, prepaid postage envelope to mail in their forms, if they preferred to do so. The researcher reassured participants at each appropriate opportunity that ethical considerations were upheld. The investigator was available to study participants throughout the study. A few study participants contacted the investigator to respond to simple questions.

Potential Benefits

There were no obvious direct benefits for study participants and each enrollee was informed of the lack of benefit. However, there may be a benefit in the satisfaction enrollees may feel by contributing to a study that may advance the knowledge about persons and how they cope with cancer.

Information To Study Participants

Information to enrollees of the study. Enrollees were briefed and provided enough information in writing for their informed consent (see Appendix L). First, each study enrollee was offered a brochure that outlined criteria for enrollee selection, the purpose

for the study and the procedures anticipated (see Appendix M). Second, each enrollee was instructed about their role in the study: (a) the completion of a demographic information sheet with basic clinical information requested, (b) the completion of the Index at the start of the study, and contact by the investigator midway through either the group support sessions or midway from the point of entry into the study (at six weeks); and (c) after the study session period (approximately 12 weeks) for the collection of the other data elements (attendance, participation in other therapies, the “intervening event(s)” question) and another Index completion. They were told the anticipated time for Index completion was 8 to 15 minutes for each completion.

Participants were informed of the risks and benefits of the study. They were also told neither their participation nor a decision to decline changed the provision of, or their options for, any other therapy. The use of the same index pretest and posttest was not explicit. General information about the Index was conveyed, such as the number of items and the content of questions.

The information was provided in person or by telephone, but a written consent was required and received from each study enrollee. The consent also outlined how to contact the investigator or a designee in order to ask or receive clarification about other information. Unless the potential enrollee declined, each was provided a cover letter (see Appendix N) that briefly restated verbal instructions (most contacts were in person). Each enrollee was also given an informed consent form, a demographic data form, the PGWB index, a study brochure, and a prepaid return envelope, addressed to the investigator.

Each enrollee was told he or she may, for any reason, and without further disclosure, withdraw from the study at any time without any negative implications to the

provision of their health care. This fact was emphasized to all participants. No monetary or other inducements were offered to participate in the study. Enrollees were also informed that they may have access to the results of the study by contacting the investigator, after the study's completion and with review and approval by the investigator's Dissertation Committee. The instructions about doing so were provided.

Information to facilitators. Facilitators in the study provided information for the professionally-facilitated characteristic of group support through the affirmation of their qualifications and training, discussed on page 83. Because facilitators were asked to complete a questionnaire, the guidelines of USD's Committee on the Protection of Human Subjects necessitated that such a level of participation be preceded by a signed informed consent' (see Appendix O). The investigator was available to each of them for questions and in some cases was present at staff meetings to introduce and discuss the study.

Data Collection and Analysis

Data Collection

At study entry and before attendance at any group session, both the support and comparison groups completed an informed consent, the demographic data tool, and the psychological general well-being index. Informed consents and questionnaires were also completed by TWC facilitators and returned to the investigator.

Once enrollees returned informed consents, the demographic data tool and completed the first PGWB index, all enrollees were asked to make a determination about their initial intent to attend group support or not. For those who had the intention of attending TWC professionally-facilitated support group, they were queried about their

intention to commit to 12 weeks of sequential, once-a-week sessions, lasting between 1.5 to 2.0 hours each. Data collection occurred for all study enrollees at three points: before attendance at support sessions or study entry, at midway through the support sessions or study entry time, and then again at the completion of the final data collection period, about 12 weeks after study entry time.

Information was documented on the monitoring record form at the beginning of the study, midway through the study and immediately following the completion of 12 weeks of group support sessions or 12 weeks from study entry. After approximately 12 weeks from study entry or when 12 group sessions would have convened, each enrollee was asked to complete the PGWB index. In all cases, study enrollees were mailed the PGWB index with a cover letter providing instructions and explaining closure of the study and their participation (see Appendix P). In each case, a self-addressed prepaid postage envelope was included for its return to the investigator. Both groups at the close of the study were also queried by telephone about any intervening life events that they or someone close to them may have experienced during the last three months. An intervening event was explained as one perceived by a study participant to have altered their life or perspective in some important way.

Data Analysis

The assertion of this study was that participants in professionally-facilitated support groups would have better psychological well-being scores than those who did not participate. The null hypothesis was that there would be no significant score changes from pretest to posttest between the two groups at a .05 significance level. A medium size effect of .30 SD and a power of .80 were used as the statistical parameters (Lipsey, 1990).

Descriptive statistics. Frequency, percentages, ranges and means were used to describe the sample population as reported on the participants' demographic data form. Importantly, age and stage of disease, two covariates, are described by central tendency measurements. Information provided by facilitators in the questionnaire also was described to report the degree of qualification and training uniformity among facilitators, consistent with TWC criteria. Data from the monitoring record about group support attendance and use of complementary therapy, and in some instances, case comparison, were reported using descriptive approaches. An association between data elements, such as scores on the PGWB index and descriptive data and complementary therapies, were briefly explained, particularly if analyses did not support an inferential statistical capacity to explain data or data was too limited to reveal useful and pertinent information.

PGWB Index. An initial analysis was performed to determine the central tendency distribution of the DV (Psychological General Well-Being [PGWB]) among the study enrollees completing the posttest. Secondly, the subscales of the PGWB were examined for internal consistency and reliability for the sample population. In a supplemental analysis, an ANCOVA design was applied to subscale data followed by testing a general linear model, adjusted for age and stage of disease. The relationship between the covariates and PGWB are discussed below, under the ANCOVA design.

Inferential statistic: ANCOVA design. An ANCOVA design was employed to test the effect of predisposition (pretest), stage of disease and age on PGWB scores. The first scores on the PGWB index at study entry and posttest scores for analysis were compared. A test for a between-groups design was conducted at a significance level of .05. Other parameters determined apriori (in consultation with a statistician) were a medium size

effect at .30 with a power of .80 (Lipsey, 1990). The covariates for analysis were: age, stage of disease and predisposition (pretest results).

Because the effective use of ANCOVA is dependent upon important relationships between data elements, a number of pre-determinations were made to test these assumptions for the prudent use of ANCOVA as the inferential test statistic. Tests consistent with established criteria were performed to test the equivalency of the two study groups. Homogeneity of variance tests were performed to determine if the two samples being compared could be assumed to belong to the same population, or if they had equal variances. Criteria has been established to what may be accepted as “homogeneous enough” (Black, 1999, p.419). One assumption in ANCOVA is that there is homogeneity of regression, the covariate should have the same relationship with the DV across groups that are being compared. The term “hyperplanes” in Chapter 4 denotes the use of three covariates for the testing of the violation (Stevens, 2002).

A second ANCOVA assumption is that the relationship between the dependent variable and each covariate is linear, and a linear relationship exists between all pairs of covariates (Polit, 1996). Scatterplots provided graphic representation of the relationship of the PGWB with each covariate to display the degree of linearity. A scatterplot that demonstrated the collective relationship between covariates and the PGWB could not be displayed for technical reasons. Pearson’s correlations were then performed to determine the covariate’s relationship with each other and with the dependent variable.

In particular, the use of the pretest results as one covariate may confer more power to the study by reducing error factor, because a randomized approach for study group comparison was not used. The use of covariates was intended to maximize the

equivalence of the support and comparison groups. Limiting the number of covariates, especially with smaller sample sizes is advisable. Too many covariates increase the chance of intercorrelation and may be redundant in reducing error, causing lower power (Stevens, 2002).

Although the study had three covariates relevant to the study, the covariates were chosen sparingly and carefully for the statistical reasons discussed. If strong evidence of intercorrelation between the covariates was evident, the investigator could exercise the option of omitting the non-linear covariates from the analysis to observe the results using an ANOVA for the data assessment. After the ANCOVA was performed and results assessed, data were also assessed using ANOVA. Because the covariate data elements were collected for the study, either ANOVA or ANCOVA as the statistical procedure for analysis can be performed (Black, 1999; Polit, 1996).

Stage of disease. Stage of disease was the stage documented in enrollees' medical record, or the stage provided by the enrollees' attending physician, usually an oncologist. Exceptions are reported in Chapter 4. The guiding principles for translating the exceptions (six cases) for the study purposes are presented below and are predicated on the narrative documentation in the medical record or re-affirmation by the attending oncologist.

In order to stage cancers for severity and treatment, different classifications and grouping systems have been developed for different primary sites, often based on cancer typology related to molecular and clinical characteristics. The American Joint Committee for Cancer (AJCC) and International Union Against Cancer (UICC staging system (TNM) has been used for most cancers. Stages 0 to IV with sub-classifications of IIA, IIB

and IIIA and III B are groupings for most cancer sites (Fang & Forastiere, 2001).

Lymphomas, Myelomas and Non-Hodgkin's Lymphomas are most often classified using the AJCC in conjunction with Ann Arbor, Cotswolds, the Revised European-American classification of Lymphoid (REAL) and the World Health Organization (WHO) systems. Accordingly, staging is expressed from I through IV with each stage divided into A and B categories. These cancers may also be grouped by some oncologists into histologic entities classified by clinical behavior into indolent, aggressive and highly aggressive lymphomas (Guitierrez & Wilson, 2001).

The Durie-Salmon clinical staging system is used for multiple myelomas (Sauntharajah & Liu, 2001). Although this clinical staging system may not be a good guide for prognosis, it is often used for protocol purposes. Staging is from I through III with subclassifications of A and B for each. There is a separate classification for Human Immunodeficiency Virus-associated Lymphomas using the REAL and the WHO (Saif & Little, 2001). No study participant had an Acquired Immunodeficiency Syndrome-related cancer diagnosis.

Qualitative data: intervening event question. The operations of qualitative methods were used to analyze responses of study enrollees during the final telephone contact. The content of responses was in response to one specific question about whether an event had occurred during the study period to affect their perception about their lives during the study period. The question had a pre-determined focus to hear from enrollees their spontaneous responses in order to document and analyze a potential relationship between their responses and PGWB scores for analysis. Implicit in the lives of study participants were the personal happenings during the study period, called events for this

study. These events may prompt or change the affective domain from which study participants completed the PGWB index at posttest. The record of inquiry and the analysis would render what was implicit, in this and many other studies, explicit for the study purposes. The inquiry was to add a dimension to the data for interpretive purposes by reporting this contextual element.

Instead of a methodology for the basis of content description, methods or operations of qualitative research were employed to provide an accurate representation of the data. At the same time each response was analyzed to determine if categories could be identified based on the limited scope of the data. The event question required a narrative response. In the case of this study, respondents conveyed their answers by short interviews over the telephone. These were short answers, documented by the investigator. Although the analysis of these cannot be tied to a qualitative research paradigm, the approach used many of the techniques embedded in qualitative research.

In order to provide an interpretation of the data with rigor, multiple methods, common to qualitative analysis were used. Data derived were analyzed by isolating comments, reviewing for recurrence and consistency, and finding particulars that seem to go together. By noting the frequency of similar thoughts, and the importance given by respondents during the interview, the investigator clustered particulars into categories. Clustering involves subsuming particulars into general ideas (Miles & Huberman, 1994). The general were then defined into three categories, described in abstract terms as investigator-based interpretation.

Analyses of the responses were to achieve a perspective about enrollees' sense of events, during a brief and one time contact, and how those who reported events,

interpreted them. The research question was meant to capture what may have happened during the study period that made a difference in the minds of enrollees, as a variable on results. After data was recorded, it was analyzed and compared with the PGWB posttest scores, for those enrollees who responded to the question and provided data that could be synthesized.

Supplemental analysis. In some instances, additional quantitative results, PGWB scores and PGWB subscale results, central tendency descriptions and inferential data were presented as addenda or supplements to the findings, because meaningful information was derived from these analyses. These data were not part of the initial projected plan for data analysis.

Limitations

Enrollees chose to participate in group support or chose not to attend. Although randomization provides a stronger statistical study design, due to the severity of illness of study participants, the investigator found it unnecessary to insist on randomization, a requirement that might compromise study participants by discouraging access to a service such as group support. A psychological well-being index was used to evaluate the effectiveness of group support. Limitations were: (a) therapies were employed by participants during the study, potentially affecting physical and/or psychological well-being (such as relaxation, music, yoga and meditation), which may mediate the outcome. Access to these services were described, but were not controlled. Although many factors may influence the dependent variable, psychological well-being, only stage of disease, age and pretest scores were measured and analyzed as covariates. Too many covariates increase the chance of intercorrelation and may be redundant in reducing error, causing

lower power. Further, these variables were selected after the research review substantiated their possible influences over others that were not adequately substantiated in the research reviewed (Stevens, 2002). Finally and importantly, the low number of study participants who attended group support severely compromised statistical analyses. But, this fact was significant in and of itself.

Gender was not a covariate because the literature was sparse, inconclusive and vague regarding its interrelationship with group support. Therefore, adding gender as a covariate would have actually contributed to statistical error (Stevens, 2002). There may be an interrelationship between the chosen covariates and psychosocial morbidity, but these variables were evaluated on the basis of their relationship to the psychological well-being measurement, not to determine psychological risk or vulnerability. Individuals were staged by clinical disease, but were not staged by the degree of psychosocial risk. For instance, if other factors not in the study design conferred a different degree of risk for psychological morbidity, these degrees of risk were not analyzed for their potential influences on the outcome. The control for psychological predisposition was the pretest.

Chapter 4

Results and Discussion of Findings

The research findings are presented in this chapter. First, a description of the study population is presented followed by analyses and discussion of the results as these relate to the research questions and the framework of the study. Responses to the intervening event(s) question reflect a qualitative value to the study to capture and better understand one's unique and individual context from which the PGWB was completed by and measured for each study participant. A supplemental interpretation of data is also included to describe observations that may contribute to the study's value. Finally, information is presented, which although anecdotal, may add to the nature and perception of group support based on what was voluntarily shared by the study participants.

Description and Discussion of Sample Population

The demographic and illness related information were analyzed by simple frequencies and percentages through measures of central tendency and variability. For other information, such as facilitator qualifications, complementary therapies and the "intervening event" question, descriptive presentation along with qualitative techniques was used to analyze the data. Because facilitator qualifications function as a control for the study, these results are discussed first.

Facilitator Qualifications

Since facilitator qualifications may affect the kind of group support within which attendees participate, facilitators were asked to complete a questionnaire that described their preparation to lead group support sessions. All facilitators completing questionnaires had graduate degrees that supported therapeutic relationships with clients. All had California state licenses or certifications that enabled them to perform therapeutic functions as independent practitioners. Each facilitator had attended The Wellness Community's (TWC) three-month orientation or had participated in an internship program at TWC. In addition, at least 19 of the 23 had additional specialized training. Respondents documented these training programs as: "Grief and Recovery", "Clinically Guided Imagery", "Brain Tumor (specific training)", "Death and Dying", "Adolescent Bereavement", "Attitudinal Healing" and "Group Therapy".

Table 4 summarizes facilitator responses. Listed across the table are their formal education, licenses or credentials and years of experience. Results were consistent with the TWC's requirement that every facilitator have at least graduate education in a related field that prepared them for supportive counseling. Seventeen of the 23 facilitators had over six years of experience, 9 of who had more than 10 years of experience. These data reflected facilitator qualifications were consistent with TWC criteria. Inferential statistics were not performed.

Table 4

Facilitator Qualifications, N=23

Education		Credentials/Licenses		Experience in years	
Degree	<i>n</i>	Type	<i>n</i>	Time	<i>n</i>
Masters/Counseling	14	MFT	15	<one year	0
MSW/Social Work	3	LCSW	3	2-5 years	6
MSN/Nursing	1	RN	1	6-7 years	5
PsyD/Psychology	*5	Clinical Psych Lic	4	8-10 years	3
*MD (also had PsyD)				>10 years	9
Totals	23		23		23

General Demographics

Fifty-nine persons agreed to enroll in the study with 52 (88.14%) persons ultimately completing all portions of the study. Two enrollees died during the study period, one of whom however completed the final scheduled telephone interview, which included the intervening event question, and his response is included in that data.

Another enrollee, who had intended to join group support, still had not done so eight weeks after study entry and had not met the TWC orientation requirement. With mutual agreement, this enrollee withdrew from the study. Another enrollee was hospitalized near study closure and was not feeling well enough to complete the final queries and therefore her information is not included in the demographic information or the study's data analysis. In summary, 52 (88.14%) enrollees completed all portions of the study. Fifty-six enrollees (94.92%) completed all but one portion, the posttest questionnaire,

and therefore all of these individuals are included in the demographic data and qualitative analyses, but only 52 (88.14%) are included in the ANCOVA analyses.

Table 5 displays gender, income, education, race/ethnicity marital status, living arrangements and employment information derived from the demographic data form. Tables 6 and 8 summarize study covariates, age and stage of disease. Table 7 lists the cancer by primary site. In general, the general demographic and cancer specific data did not point to a unique population. The profile of study members supports the likelihood that questions posed to study participants were understood and that there were no barriers due to language, culture, or reading proficiency.

Gender. Seventy percent of participants ($n=39$) were female and 30% were male ($n=17$). These data are more likely due to the predominance of females encountered in oncology sites where recruitment was the most successful, rather than a reflection of a gender bias to enroll in the study. Although, site of disease, discussed in Table 7, was likely affected by gender bias, it is not unusual to observe this bias in studies that research psychosocial domains (Kornblith, 1998).

Income. Income ranged from 0 to over 100,000, with peaks at the 35,001 to 50,000 range ($n=12$) and then again at over 100,000 ($n=9$). The next ranges most frequently reported are 0 to 10,000 ($n=7$), 21,001 to 35,000 ($n=6$), and 65,001 to 80,000 ($n=6$). Seven participants did not respond. Older study respondents were more likely to report income at the lower levels, with the 50 to 65 year old participants more likely to report income above 65,000.

Education. Fifty-nine percent ($n=33$) of study participants had completed at least 15 years of schooling with 36% ($n=20$) reporting post-graduate education. These results

are consistent with the literature reviewed indicating some relationship between attendance at group support and higher education levels.

Race/Ethnicity. Respondents were asked to “fill-in” their answers to the race/ethnicity query. Table 2 displays all responses with three participants not responding. Eighty-nine percent ($n=50$) of respondents entered they were “White” or “Caucasian”. Therefore, the sample population represented a highly homogenous group without significant racial or ethnic differentiation.

Marital Status/Living arrangements. Although the study participants were almost twice as likely to be married, 60.71% ($n=34$), living arrangements were considered to be more important to the study. Living arrangements may be an indicator of support or burden. About 20% ($n=11$) reported living alone; whereas, 75% of participants reported living with someone else. Of this number, 57% ($n=33$) reported living with someone who was not dependent on them for their care, versus 20% ($n=12$) who reported that they were responsible for at least one other person.

Differences in level of social support and from whom social support is available and sought may modify the sense of well-being. The sources of social support may need to be distinguished in studies, in some studies a principal source is a partner, often a spousal partner (Spencer, Carver, & Price, 1998). Questions were not specific enough to account for, or implicate an influence on other study variables or from whom support may have been received.

Employment. What significance employment status plays, if any, in studies of this type is not known. There may be a correlative interaction between education, income and employment; or, there may be a potential relationship between this

composite, and who is likely to join studies. If employment status has a role, respondents were almost equally distributed into two categories, 30% ($n=17$) who were working full or part-time, and almost 38% ($n=21$) who were retired and not working. The other respondents were divided among the categories of unemployed, including those on a leave of absence. Only one person did not respond at all to the question.

Table 5

General Demographics, N=56

Gender			Income		
	<i>n</i>	%		<i>n</i>	%
Male	17	30.36%	0 - 10,000	7	12.50%
Female	39	69.64%	10,001 - 20,000	3	5.36%
No Response	0	0.00%	21,000 - 35,000	6	10.71%
			35,001 - 50,000	12	21.43%
			50,001 - 65,000	4	7.14%
			65,001 - 80,000	2	3.57%
			80,001 - 100,000	6	10.71%
			100,000+	9	16.07%
			No Response	7	12.50%
Education			Race/Ethnicity		
	<i>n</i>	%		<i>n</i>	%
Less than 12 years completed	2	3.57%	Black	1	1.79%
12 to 14 years completed	20	35.71%	White	50	89.29%
15 to 16 years completed	13	23.21%	Filipino	1	1.79%
Post graduate education	20	35.71%	Hispanic	0	0.00%
No Response	1	1.79%	Jewish	1	1.79%
			No Response	3	5.36%
Marriage/Liv Arrangement			Employment		
	<i>n</i>	%		<i>n</i>	%
Live alone	11	19.64%	Unemployed	6	10.71%
Live with at least one other person, who is not dependent on my care	33	58.93%	Leave of absence	4	7.14%
I am responsible for at least one person(s) living with me	9	16.07%	Full-time	13	23.21%
Other:	2	3.57%	Part-time	4	7.14%
No Response	1	1.79%	Unemployed, but not retired	1	1.79%
			Retired and not working	21	37.50%
			Uncompensated Volunteer	1	1.79%
			Other	5	8.93%
			No Response	1	1.79%

Cancer and Demographic Factors Used for Covariates

Age and stage of disease represents two of the study's covariates. The following discusses both these covariates. All participants included in the study met criteria for date of cancer diagnosis: All study participants were diagnosed with a new or recurrent diagnosis of cancer within the last 18 months. Seventy-eight percent were in their first

year of being diagnosed with the remaining study participants (22%) diagnosed between 12 and 18 months. Site of disease is reported in Table 7. It was not a covariate in the study, but it is still relevant to the population's profile.

Age. Table 6 displays the age categories. Seventy-eight percent ($n=44$) of study participants were in three dominant age bands, years 50-59, years 60-69 and years 70-79. Eighteen percent ($n=10$) were 49 or less years old, with the youngest participant at age 29 years. The mean age was 60.16 years old ($SD=12.66$; $Mdn=61$). There were 11 individuals whose ages clustered in the range from 70 to 73 years old.

Although nationally-based cancer statistics reflect a relationship between age and primary site of disease, the age demographic for this study is more likely a result of who was scheduled for an oncology visit or treatment, a convenience sample. There were not age selections for the study. Most persons who enrolled for the study were approached based on their availability at each site. Cancer incidence or prevalence may be a factor, since breast cancer is the most frequently defined primary site of cancer for this study.

Table 6

Age Categories N=56

Age	<i>n</i>	%
21-29	1	1.79
30-39	2	3.57
40-49	7	12.51
50-59	17	30.36
60-69	12	21.43
70-79	15	26.79
80+	2	3.57
No Response	0	0.00%

Stage. All stages or groupings of cancer disease were either verified by the medical record of each study participant or by each participant's attending oncologist. One difficulty in the study's data analyses was to overcome the complexity of staging and the variation in the staging systems for cancer types and sites. No references were found that provided a translation of one set of stages for another to fit the research purpose. Sub-classifications of stage were rarely documented in the medical record. Since by far most cancers were classified from Stage 0 to Stage IV, cancer types having another classification ($n=6$) were matched to the closest severity stage using Stage 0 to Stage IV, within the criteria discussed in chapter 3. This approach may also be justified from the standpoint that, despite in-depth clinical information available about staging, in some cases stage identification was inconclusive given the nomenclature for each cancer type and the criteria overlap between stages (Abraham & Allegra, 2001).

In this study, there were six cases where stage was not described using uniform criteria and language. The language was interpreted into Stages 0 to IV for the research purpose. Three participants with Non-Hodgkin's Lymphoma were classified. Two participants described with a "low grade" Lymphoma were both categorized as Stage II, given their recurrence and treatment picture and one participant was categorized at Stage I, who is in remission at the time of this writing. Two participants diagnosed with Multiple Myeloma were classified into Stages I and IV respectively. In the first case, Stage I, was described as "mild" and "smoldering". The second case interpreted as Stage IV, was described as "advanced". One study participant with a cancer diagnosis of oligodendroglioma, described as low grade (early stage), was classified as Stage I. Staging proposed by the WHO is Grades I through IV (Mansky & Hamilton, 2001).

Stages interpreted for the study's purpose, not documented in the medical record, were verified by each enrollee's oncologist.

Table 7 summarizes the staging information used for the covariate calculation for ANCOVA. Stages III and IV represent 44.22% of the population's total; whereas, Stages 0, I, and II comprise 55.76%. Nearly half of the study population were at a more severe stage of cancer disease (Stages III and IV).

Table 7

Stage of Disease Information Used for Covariate Calculation

Stage	N=52	Percent of N
Stage 0	1	1.92
Stage I	8	15.38
Stage II	20	38.46
Stage III	9	17.30
Stage IV	14	26.92

Site. Site of primary cancer is important to record and report in order to adequately describe and differentiate this study's population from others. Zabora, BrintzenhofeSzoc, Curbow, Hooker, and Piantadosi (2001) reported the prevalence of psychological distress may vary with cancer site. Cancer sites mirrored the population characteristics of many research studies and therefore, unique attributes were not noted (Kornblith, 1998). Given the predominance of female gender in the study population, it was not surprising that the breast was the primary cancer site for 33.93% ($n=19$) of study participants. The distribution of primary cancer sites among the remaining study

participants was variable. Table 8 outlines the primary site of cancer for the study population in ascending order of occurrence.

Table 8

Primary Sites of Cancer for Sample Population, N=56

Primary Site	% of Total/ n
Breast	33.93 (19)
Non-Hodgkin's Lymphoma	19.64(11)
Lung	12.50(7)
Multiple Myeloma	10.71(6)
Colon	3.57(2)
Ovary	3.57(2)
Prostate	3.57(2)
Melanoma	3.57(2)
Brain	1.79(1)
Endometrium	1.79(1)
Leukemia	1.79(1)
Pancreas	1.79(1)
Tonsil	1.79(1)

Group Comparisons

Descriptive Analysis

A comparison between group 1, support, and group 2, no support, as displayed in Table 9 reveals differences. Mean age of Group 1 is 50.67 ($SD=11.38$). Group 2 is 12 years older ($M=62.72$, $SD=11.96$). Stage of disease is more severe for Group 2 at 2.60

($SD=1.09$, range 0-4). Group 2 mean pretest scores are nearly 20 points higher ($M=77.05$, $SD=16.14$) than group 1 ($M=57.22$, $SD=17.41$). However, posttest scores indicate a difference of 10 points between the two groups, with group 2 remaining higher at posttest. Pretest-posttest score differences between the two groups are notable. Group 1 has a 12 point increase (21.16%) in mean score difference pretest from posttest, while group 2 has an increase of about 2 points over pretest scores (2.56%). The range of scores in both groups at pre and posttest times represent 55 and 44 points respectively in Group 1 and 59 and 57 points in Group 2.

Table 9

Descriptive measurements between Group 1 and Group 2

Measurement	<u>Group 1: Support $n=9$</u>			<u>Group 2: No Support: $n=43$</u>		
	Mean	SD	Range	Mean	SD	Range
Age	50.67	11.38	29-68	62.72	11.96	30-81
Stage	2.0	1.00	1-4	2.60	1.09	0-4
Pretest	57.22	17.41	34-89	77.05	16.14	44-103
Posttest	69.33	15.57	50-94	79.02	15.42	47-104

Statistical Screens

ANCOVA like many other inferential tests is based on a number of statistical assumptions. Because the sample size of the comparison group is small ($n=9$), there is a much greater likelihood that these assumptions may be violated. The following elaborates on the results of the preliminary statistical screens required by an ANCOVA design.

Tests of normality. Figure 2 is a histogram that outlines the results of the posttest (DV) distribution. It represents a normal distribution ($SD = 15.74$, $M = 77.3$); however, it

has some degree of a leptokurtic shape (kurtosis= -.972). There is some resemblance to a bimodal distribution; noteworthy is a secondary frequency peak between scores of 59 and 67. Despite these variations, it meets standards for a normal distribution.

PGWB (DV) and predicted relationship with covariates. Figures 3, 4, and 5 are scatterplots that represent each covariate's relationship with the dependent variable (DV). Table 9 displays Pearsons correlations' results, the relationship of the DV with each covariate. Age did not significantly relate to the posttest ($r = .061, p = \leq .05$). Although both the pretest and stage of disease are correlated, Pearson's correlation of $r = .423, p = \leq .05$ for the Pretest and $r = .362, p = \leq .05$ for Stage may be considered a weak relationship with the DV in both cases (Polit, 1996). The covariates should have a linear (parallel) relationship with one another. The linearity between covariates could not be demonstrated (See Figures, 3, 4, and 5), as the correlation data indicated. Each line has a different slope, which means the value of each variable does not vary consistently, but these do not have a curvilinear relationship.

Figure 2. Distribution of DV (N= 52): $SD=15.74, M=77.3$

Figure 3. Age in Years and PGWB Posttest

Figure 4. PGWB Pretest and PGWB Posttest

Figure 5. Stage and PGWB Posttest

Table 10

Correlations: Relationship Between Covariates and PGWB (DV)

Covariate	N=52 for each calculation	Posttest N=52
Age	Pearson Correlation	.061
	Sig. (2tailed)	.668
Pretest	Pearson Correlation	.423
	Sig. (2tailed)	.002
Stage	Pearson Correlation	.362
	Sig. (2tailed)	.008

Homogeneity of regression. As discussed in Chapter 3, tests consistent with established criteria were performed to test the equivalency of the two study groups. One assumption in ANCOVA is that there is homogeneity of regression, the covariate should have the same relationship with the dependent variable (DV) across groups that are being compared. A second ANCOVA assumption is that the relationship between the dependent variable and each covariate is linear. And, that there is a linear relationship between all pairs of covariates (Black, 1999; Polit, 1996). Table 10 indicates age did not have a significant correlation with the DV. Table 11 demonstrates heterogeneity of regression, which reaffirms an interaction exists. In other words, there are not common regression slopes suggesting that correlations are not the same between each covariate and dependent variable within each population of the study. The results indicated when the covariates are pooled, there is a significant interaction, $F(4,47) = .013, p \leq .05$ with

group support. These results represent heterogeneity of regression, which lowers statistical power.

Table 11

Test for Homogeneity of Variance (regression hyperplanes (3CV))

Source	Sum of Squares	df	Mean Square	F	Sig
Within +	7264.39	44	165.10		
CV	90.38	3		.18	.908
CV by IV	935.95	1	935.95	5.67	.022
Group	1996.24	3	665.41	4.03	.013
Total	12629.77	51	247.64		

PGWB and subscale testing. Different population samples may yield different results on the correlation between subscales. Subscales were examined with the study sample to test internal consistency and the reliability of each scale. Both the pretest and posttest subscale results are reported. Tables 12 and 13 display the psychometric properties of each subscale compared with published statistics from the Rand study of 1,209 residents of Ohio ages 14 to 75 years, who were not specifically an ill population (Dupuy, 1984, Ware, 1987). Even when illness was not a factor, the mean and standard deviation between the study population and the Rand study was strikingly similar. The two exceptions are the means of the General Health and Vitality scores at both pretest and posttest times as compared to the Rand study population. Given the chronic and sometimes acute illness of the study population, the departure from the Rand means in these two subscales was an anticipated difference.

The reliability measures were equally consistent. Alpha coefficients on pretest subscales ranged from .54 (General Health) to .91 (Anxiety) and on posttest subscales, the range was from .68 (General Health) to .88 (Anxiety). These compare to the range of .72 (Self-Control) to .88 (Anxiety) on the Rand results. General Health on both the pretest and posttest scores were the lowest coefficients as compared to Self-Control (.72) in the Rand group. The illness characteristic in the study group may account for these differences.

Table 12

Descriptive Statistics for PGWB Subscales (Based on sums) N=58 pretest, N=52 posttest

Subscales	No Items	<u>Pretest</u>		<u>Posttest</u>		<u>RAND</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
ANX	5	17.39	4.92	18.30	4.14	17.89	4.67
DM	3	12.41	2.08	12.42	2.32	12.36	2.54
PWB	4	12.56	3.76	12.78	3.50	13.15	3.64
SC	3	12.27	2.65	12.30	2.64	13.00	2.26
GH	3	8.50	2.91	9.13	2.97	12.21	2.50
VIT	4	11.37	3.96	12.00	3.85	13.57	3.51
PGWB	22	74.50	20.28	76.93	19.42	82.18	15.68

Table 13

Alpha Coefficients for Each Subscale

	Pretest	Posttest	Rand
Subscales	N=58	N=52	N=1,209
ANX	.91	.84	.88
DM	.79	.82	.84
PWB	.84	.80	.83
SC	.78	.73	.72
GH	.54	.68	.73
VIT	.86	.87	.81
PGWB	.94	.93	.94

Findings Related to Research Questions

The descriptive information about the data results is discussed followed by the presentation of the inferential results, ANCOVA. Thereafter, further descriptive information discusses the findings from complementary therapies, attendance and the outcome of the final telephone interview, which includes the “intervening event” question. The “intervening event” question was analyzed using qualitative methods. A supplemental section is included in some instances that elaborates on phenomena in the study worthy of discussion, although not part of the study’s initial aims.

A number of preliminary data quests were pursued in order to respond to the research questions of the study. In some instances, supplemental data and analyses are

included and are aligned with each question, when relevant linkages could be made. The research questions were the following:

1. Does psychological status (PGWB) improve for persons with cancer with attendance at professionally-facilitated group support, as defined?
2. Do factors such as age, pretest and stage of disease play a significant role in predicting the effectiveness of group support as measured by the PGWB?
3. If group support is an important action for clients with cancer to undertake, must they participate with a threshold or level of attendance in order to benefit (improved PGWB scores)?
4. Does engagement in complementary therapies reveal a potential association between the scores on the PGWB scores and participants' of group support?
5. Is there a context revealed by the description of intervening events experienced and perceived by study enrollees during the study period that may have altered PGWB scores?

Question 1: Relationship of PGWB and Group Support

The principal aim of the study was to demonstrate the influence of group support on psychological well-being. The hypothesis was that PGWB posttest scores would be higher for individuals in the support group. ANCOVA was the test statistic to determine the effect of the independent variable on the PGWB posttest.

ANCOVA Results. Table 14 describes the central tendency measurements for the posttest between the two groups. It replicates the results already displayed in Table 9. There are 10 points between the two mean scores, with the higher mean in the

comparison group. The significant difference in the “ n ” of each group may account for this unanticipated difference. Standard deviations are equivalent for both groups.

Table 14

Central Tendency Measurements for DV (PGWB)

GROUP	<i>M</i>	<i>SD</i>	<i>n</i>
1 Group support	69.33	15.57	9
2 No group support	79.02	15.42	43
Total (range 47-104)	77.35	15.74	52

The SPSS version 10 program (1999) calculated the computations for the ANCOVA test statistic from the data entry converted from a Microsoft Excel program. After adjusting for the covariates, the between subject (group) effect for the effect of group support on the DV was not significant at $F(4,47) = .097$, $F = .757$; $p \leq .05$). Table 15 displays the applicable measures. Age was not a significant influence [$F(1,50) = .297$, $p = .588$, $p \leq .05$] on posttest scores. Stage [$F(1,50) = .5185$; $p = .027$, $p \leq .05$] and pretest [$F(1,50) = .6873$; $p = .012$, $p \leq .05$] interacted with group support on prescreening for ANCOVA assumptions. Therefore, these results must be mitigated by this violation.

Table 15

ANCOVA Results: Tests of Between Subjects (group); Effects for Posttest, Using Age, Stage and Pretest as Covariates

Source	Sum of Squares	<u>df</u>	Mean Square	F	Sig
Age	58.572	1	58.572	.297	.588
Stage	1021.577	1	1021.577	5.185	.027

Source	Sum of Squares	df	Mean Square	F	Sig
Pretest	1354.236	1	1354.236	6.873	.012
Group	19.121	1	19.121	.097	.757
Error	9260.537	47	197.033		
Total	323716.000	52			

Question 1: Supplemental Data Analyses

It may be important to use the data to detect differences between pre and posttest scores and how these compared across individuals and between the groups.

PGWB score comparisons: levels of distress. Table 16 distributes the test score data into levels of distress. Percentages are not included because the number values are small and may distort the data. Categories of distress levels are as these were reported by Dr. Dupuy from the PGWB schedule.

Table 16

Levels of Distress for each study group

Levels of distress	<i>n</i> = 9 group support		<i>n</i> = 43 no group support	
	<u>Score <i>M</i> and <i>SD</i></u>		<u>Score <i>M</i> and <i>SD</i></u>	
	Pretest	Posttest	Pretest	Posttest
	57.22, 17.41	69.33, 15.57	77.02, 16.14	79.02, 15.42
0 to 60 severe distress	4	4	7	5
61-72 moderate distress	2	2	11	9
73-110 pos well-being	3	3	25	29

Table 16 distributes the study population into three categories, the sample size of nine in the group support sample prohibits conclusions. Forty-three in the comparison group, with over half in the positive well-being range should induce comment, if it were not for the following observation. The shifts in degrees of distress are unremarkable and are not helpful in determining change over time because these changes are inconsistent from pretest to posttest. There are also not paired changes among the same individuals in either study group. For example, the four individuals in the severe distress ranges are different individuals when pretest results are compared to posttest results. This is also true of the other two distress ranges. Both groups had individuals with scores that deteriorated from pretest to posttest periods.

PGWB score: case discussion. There were 20 cases where specific pretest and posttest scores changed by 20% or more. Table 17 distributes score data with a comparison of between group scores with negative change from pretest to posttest in order to analyze deterioration in scores. The range was from -59.3 to +63.9 percent.

Cases were equally divided between persons whose scores improved and persons whose scores deteriorated over the study period. The highest positive change was at 63.9% from pretest to posttest, an individual with stage IV breast cancer who intended to participate in group support, but never attended any sessions. However, throughout the study period she sought one-on-one psychological counseling, which she found profoundly beneficial. The next highest positively changed score (42.65%) was an enrollee with Stage II breast cancer, who attended 10 sessions of group support. Her score was followed by two enrollees with +42.35% and +42.17 % positive score changes respectively, one of whom with Stage I breast cancer, who attended 8 sessions of group

support, the other with Stage IV multiple myeloma, who did not attend any group support sessions. From the persons described, only one person accessed complementary therapies on a routine basis.

In contrast, the highest negative change (-59.3%), was an individual with Lymphoma (Stage I), who did not plan nor attend group support, who had resumed full-time work, and who was in complete remission. Although he reported he was tired, he also reported that he had “lots of great support from church and family”. The next lowest negatively changed score (-48.0%) was an individual with Stage III lung cancer, who had attended four sessions of group support, but reported neither having the physical energy nor the psychic energy to attend thereafter. She stated that she found the group sessions “too depressing”, but she was searching for another group to join. She did relaxation therapy routinely and found that it had a positive effect. Finally, a negative change (-43.4%) was exhibited by an individual with Stage II multiple myeloma, but who attributed his change in affect according to his event responses, to his wife’s recent illness.

Table 17

Comparison of Group Scores with Negative Change

Group	<u>n scores deteriorated</u>	<u>M Score Deterioration,</u>
	from pretest to posttest	Range and % change
Group Support, <i>n</i> =9	4	-14.75(range-2 to-24) 25.95%
No group support <i>n</i> =43	16	-11.75(range-1 to-35) 18.34%
No change	1	0

Question 2: The Influence of Covariates, Age, Stage of Disease, and Pretest on the DV.

Another aim of the study was to examine the relationship of extraneous variables, age, stage of disease and pretest on the dependent variable. The preliminary assumptions were that the three extraneous variables chosen from the literature review, age, stage of disease and pretest would covary with the dependent variable. It was predicted that increasing age would have a positive relationship with PGWB posttest scores, stage of disease would vary inversely with PGWB scores, and pretest scores would have a linear relationship with posttest scores. As reported, there is an interaction between the covariates and the PGWB posttest. To partition results of each covariate from the ANCOVA statistical computation in Table 15 does not contribute pertinent information to their effect on the dependent variable. Due to the results of the interaction reported, the adjusted means of the ANCOVA results may have an increased error: age ($p = .588$), stage of disease ($p = .027$), and pretest ($p = .012$), and therefore may not account for significant error variance.

Questions 1 and 2: Supplemental Data Analysis

ANOVA. Given the results of ANCOVA and the interaction between the covariates, and the covariates with the DV, an ANOVA was performed to review an analysis without the covariates. If the covariate error term is high, it may sometimes mask the effect of the independent variable. Table 18 displays these results. The removal of covariates' effects from the analysis did not change the results. Significance was measured at $F(1, 50) = 2.928$, $p = .093$, $p \leq .05$. Although the result represents a stronger

relationship between posttest and the support group without the covariates, the result is still not significant.

Table 18

ANOVA Results

Source	Sum of Squares	df	Mean Square	F	Sig
Corrected Model	698.792	1	698.792	2.928	.093
Intercept	163802.792	1	163802.792	686.460	.000
Group	698.792	1	698.792	2.928	.093

PGWB subscale analysis. The review of subscale results as these relate to between group findings were not an intended analysis of the study, but specific information is relevant. The results are presented here as a supplement to both research questions one and two. Subscale scores on the PGWB Index were tabulated and then an ANCOVA design was applied to the data. The results were not significant on any subscale. A general linear model was then applied to the data, which included age and stage of disease. The model compared change in scores over time with the pretest and posttest as dependent variables. An abbreviated version of the descriptive and inferential results are displayed in Table 19, since this was manipulation of data and the statistical test was not directly related to the hypotheses as posited. The significance column in bold was the most pertinent. The analysis indicated at an alpha of .05, there were not significant results on the subscales of positive well-being ($p=.425$), self-control ($p=.137$),

general health ($p=.869$) and vitality ($p=.961$), but results were significant on the subscales, anxiety ($p=.017$) and depressed mood ($p=.028$).

Table 19

Subscales: Descriptive and Inferential Results: N=52 for Pre and Post Test

Scale	G PreT M	G PosT M	NoG PreT M	NoG PosT M	MS	F	Sig
ANX	11.11	16.11	18.53	18.76	60.75	6.16	.017
DM	10.00	11.77	12.93	12.55	16.59	5.16	.028
PWB	10.44	11.55	13.09	13.46	4.28	.648	.425
SC	9.77	11.00	12.86	12.58	7.44	2.29	.137
GH	7.44	8.33	8.55	9.30	.134	.028	.869
VIT	11.33	11.55	11.34	12.09	2.101E-02	.002	.961

Question 3: Level of Attendance on PGWB Posttest

An aim in the study was to examine attendance levels on PGWB posttest scores. It was predicted that those persons who had chosen to attend group support and attended sessions on a regular basis, at least nine of the 12 sessions (75%), would have higher PGWB posttest scores than those support participants who attended less sessions. Nine enrollees of the study selected to attend group support. From this number, three persons achieved the attendance threshold, 75% of total sessions or nine sessions. The others did not attend on a regular basis. Two persons stopped attending after three and four sessions respectively. The sporadic attendance of group support by most individuals prohibits a valid scientific summary of the findings and its potential effects on group support.

Question 4: Participation in Complementary Therapies: Is there a potential association?

The aim of the study was to describe complementary therapies in order to explore how these may affect results and provide information for future research undertakings. Because of the range of complementary activities and the variation of their anticipated use across both study groups, it was predicted that complementary therapies would not affect the outcome of the study. Complementary therapies were defined as music relaxation, massage, yoga or any other formalized activities participants described as doing in order to help them through the cancer experience, but not specifically to diminish cancer pathology. Formalized means activities were scheduled routinely and were offered by a trained or credentialed person. However, enough study participants engaged in their own versions of complementary therapies to include these. Mostly, participants did not attend any “complementary therapies”. And, when they chose to do so, these were not widely attended nor attended consistently.

Table 20 describes study participants who engaged in complementary therapies or activities. Eight participants reported attending formal therapies. Three participants reported they had engaged routinely in a personalized schedule of complementary activities. Participants (10) who self-engaged in therapies independent of formalized sessions, did not track frequency, and participation was most often sporadic, infrequent and unscheduled through the study period. These “therapies” were mostly self-help tapes. Exercise in one case was playing golf routinely, three times a week. Thirty-five or 63 % of the 56 study participants included in the analysis did not attend or self-engage in any complementary activities. Given the data, on visual inspection of PGWB posttest scores, an association was imperceptible.

Table 20

Summary of Complementary Activities

Activity	<i>n</i> Formal	^a Frq through study period	<i>n</i> self-engaging routine	<i>n</i> Sporadic self-engaging
Music	-		2	1
Relaxation	^b 2	^b 4,6	-	3
Massage	^b 4	^b 6,10,12,1	-	-
Meditation/Yoga	-	-	-	1
Yoga alone	-	-	-	1
Meditation alone	-	-	-	1
Exercise	-	-	1	1
Imagery	1	5	-	1
Combination Imagery/Music	1	10	-	1
Totals	8	**	3	10

Note. ^aFrq.= the number of sessions attended. ^bFormal relaxation therapy was accessed by two participants, with each participating in four and six sessions respectfully. The massage therapy was accessed by 4 participants. In the next column, the frequency is documented sequentially for each one.

Question 5: Qualitative Analysis of the Intervening Event Responses

Events may transform the lives of study participants. Therefore, as a potential relevance on study results, participants were asked, if in the preceding 12 to 14 weeks from study entry, there was an event they experienced (or an event experienced by

someone else close to them) that made a difference in their perception of life, or in their life living with cancer.

The aim of this question was to uncover potentially pertinent events as described by study enrollees for their effect on the measurement of psychological general well-being, the outcome variable. In doing so, use as rigorous approach as the data would permit to analyze the content of responses. The responses were most often brief, with little or no elaboration. Responses that could be extrapolated for meaningful content, although brief, are all represented.

Fifty-six study participants responded to the question. Although there was some overlap in how persons responded to the question, responses fell into three principal categories: (1) Many after asking for more clarification about the question, still responded with a “no” or “I don’t think so” answer, ($n=28$); (2) Some responded in ways that were consistent with the question ($n=11$); and, (3) Many did not answer the question specifically, but chose a personal response, presumably more compatible with what they wanted to convey ($n=17$).

First category: no response. Those who responded “no” to the question were often emphatic about their response. Some who had “no” replies were at low emotional points with their cancer experience; others were at high points (feeling much more positive about their lives). Those at high points, often either did not have events to discuss or they reflected that they felt better. In speaking with each of those who felt more positive, it was as though a discussion might threaten a newly found euphoria.

Second category: responses corresponding to question. For those who responded to the question specifically as queried, six reflected an event(s) that they considered a

negative influence: a son in his thirties diagnosed with lymphoma, a close uncle that died, sale of a home (the home, a haven for the horticultural interests of the study participant, but his wife insisted on selling the home), and one participant's spouse, who had a life-threatening stroke. In the last case, the gentleman stated: "It would be impossible for anyone to feel happy and energetic when a loved one is so down". In fact, he was reluctant to complete the posttest questionnaire because as he stated, "this is not about the cancer" (the feelings he reported). He said that if it was not for his wife's illness, he would feel great (emotionally). A fifth respondent related, "I'm upset about us (the U.S.) going to war with Iraq. All this depressing news, all the yellow journalism". And, the sixth person stated that her concern was about a newly experienced and periodic confusion that she was trying to sort out. She was not sure how much to attribute to her memory lapses or to her emotional instability.

The other respondents ($n=5$), reflected what they considered uplifting events in their life: (1) a trip to visit a sister that was inspiring, (2) a surgery for a possible recurrence of cancer that was not only negative for recurrence, but also preserved her reproductive capacity, (3) the birth of a granddaughter, (4) the purchase of a personally important dream house; and (5) a supportive partner, who recently "moved-in".

Third category: responses inconsistent with question. Discussion of the third category is included here: those that did not provide answers that corresponded exactly to the query posed. Two principal themes emerged. Although the themes may be inextricably linked, there may be more clarity and benefit to discussing these separately. One theme focused on the cancer disease-- the integration of treatment, stage or severity with one's physical existence that in turn affected one's perception of life. The second

theme was centered around personal philosophies, deeply embedded, but subject to a constant challenge of re-evaluation because of the cancer experience.

The first theme generated by respondents was partly prompted by their reaction to the timing of queries and their treatment and prognosis. Some felt their outlook and responses would be very different if queries were posed a year ago when they first heard about their diagnosis. Others modified their perspective based on where they were with treatment regimes. Some individuals just felt better at the halfway point of treatment and again upon its completion, as though then they could put this part (the cancer part) of their lives behind them. In contrast, a few persons felt insecure with the sudden revelation that they would not see their providers as much once treatment ended.

Vulnerabilities were expressed that translated to a physical and emotional loss of independence: "I am so tired, I worry about doing things on my own" (age 45 years). Another person stated, "When I thought my husband may leave for the weekend, I was concerned. I had not been alone since I started Chemotherapy (age 68 years)". This statement was made from a woman who presented herself as a confident, self-assured individual. Another stated, "Being weak and tired really awakened me to old age" (male, age-58 years). One respondent stated, "I had to adapt to every 'chemo' session. After my first treatment I felt pretty good, so that was my expectation; after the second treatment, I felt bad" (female, age 39 years). She was elated when she felt less ill than expected, then disappointed when the next experience was not the same.

The next series of responses provides support for the principal theme of cancer as a life changing event and the consequent thoughts and behaviors. A few responses indicated that study participants would assert more self-protective limits on themselves

and others. One respondent voiced what others inferred, “I learned to put my self first. I don’t try to please everyone”. Another person stated, “I have let go of a lot of controls in my life” (speaking of controls for which she had always insisted).

Others focused on behaviors that put emphasis on what they thought was important in life. One person stated, “I appreciate my family more. I have a spiritual relationship with God, but once in awhile the worry creeps in”. One person stated: “ I feel cancer brings out the best in people, a new depth that feels good right now”. Another wrote, “At 72 years old with Stage IV Liver Cancer in 2001, I feel fortunate to have received the best medical treatment available, and [I] am now able to run, walk, play golf, travel, dine out, and visit friends ‘&’ grandchildren (4) occasionally with no pain or restrictions. I am grateful for every day for the rest of my life. My thanks to Dr. ‘X’ and the staff for giving me another chance of life”.

A few responded in ways that demonstrated how they felt different from others and sometimes isolated. “I don’t have time to do anything; I don’t want to tell anyone how I feel, they always have suggestions: ‘You have to have a positive attitude’. If I were a single man, I would probably go to group support” (male, age, 76). Another study participant shared, “I did not want to be babied....I was not a survivor....I do not see myself as a victim....What about all the other people that suffer from disease”. (female, age 46)

Relationship of responses to PGWB scores. From the data provided by enrollees, 11 responded directly to the question. Each of these eleven respondents were able to distinctly determine for themselves whether events they described affected them in either positive or negative ways over the study period. Ten are reported here (one enrollee did

not complete the PGWB posttest). Table 21 represents each of the ten enrollees. All results are listed to reflect if and how the enrollee-determined positive or negative event affected PGWB scores. The ten are equally distributed, five who perceived events as positive and five who perceived events as negative. For ease of interpretation, enrollees who perceived events positively are listed first, followed by those who perceived events as negative.

On visual inspection, Table 21 outlines one person attended group support (2 sessions). PGWB score changes ranged from -30 to +24 (.01% to 38.88%), without a detectable association between positive and negative events. There were score improvements and score deterioration from pretest to posttest in both groups of enrollees, those who reported positive events and those who reported negative events. No pattern emerged to remark about the relevance of the intervening event question in order to predict direction in PGWB scores.

Although the other enrollees provided comments as previously described, the comments did not correspond to the question ($n=17$). These comments reflected their desires to comment about a number of topics. Despite what importance these may have, these cannot be differentiated from how these comments may have affected them and their PGWB scores from those who elected not to comment ($n=28$ for “no” answers).

Table 21

PGWB Pre and Posttest Score Comparison for Effect of Intervening Event

Enr/Event +/-	Pre and post scores	Score Change	% change	Gr/No Gr.
#1 positive	69,93	+24	+34.78	No Gr
#2 positive	63,48	-15	-23.80	No Gr

Enr/Event +/-	Pre and post scores	Score Change	% change	Gr/No Gr.
#3 positive	77,78	+1	+01	No Gr
#4 positive	54,75	+21	+38.88	No Gr
#5 positive	61,59	-2	-.03	No Gr
#6 negative	53,62	+9	16.98	No Gr
#7 negative	99,69	-30	-30.30	No Gr
#8 negative	95,100	+5	+5.26	No Gr
#9 negative	67,57	-10	-14.92	Gr
#10 negative	99,100	-1	-.01	No Gr

In summary, fifty percent of enrollees provided responses that were pertinent to persons with cancer, but were not confirming in revealing an association for PGWB score changes for the aim of the event question. The aim of the event question was to isolate an extraordinary factor (as perceived by enrollees) outside of the activities of daily living and life living with cancer that may affect results. Other than enrollees who could self-determine “intervening events” as described, it was assumed that pre and posttest scores on the PGWB incorporated the net effect of the varied circumstances encountered by all study enrollees during the study period.

Summary: intervening event question. The limitations of the short answers provided by the respondents, and the aim of the question prohibits a methodologically sound qualitative summary, but a brief synopsis is appropriate. Fifty percent of the enrollees declared there was no event that affected their lives during the study period. Of the remaining enrollees who commented, 11 (10 could be used for analysis of PGWB

effect) provided brief answers that were consistent with the question, the others chose a response ($n=17$), which did not correspond with the question.

From what study participants shared, life in the context of cancer, its treatment, its prognosis, with an array of changing dimensions prompted rethinking of prevailing philosophies for respondents. In some cases, cancer inflicted an ebb and flow of mindset, precipitated by the disease, its symptoms, its treatment and the drama of elation and crisis these may cause. Even with an excellent prognosis, comments indicated that there was a worry factor of recurrence. For some persons, uneasiness ensued because of discontinued reassurance when frequent examinations by their providers were diminished and with less disease screening when treatment ceased.

Supplementary Comments

The bias not to select to attend group support over the decision to attend deserves comment. Since the reasons for not attending group support was not part of the study's design, what is offered here is informal and is an effort to draw attention to the need for further exploration. The reasons volunteered by study participants are paraphrased in the following. These should be considered with caution, since these were not methodically derived and do not represent the entire study population who selected not to attend group support. However, these are listed by the frequency with which comments were mentioned:

- ❑ I do not think these would be helpful ($n=8$).
- ❑ I do not want hear others talking about treatment and problems. I do not think that would help me ($n=7$).
- ❑ I have enough support through family and friends ($n=7$).

- ❑ I would go if it was convenient (scheduling and distance an issue) ($n=4$).
- ❑ Sometimes I just don't have the energy to think about doing one more thing ($n=4$).
- ❑ I wanted to go, but no one ever called me back ($n=2$).
- ❑ I don't know much about it ($n=2$).
- ❑ No one has ever mentioned it ($n=2$).

Summary of the Findings

An ANCOVA design was used as the test statistic, with age, stage of disease and pretest as the covariates in the study's design. Persons who met the study criteria made a decision to attend group support or not attend, the comparison groups. Access by enrollees to complementary therapies were monitored during the study period and participants' initial choices to attend or not to attend were also monitored. The number of sessions attended was monitored for those who elected to attend group support. Three contacts were made to study participants for brief interviews during the study period. In the third contact, the interview queried respondents about whether an event had affected participants' lives in the preceding 12 to 14 weeks.

Descriptive findings indicated the two groups compared in the study had differences in mean age, stage of disease and pretest and posttest results. All findings were compromised by the small sample size in the support group ($n=9$) and the sporadic attendance of group support by most individuals. On preliminary screening, the covariate, age, did not significantly relate to the dependent variable, Psychological General Well-Being (PGWB) at $r=.061$, $p \leq .05$ and pretest and stage of disease only weakly correlated ($r=.423$, $p \leq .05$ and $r=.362$, $p \leq .05$). Alpha coefficients for each subscale of the PGWB

index ranged from .54 to .91 on the pretest to .73 to .87 on the posttest, when data from the study's population were tested.

When data was tested with ANCOVA, group support was not significantly related to PGWB ($p=.757, p \leq .05$). The subsequent ANOVA performed did not have significant results. When a general linear model was applied to data, results were significant on the subscales, anxiety and depressed mood.

Only three persons achieved the attendance threshold, 75% of total sessions or nine sessions. Most persons did not access complementary therapies on any scheduled or routine basis to draw inferences about the data. Intervening events as reported and interpreted by enrollees did not affect the direction of PGWB scores.

There were enough individuals with disparate and inconsistent PGWB scores particularly among the non-participants of group support to warrant mention. The most significant observation of these, although not determined by inferential statistics, was the large number (25 at pretest and 29 at posttest, $n=43$) that had scores in the positive well-being range. Further discussion and interpretation of all findings are in Chapter 5.

Chapter 5

Summary, Conclusions and Recommendations

Persons with cancer are often psychologically transformed by the disease process, its treatment and the ongoing sequelae of a chronic illness. Many persons access a variety of services to improve or sustain their psychological health. Many of these therapies despite their prevalence in our secular culture have not been demonstrated to be effective. Group support may offer psychological relief to some individuals diagnosed with cancer. However, group support had not been measured for what may be the net effect of group support, improvement in psychological well-being. The next paragraphs discuss the findings of the current study, its relevance to the literature, its strengths and weaknesses, followed by the implications for further research.

Discussion of Findings

The study explored the effect of group support on psychological well-being (the DV), while attempting to make clearer the relationship of age, stage of disease and predisposition (pretest) extraneous variables, and these effects on the DV. Other aims of the study were to better explicate the relevance of complementary therapies and other life issues that may confound results, what were called “intervening events” during the study period. Because the content and the administration of group support can and does vary, all group support was attended through a TWC site. Facilitators assigned to group

support and the facilitation were consistent with TWC policies and criteria as a control of the kind and type of group support administered during the study period. All the findings must be addressed in the context of sample size. The deviation from the “ N ”, which at the outset of the study’s design was proposed as 45 participants for each study group (excluding the attrition anticipated), was a severe limitation in the analyses of data. The disparate enrollee election bias towards non-participation in group support, the comparison group was also a limitation in the analysis of data elements and the research questions as planned. Whether each covariate would correlate with the DV if more participants were in the study and more joined the support group, remains unresolved. These are serious considerations when reviewing the results. Despite these shortcomings in this research study, there were observations and findings worthy of attention. The following discusses the study’s results in the sequence with which data were analyzed.

General and Cancer Demographics: Covariates

The general demographics were unremarkable and unlikely to affect results; however there were differences between the two study groups that are noteworthy, and may, with equal sample sizes, reflect important revelations. These are outlined in the next paragraphs. The support group was twelve years younger ($M=50.67$; no support $M=62.72$) although age, a covariate, did not correlate with the DV as predicted in the ANCOVA results ($p=.588$, $p \leq .05$). The cancer demographics were also unlikely to affect results, but their description in the study is still important as researchers seek more information particularly about how site and stage of disease influences psychosocial status. Sample size limits conclusions; results cannot be generalized.

Stage of cancer illness did not correlate with PGWB in this study on preliminary screening, but demonstrated significance in the ANCOVA design ($p=.027$, $p\leq .05$).

Studies with a larger “ N ” in the population sample may identify a relationship. In group 2, no support, stage of disease was .60 higher than group 1 ($M=2.60$; $SD=1.09$; Group 1 $M=2.00$; $SD=1.00$), but stage of disease had a weak association with the DV ($r=.362$, $p\leq .05$), and therefore the significance of stage of disease, despite the significant finding when ANCOVA was applied, must be mitigated.

When scores were examined, persons at Stages III and IV were just as likely to score favorably on the PGWB scales as persons with Stage I and II disease. Persons at Stage IV had high pretest and posttest scores. Others, at Stage I disease, had consistently low scores at pretest and posttest.

PGWB Outcome: Descriptive and Inferential Analysis

Mean pretest scores for Group 2, no support, were 20 points higher than Group 1 (Group 2: $M=77.05$, $SD=16.14$); Group 1: $M=57.22$, $SD=17.41$). At posttest, the difference between the two groups narrowed and was just under 10 points at 9.69. Overall posttest scores improved in Group 1 by 21.16% ($M=69.33$, $SD=15.57$), with score improvement in Group 2 at 2.56% ($M=79.02$, $SD=15.42$). Score ranges for both groups were considerable, with the lowest score occurring in Group 1, 34 at pretest, and the highest score occurring in Group 2, 104 at posttest. Low pretest scores, such as those revealed by Group 1, may contribute important information about how psychological screening may predict who benefits from those who attend group support.

Group support did not have a significant influence on the measurement of Psychological General Well Being with ANCOVA [$F(4,47) = .097$, $p=.757$, $p\leq .05$].

Even when the covariates were removed and an ANOVA was performed, the results were not significant. These results were not surprising given the number of study participants in the support group. In findings discussed thus far, generalizability is not only ill-advised with the limitations of one study population, but the unequal sample sizes study compel fundamental and critical scientific caveats.

There were other findings, when the scores on the pretest and posttest of each of the study participants were reviewed and compared (Tables 16 and 17). The range and disparity of the PGWB results should capture our attention. Persons with low scores improved over time without participation in group support. Other persons' scores deteriorated over time with or without participation. One may expect deterioration of scores in the comparison group, but scores also deteriorated for those in the support group. Although these results may be mitigated by the small sample size in the support group, deterioration in the comparison group is noteworthy with a mean of 11.875 for 16 individuals ($n=43$). However, some scores occurred at the high point of the distress range and others at the low point in the range.

Many of the other cases whose scores fell within the 20% criteria in either direction, did not exhibit a pattern that may be suspected as either induced by severity of illness (symptomatology), stage or prognosis. Also, a pattern could not be identified that correlated with any complementary therapies that had been accessed. Another observation is the number of individuals in the comparison group whose scores fell into the "positive well-being" range at pre and posttest times ($n=25$ pretest; $n=29$ posttest), contrary to the principal hypothesis.

Qualitative Analysis

Complementary therapies. The most popular complementary therapies are healing, relaxation, and visualization, diets, homeopathy, vitamins and herbalism (Downer as cited in Doan, 1998). Somewhere between 10% to 60% of patients with cancer use some form of alternative treatment (Doan, 1998). Of study enrollees, 37% attended or participated in some form of complementary therapy; and therefore were within an anticipated range of access according to one source. Yet, whether strict definitions from which sources were reported, or whether alternative treatment as opposed to complementary therapy carried a distinction in studies, along with frequency of use, were not mentioned. Analysis of the complementary therapy data did not reveal a relationship between these therapies and PGWB posttest scores. Too few persons accessed complementary therapies in any scheduled or routine manner to comment on how they may have affected results. For those individuals who did access therapies, many commented on the positive effect these had, but the comments were too vague to formulate pertinent remarks

An important factor influencing relative risk is a person's level of personal and social resources. A person's repertoire of methods readily available as coping responses during the course of the cancer experience conceivably could make a difference (Spencer, Carver, & Price, 1998). Complementary therapies are most often considered mind-body enhancing modes of therapy, often referred to as holistic approaches. Central to the appeal of holistic approaches to cancer is the emphasis of personal responsibility for one's health and the belief that psychological states can affect the course of the illness. The popularity of these beliefs are consistent with the general and contemporary

movement of the health promotion focus in Western society philosophy. That is to say, health maintenance through physical fitness, proper nutrition and improved mental attitude (Doan, 1998).

Health promotion is a focus in the U.S. that includes complementary therapies as a cornerstone, such as physical fitness, nutrition, yoga, and meditation, a broad interpretation. One consideration of data analysis may be that complementary therapies accessed by study enrollees may not be motivated by a cancer diagnosis. It may be these activities would have been sought regardless of the health circumstances of the individual. Others, who are motivated because of the cancer experience may believe their health will improve by keeping fit, practicing visualization and relaxation or other therapies. Doan (1998) asserts many persons with cancer feel an enhanced sense of mastery over their lives and their illness, even when long-term survival is out of the question.

Therapies were accessed so inconsistently, which may lead to the possible conclusion that either one of the explanations described may have been operating. In other words, there was no trend or pattern to help explain why persons accessed therapies or did not, and why when they chose to do so, they did so irregularly. The data was inconsistent with the popular belief that complementary therapies are accessed with some frequency among persons with cancer.

Intervening event question. The responses collected during the interview time offered meaningful data to help enhance the understanding of enrollee's cancer and life's context during the study period, but not all persons made comments. Investigator probes were also limited by the design of the study and the commitment to study enrollees to

keep contact time at a minimum. For enrollees who made comments, respondents allowed the research to incorporate a space for enrollee perspective side by side with the priority for numbers and values, without which the data would have afforded less insight.

The range of score change -30 to $+24$ and the percent of change for individual scores coupled with each enrollee's perception, would suggest that each event, positive or negative, may have a different meaning for each individual. The magnitude of an event may also affect results, but perception by enrollees was intended to drive this possible effect. The other consideration is how the status of each person's psychological well-being and their ability to cope with adversity may affect these results. Contrarily, life's daily activities, coupled with the confluence of chronic illness and timing during an event episode (positive or negative) may contribute factors and a context that were not studied.

Some research has identified normative tendencies for adjustment. One example, is that the year following diagnosis and treatment sometimes represents a crisis in patients' lives (Spencer, Carver, & Price, 1998). These tendencies have not been reviewed extensively, nor how these tendencies may correlate with the trajectory of the cancer experience over time. Events as studied may represent another factor that modifies a trajectory. Having cancer is also a series of interconnected stressful events. By the comments made by enrollees, the evaluation of the cancer experience includes a cascade of influence, which occurs over time, within the context of diagnosis, treatment, continued follow-up, recurrence, symptoms and side effects, contributing to the evaluation. Therefore, when a study is conducted, and how PGWB may be affected as a result of timing may decidedly affect outcome. The state of psych morbidity for each study participant may also play a role in results.

Many of the enrollees who responded to the question suggested by the comments made, living with cancer may become all-consuming as in consuming one's life. For others, cancer is not at the forefront, but intertwined with one's total life's script. On a micro level, it is one part of many parts in the script-- significant people and significant events on a very personal level. On a macro level, cancer is co-mingled with current world affairs and the feelings towards the international theater, with each of us part of a captive audience.

Subscale results. Results of subscales are important, important not to posit these as significant to the study as it was designed, but to highlight their potential for research in the future. Since anxiety and depressed mood were subscales with significant results (with a general linear model), these results encourage further investigation. A larger N could result in other significant subscale results. Conversely, further study with a larger N could result in acceptance of the null hypothesis, without any need to elaborate on the subscales. Alternatively, anxiety ($p = .017, p \leq .05$) and depressed mood ($p = .028, p \leq .05$) may warrant attention as separate dependent variables.

Study Results: Relevance to Literature

Group Support

Some concern was expressed by study participants that related to the interpersonal experience differences among group attendees. For example, within the group sessions specific members had experienced abandonment by their spouses, expressed during group support sessions, which in turn created more anxiety for newcomers attending group support. Yet, from focus group accounts, individuals who attended and continued to attend group support sessions consistently said, that the low moments for the group

dissipate over time (Harper, 2000 [Focus group results of participants and non-participants of group support] Unpublished raw data). Both acceptance of death and the intrapersonal crises of each member adds strength to one's individual experience with living with cancer. Most persons describe this phenomenon as "you learn if 'they' can get through the emotional turmoil, so can I". This experience is consistent with the findings of Stevens and Duttlinger (1998) that established members who attended group regularly rated group as more supportive. However, the physical aspects of attendees' stage or prognosis seemed just as important as their personal circumstances in the formulation of study participants' opinions about group support.

The content and the interpersonal dynamics of group support sessions should be considered, reflected in the phenomena discussed by attendees of group support. The stories of others expressing such events as declining health, and a graver prognosis or negative network factors adversely affecting their lives lent to attendees feeling worse, not better. These experiences did, in some cases, precipitate attendees to withdraw from group support. This finding is consistent with Helgeson and Cohen's (1996) description of downward comparisons during group support, which in turn may cause negative results.

Peer-discussion during group support sessions may also alter the perception of one's naturally occurring network. As in another study by Helgeson and Cohen (2000), some persons may feel better (upward comparisons) or worse (downward comparisons) as they re-assess their reality and adjust their perspective and expectations about their current network, based on the experiences others expressed. Reactions such as these to

group support may affect adjustments to the cancer experience that prompt both positive and negative views of support.

Psychomorbidity and group support. Staging for the severity of psychomorbidity may also be considered based on the degree of threat perceived by each individual, often influenced by the culmination of life circumstances and personality. Psychosocial screening too may be helpful as an aid in predicting which clients are likely to experience significant difficulty in their adjustment to a cancer diagnosis and its treatment as has been suggested by others (Zabora et al, 2001). It may be effective to construct profiles, which could be used to help identify clients at high risk. The profile could be helpful to all health care professionals that encounter persons with cancer.

Many factors may contribute to development of psychomorbidity screening. Factors like time interval out of treatment and the proximal time of study measurement in relationship to a definitive diagnosis may be influential on mental health status as other research has proposed (Given, Given, & Stommel, 1994; Vinokur, 1990). Beliefs about health self-control and treatment expectations may have a correlation with mental health status (Marks et al, 1986). Importantly, there are mechanisms like coping, and social adjustment that have historically emerged from the literature as influences to psychological distress (Bloom 1982; Bloom & Spiegel, 1984; Folkman & Greer, 2000; Schnoll et al, 1998). These and others may be incorporated in a screening tool for psychomorbidity.

The incongruent pretest and posttest scores among the support and comparison groups should prompt probes of the importance of stage of disease or illness and the possible coexistence of a related or an unrelated parallel stage of psychomorbidity.

Although age had a very weak association with PGWB ($r=.061$, $p\leq .05$) in this study, other studies have demonstrated age does positively correlate with improved status (Cassileth, 1984). Knowing the status of psychomorbidity may contribute to an adequate screening of how persons may be assessed for the benefit of group support.

Anderson (1992) suggested stage and severity of illness may be precipitates of psychomorbidity. Yet, psychomorbidity may be better aligned with a psychologically-based diagnosis and prognosis rather than stage of disease. A graver psychologically-based diagnosis or status may require more intensive support than those with more psychological stability, which may require less intensive and more interim support. Conversely, we may be better informed by exploring phenomena by which individuals consistently cope well with their diagnosis and treatment, despite a grave prognosis.

The degree of fear about the uncertainty of the disease and its progression may also be a factor. Recurrence may intensify psychomorbidity. Several authors have suggested recurrence may be more disturbing than the initial diagnosis because recurrence has ominous implications for longer-term survival (Kornblith, 1998; Spencer, Carver, & Price 1998). Uncertainty and recurrence deserve attention in the development of screening criteria. Research designs that direct the timing of an intervention or activity in conjunction with diagnosis, treatment phase, and recovery may better inform us, because each is a probable and critical contribution to the effect of group support.

Group support: selection and assembly. Based on the frequency of “depressing” concerns voiced by persons who attended group support, other probes may direct professionals to provide support on how individual groups for cancer support are assembled. There may be a way of structuring group support that better accommodates a

psychological or even a stage-related homogeneity among group members for pre-defined sessions that increases effectiveness. For example, an evaluation may be developed to help assess persons in their state of psychosocial evolution with the cancer diagnosis and its treatment. As Weinstein, Rothman and Sutton (1998) hypothesized, interventions are more useful when persons can be identified at various stages by their point in a unique health-decision continuum. Stage theory may have relevancy to support groups. Coupled with psychomorbidity, staging, knowing where individuals may be on such a continuum, might generate another criterion for assembling groups. Many groups already assemble based on their site of cancer disease. Groups assembled by and sponsored by formal organizations, with the resources to provide for this consideration, may explore the benefit of doing so. Assembling groups on the basis of each individual's unique stage, however, may have the undesirable effect of limiting the benefit from longer-term support attendees, some of whom have confronted adversity, and emerged with a valuable perspective to share.

Weaknesses and Strengths

As in any study, weaknesses become more apparent post design and after findings are analyzed. First the design of the study is discussed followed by other factors that may represent improvements to be incorporated in future studies. Strengths follow with less emphasis, given the unequal and inadequate sample sizes attained for the study.

Weaknesses

Design. An ANCOVA design, with a strict significance level and effect size for power, does require larger sample sizes. Although the comparison group met the requirement, the support group did not. Unequal sample sizes played a critical role in the

results. Notwithstanding these results, if the chosen covariates were re-tested with adequate and equal sample sizes, an interaction may be confirming, the covariates may not have any influence despite some of the findings of prior research. The results should prompt reconsideration of the statistical design.

The strength of the qualitative analysis was compromised by how the “intervening event” was captured. Although a function of the design of the study, at study inception these data were intended to elicit perception, but not the depth of qualitative inquiry. The similarity to qualitative paradigms were the techniques employed, to use qualitative vernacular, the themes described from the derivation of data approximating content analysis. The analysis lacked the rigor and depth required by a qualitative paradigmatic approach. For example, saturation was not achieved as in grounded theory, nor the rich interpretation found in phenomenology, but the data was all represented. The question encompassed the first phase of discovery. Qualitative tools for analyses were used to establish a focus for the data, and a means by which categories or themes may potentially emerge (Miles & Huberman, 1994; Strauss & Corbin, 1990). Although data must be mitigated by the lack of rigor, the inclusion of the “intervening event” question was also a data complement to the study, rarely observed in other studies.

Another compromise to data and results were that only three of the nine attendees of group support actually attended all 12 sessions, the threshold or “dose” of group support. Attendance and its effect on the DV cannot be analyzed given the data. Attendance is rarely reported in other studies reviewed, but research with ill populations should accommodate this modifier in studies.

Recruitment. Active recruitment efforts were diminished by a number of factors. A critical assumption was that a reasonable proportion of the population sought for study enrollment would perceive group support as one alternative to relieve tension, or anxiety or provide psychic relief. Therefore, study enrollees would attend group support in some equivalent proportion to the non-attendees. This was not the case.

The personal attention of the researcher was key in the recruitment efforts. The investigator was present at oncology sites three and four times a week to approach potential enrollees about the study. Fifty of the 56 enrollees were recruited personally by the investigator. When others spoke about the study in the researcher's absence, there were only two enrollees, both were referred by health care professionals, a physician and a nurse. Direct access to the potential study population by the researcher was critical to recruitment. When direct access was denied, enrollment dropped to almost zero.

There are a number of interacting factors that affected recruitment efforts. Consistent with the research published by Stommel, Edwards, & Given et al., (2001), the context of the first contact, levels of access, competition with other research, and organizational features, like gatekeeper control, all contributed to the recruitment outcome in this study. As indicated, the personal attention of the researcher permitted a full explanation and disclosure of the study. A review of materials, such as the questionnaires were discussed, and questions answered immediately. Although large posters and brochures announcing the study appeared at every site; and in all cases where permitted, staff were oriented to the study in order to understand and explain it to possible enrollees, only a few cases were directed to the researcher by the staff.

Organizational issues were prominent characteristics for recruitment. Gatekeepers at every access, and in some cases gatekeepers under-qualified to determine investigator-access, diminished contact with potential enrollees. On two occasions, key sites where enrollment interest was critical to the study, the leadership changed, study support lost momentum and re-entry for investigator access was predicated on volunteer input rather than organizational direction from a well-informed program leader. Commitment by the organization clearly was beyond written permission and required an understanding and a willingness from the organization to embrace the research project and take ownership of supporting access operations. Finally, at another site, the investigator was competing with a well-funded, large and prestigious university-based study, for which the site leadership admitted, came first.

In both directions, site-sampling bias existed beyond the inherent bias embodied by enrollees who decided to attend group support and those who did not. Enrollees recruited from TWC predictably had a bias towards joining group support. Enrollees recruited from oncology sites had a bias towards not attending group support; this phenomenon was not anticipated. In part, this bias may be explained by oncology provider bias, since one provider, in retrospect, had an unfavorable perspective towards group support. However, another provider from whose site an equal number of enrollees were recruited, was a strong advocate of group support. This view may also be expanded to what Neumark, et al. (2001) posited: “sampling bias starts with subjects who are eligible, but do not participate” (p. 363).

Another more insidious and intangible barrier to recruitment is the protection of the client base within organizations, particularly community-based organizations,

unlikely to have formal research policies and which are frequently managed in part by a volunteer staff. Protection of clients, clients particularly perceived as the most vulnerable, are sometimes guided by untrained and ill-informed staff. Allegiance to programs may also circumvent research efforts in favor of non-research activities. Importantly, organizations as these, do not consider the ethical considerations of diminishing the opportunity for research engagement on behalf of clients, effectively making the decision for “their” clients. The terms used are deliberate because “their” is often a presumption of possession, as in ownership, “they’re my patients or clients” that warrants ethical and legal review to provide the proper framework by which research should be considered by these organizations.

Professional bias may also play a part in shaping the perspective of their clients about group support, which in turn may have affected recruitment and self-selection. Because recruitment sites included oncology offices and large cancer centers where oncologists and nurse oncology specialists practiced, professional biases were observed. Some physicians and nurses felt group support was unfavorable for many of their clients. Other professionals referred their clients to group support readily. Neither professional cohort is likely to be well-informed of the results of research in this area and how group support is managed in different environments, in different sites and by different facilitators.

In summary, establishing a relationship with an organization in order to conduct research is often an arduous and unfulfilling process. Even when signed agreements are obtained, the barriers have not been removed, they have just begun.

Group support. There were other issues underestimated in the design, which precipitated lost research opportunities. The comparison group may have offered critical data by their non-attendance of group support. Although a few non-participants did not attend group support for practical reasons, many more were determined not to attend for other reasons. These reasons were not included in the design of the study. In anecdotal discussion, study enrollees did not attend because of their visions of the lack of benefit – scenarios of sad stories, self-pity visions, and in their opinions, self-destructive perspectives that would be perpetuated by joining a group. Others, seemed centered, cheerful and did not anticipate the need, their assessment and decision not to attend seemed appropriate for them. An opportunity may exist to better understand these perspectives, and expand our knowledge about group support.

Demographic considerations. In the 59 participants who initially enrolled in the study, 56 responded to the fill-in question that addressed “race/ethnicity”. Fifty enrollees (89.29%) completed the question with “White or Caucasian”. The demographic representation is consistent with many other studies that report race, ethnicity or both. Race in the literature reviewed was reported more frequently than ethnicity, when these demographics were reported at all. Given the demographic representation of enrollees and the lack of ethnic representation, there cannot be any inferences drawn. Future studies may require well-informed techniques to garner interest from other cultures to join studies investigating support groups.

Clearly, there is a need to incite exploration about why there may be a profound absence of participation by other ethnic groups with the dramatic and changing US population. Presumably, persons of different ethnicity, who agree to participate in

studies, may reflect diverse cultural interests, with a potential for different results in studies. More discussion is presented in a different section of this chapter.

Strengths

Demographic. Although the population sample had a disproportionate number of female participants ($n=39$), males in the sample ($n=17$) represented 30.36%, which is more than many other studies reviewed. There is a predominance of women in many group support studies, with many studies without any male participants.

Retention. Davis Broome and Cox (2002) recently reported their findings of a review of retention strategies in 21 community-based studies that met their criteria. Of the retention outcomes reported between 1990-1999, between 44.4% to 99.0% of study enrollees were retained. Study periods ranged between 12 weeks and two years. Reasons cited for retention were the number and timing of follow-up contacts (including between assessment contacts), the study's significance (as related to enrollees), and providing meaningful incentives. Other reasons correlated with attrition were illness severity, poorly trained staff and time-consuming contacts. In this study, 52 of 59 enrollees were retained throughout the study period, 52 completed all parts of the study, three completed all parts but the posttest, three were lost to follow-up due to death (2) and ineligibility discovered after pretest (1). Of the 56 enrollees, 52 were retained until study closure, a 92.85% retention rate. The retention rate was achieved with 44% of the enrollees at Stage III or Stage IV disease.

The design of the study deliberately reflected a consideration for the severity of illness likely to be encountered. Initial contact was often during times where enrollees were in recliners receiving intravenous treatment and were receptive to a discussion about

the study. A commitment to maintain short periods of contact during the telephone interviews planned was made and reviewed during the initial explanation of study components to potential enrollees. During these initial contacts for recruitment, several enrollees frequently alluded to their wishes that interviews be brief, although not an explicit condition to their agreement for study participation. Although allowing the study enrollee to choose how much information and how much time was shared with each interview beyond the intent of the query, time may have affected the study's qualitative elaboration; it could have also positively contributed to successful enrollee retention. Investigator skill, ability to dialogue about the study readily and the legitimacy of the study by the investigator's credentials were also important to enrollees during the study period. Despite weaknesses in recruitment, retention was a strength, reflected in part to a design strength that enrollee retention.

Quantitative analyses. Although there was the probability the study's outcome would not have significant results, unequal sample sizes a preeminent signal, several statistical analyses were applied to the data for scientific rigor. The preliminary criteria for the application of ANCOVA were tested, other inferential statistics: ANOVA, a general linear model (subscale analysis), and descriptive approaches were undertaken to uncover how the data collected may be reviewed, analyzed and inform research.

An important strength of the study was the selection of the instrument for psychological general well-being measurement, the PGWB index. As reported in Chapter 4, the PGWB index had significant results on each subscale alpha coefficient for the sample population, with one exception, general health (.54), which may be related to the chronic illness of the study population. When compared to other test populations (Rand)

results held up to statistical scrutiny with significant alpha coefficients in all subscales (pretest total= .94; posttest total= .93).

Finally, despite the limitations in descriptive analyses from the complementary data and “intervening event question”, therein lies a strength in at least data accrual, a void in other studies. In other studies reviewed, complementary therapies were not documented, unless these were part of a complex intervention design. Likewise, there was not the design consideration for effect of the inevitability of life occurrences during a study period, a likely contribution to outcome.

Demographic, Social, and Cultural Implications

Factors that determine the psychological adjustment to cancer are society-derived (beliefs and knowledge), patient-derived (intrapersonal) and cancer-derived (site, stage, and symptoms) according to Holland (1998), but there are many other factors that expand this base of predisposition to adjustment. Predictors of and changes to the measurement outcome of psychological well-being may also be a product of demographic, social and cultural variables. The following highlights how these variables may affect the measurement of psychological well-being and influences in the outcome of this and past studies, and in future research.

Socioeconomic Status and Psychological Support

Socioeconomic (SES) status and its association with health is not new. However, cancer disease sparks interest because of the contrast between incidence and mortality patterns. While the incidence of cancer may vary with decreased and increased SES for many cancer sites, the pattern of cancer survival is consistent. As SES decreases so does the rate of survival (Balour & Kaplan, 1998). Thus far in studies most of the pathways

responsible for the outcome of survival are associated with SES factors that may cause exogenous differences. Lifestyle, access to medical care, and health behaviors affect one's exposure to cancer and its agents. Social class in studies have also demonstrated that tumor stage at diagnosis, "late-presenters", may be one reason for decreased survival (Balour & Kaplan, 1998). If SES is a factor in survival, and access to medical care is one but many issues, then perhaps, SES may also be a factor in how and if psychological or group support is accessed.

Vulnerable populations have been defined as social groups who experience health disparities and or increased exposure to risk . Subpopulations may be identified by color, poverty, age, gender, disease, immigrant status and or religion. Although history and oppression varies with different populations, almost always the common denominator has been diminished or disproportionate resources. Vulnerable populations have become synonymous with the underserved (Flaskerud et al., 2002). Despite the improvement in the nineties with a focus on establishing the existence of health disparities by the comparison studies between the advantaged and the disadvantaged, psychosocial risk in the literature was more distinctly about socioeconomic risk. Psychological morbidity among vulnerable populations has not been on the research agenda. The underserved have also been underrepresented in much of the research (Weston, Rapkin, Potts, & Smith, 1998). The following discusses why we may continue to know so little about psychological responses to cancer among vulnerable populations, and in doing so, help illuminate their underrepresentation in this study as well.

Recruitment

Despite the community-based study done here, with multiple sites across local, but extensive geography, there was an underrepresentation of persons of color and ethnicity. By observation, there was also what appeared to be an underrepresentation of non-white persons seeking care at the clinics and hospitals where recruitment was done. Additionally, the more functionally-infirm someone was, the least likely they were to join the study. For example, persons who felt very tired and were symptomatic from disease or treatment at first contact, were less likely to enroll in the study. Others, were fearful that fatigue and illness would set in soon during treatment and were reluctant to make a commitment to a study, not knowing how they would feel in the weeks and months to come.

Age did not seem to be a decided factor, but in other studies greater functional impairment and cancer diagnosis, along with age played roles in whether consent was obtained for studies. Although researchers have found cancer diagnosis and treatment made recruitment and retention of this population challenging, other researchers reported race did not affect consent, but raised odds of drop out after consent (Neumark, Sommel, Given, C. and Given, B., 2001).

Potential Barriers to Group Support

SES, low educational attainment, male gender, older age, drug usage, and low rates of health utilization are characteristics that describe persons least likely to participate in community health efforts. The role of gender in the underserved has been equivocal because health messages tend to be received by women more than men, despite the message (Weston et al., 1998).

If the health promotion message, self-help and prevention models are less likely to reach and be understood by underserved populations, programs like group support are unlikely to be accessed by vulnerable populations. Further, as cultural or ethnic barriers persist, the means by which one may hear the message persists as a barrier too. For instance, interventions or health promotion efforts are often not culturally grounded. Some health behaviors by the underserved are adaptations to a history of oppression, where mistrust prevails.

Access to group support may be further compromised by cultural differences. Non-western cultures sometimes believe illness is a punishment. Current theoretical models often are Eurocentric, without accommodation for other belief systems. In non-western traditions, family is often central to decision-making about if and when care and support is accessed. Individualism, and a reliance on others (outside the family), traits for accessing and benefiting from group support, are not often valued in Asian and Middle-Eastern cultures. Group support strategies are also not anchored in the cultural mores of others, but rather assumes a Western norm for communication (Weston et al., 1998)

Finally, there is a myth about an existing homogeneity among the underserved. There are cancer risk differences and there are psychological differences embodied in different beliefs and values. There are inter-group differences and there are intra-group differences (Weston et al., 1998). Persons are members of a group aligned with values and mores, but they are each, first and foremost, individuals. The individual, aligned with unique identities exclusive of a population subset, is sometimes lost in the popular and current trajectory of the well-intended healthcare agenda of serving the “vulnerable”, the marginalized, and the underserved. Our current structure and strategy for recruitment and

understanding the psychological risk which may manifest in vulnerable populations will not yield results. In the view of Flaskerud and Nyamathi (2001), we need another paradigm to understand health and access disparities.

Recommendations for Further Research

The study of group support and its effect on psychological well-being still has merit. The statistical weakness with unequal sample sizes should not preclude further study nor discourage the possibility that group support may have a net effect of improving psychological well-being. Replication of the study may reveal different outcomes with equal sample sizes. The use of the PGWB instrument with a similar study design at higher recruitment levels may yield significant results. The use of ANCOVA should be examined, particularly since age and stage of disease were not significant extraneous factors, and other results support other life and disease factors, which may be influential in results. Subscale results indicated there may be value in exploring anxiety and depressed mood, but these and other like intrapsychic measurements should be pursued without prematurely dismantling net psychological assessment in favor of component scores. Multi-scaled instruments have been studied extensively in the literature, with equivocal results.

Although the group support as studied did not have significant results, many other phenomena were revealed by the study. The underlying causes of recruitment leading to dramatic disproportionate sample sizes may require more investigation. Despite organizational issues as a contribution to enrollment inequities, there was a pronounced disinterest in group support attendance by many who the investigator encountered in the enrollment effort. There were score disparities in both groups at pretest and at posttest

times, enough to speculate on the possibility that individual differences played a greater role in score differences than participation in group support. Findings such as these may be confirming to other research that intrapsychic mechanisms are critical to coping with chronic disease and may also be a decisive factor in determining who benefits from and who attends group support.

A better understanding about persons who do not attend group support is needed. Some persons who do not attend lack awareness or have practical reasons for not attending, but there may be two kinds of persons who may readily inform us. Persons who elect not to attend because they have a favorable psychological status and an innate ability to cope or adjust to psychological distress. Second, persons who don't attend because of negative visions of what support groups are, and the role they might need to play in group interactions.

Despite the lack of significant results in the quantitative component of this study, the inquiry performed by qualitative methods revealed substantial information from which to formulate subsequent research endeavors. The description of the event query, although most often responded to with short answers, the short answers were informative. By coupling the findings from this study, with an expansion of the intervening event query and finally a qualitative inquiry that pursues a better understanding of non-attendees of group support, we may expand our discovery.

Another substantial area for further research efforts is research that directs attention to psychomorbidity risk screening in order to help determine who benefits from group support. More studies may be valuable that pair individuals with their place on an evolution continuum based on their stage or adaptation of living with chronic illness that

incorporates many factors. These and other investigations may also tell us more about, how and if, the assembly of groups make a difference. Do some persons benefit more from the interaction of groups of persons with cancer that are deliberately homogenous? If so, on what basis should homogeneity be determined: age, disease factors, psychological morbidity, evolution of illness continuum?

The culturally diverse communities in which we now live, the changing of the social and ethnic make-up of the U.S., begs another question about the homogeneity of group support. Should homogeneity extend to a more serious consideration about the differences by which cultural beliefs and the resulting symbolism about health care are incorporated into the assembly of groups? The effectiveness of group support is, at least on speculation, dependent on individually –based endogenous values and strengths. The individual is shaped by familial-cultural attachment, and then by the exogenous influences generated from within a localized milieu or socio-cultural foundation. Explanations and beliefs about cancer causation affect psychological adjustment. Cultural factors, including the influence of language, how disease is discussed and how psychological distress is perceived and reported may affect outcome (Die-Trill, 1998).

Ultimately, cultural factors culminate in a view of group support and how one considers it for psychic relief. However, if group support is contemplated, is it available and accessible by its structure, language and context so it is useful to individuals with very distinct cultural orientations and their corresponding psychological responses to illness? In some communities, particularly Latino geo-communities, group support is offered in a cultural context. In many other geographic and culturally-distinct

communities, the affective domain of culture and language is ignored and does not help us to understand if group support may be beneficial.

People differ in their repertoire of coping responses. Group support was studied because it is one that persons with cancer may choose to cope and it is clear that research has yet to uncover the effect of group support. The content of group support sessions requires more attention. It is still unclear what kinds of group support sessions may be the most beneficial, if at all. We have yet to differentiate for effect, the kind of sessions, which focus on education from professionally-facilitated with a singular focus of group interaction dynamics, as compared to multi-varied sessions with other features, such as music, relaxation, and other modalities.

Although complementary therapies in this study were not accessed enough to provide useful information, the growing popularity and the increasing availability of these services is likely to and should spur more study and more controversy. The context within which any service is considered is important and should be described. How persons are using and interpreting resources at hand like complementary therapies helps us understand potential benefits, and how much to weigh these in a research design.

Despite secular discussions of the availability and the popularity of attending complementary therapies in western culture, few persons in the study accessed these therapies, and when they did, they attended these inconsistently. It may be that what we define as complementary therapies, are not what persons with cancer are doing. These may not have relevancy to persons with cancer specifically, but are more tied to a wellness paradigm that prevails in our popular culture now, a representation of trend, not necessarily a direct benefit for an ill population.

Because complementary therapies are difficult to self-measure for effect and benefit, when health improves, prognosis is better, or disease is in remission, persons may abandon their effort. Likewise, when disease or symptoms have progressed, persons may abandon the effort because the activity has not yielded the desired result. Perhaps, the most plausible explanation is that the use of complementary therapies is just a small part of an extraordinary journey, the cancer experience. With episodic acute illness, and a long-term sequelae from a cancer diagnosis, it may be that the experience causes a waning effect, a wandering commitment to complementary therapies, given the unevenness of the cancer experience itself.

Finally, studies about the complexity of life and the interpretation one may attribute to their experience with cancer may illuminate our understanding of how group support may help. Persons living with cancer have vastly different reactions to the diagnosis and its ongoing sequelae--for some living with cancer prevails over all other life activities, a formidable force. For others, it is secondary to other vital scripts occurring in one's life.

Conclusions

Although the findings from this study's sample prohibits generalizing to other populations, the following is suggested: (a) measurement of psychological status may be complex; (b) there are confluence's to the determination of psychological-well being as suggested by descriptive and qualitative data; (c) group support may not improve psychological well-being or there may be a subset of individuals that benefit; (d) the PGWB schedule may not be the best measure to adequately determine the effect of group support; and, (e) it may be helpful to develop screens to better detect psychological

morbidity; and, by doing so, help those that are at higher risk for sustained psychological morbid states.

It may be that the complexity of disease, paired with the complexity of psychosocial health and morbidity creates a very complex model by which to study a psychosocial action that may benefit participants consistently. The initial premise of the study was that the selection of a single measurement for psychological status was a better approach than a multi-scaled instrument. The study's results, although not significant, indicated that there may be multiple reasons for why group support may not be efficacious. Some speculation is warranted to further incite and motivate researchers and other studies.

The PGWB measurement, given its reliability and validity as an instrument is an unlikely culprit for the lack of significant results, but unequal sample sizes may be one probable agent. The other explanation is the possibility that persons' psychological status is determined and transformed by a variety of life events and circumstances beyond what the study attempted to measure. These phenomena may be united with a pre-existing and prevailing disposition to cope well with adversity, or conversely, require support during an episode of illness.

The confluence discussed may suggest that a better understanding of individual psychosocial risk is required to first screen individuals and then understand how participation in group support interacts with individual risk profiles. It may be that group support does not lack efficacy, but instead and more importantly, research may need to determine who may benefit from its effects.

Although the results from the quantitative analysis must be mitigated, the outcome of the quantitative analysis and the qualitative inquiry indicates there are significant opportunities to learn more about the effects of group support. Despite results replicating the equivocal outcomes of other studies, this study has informed research by the choice of measurement, the possibility that psychological well-being may be a measurement of choice in group support studies. It has also broadened the research investigation by extending study exploration to complementary therapies and intervening events. Finally, by the outcome of recruitment and the perspective of non-attendees of group support, it revealed the position asserted by proponents of group support, a position that purports a prevailing access and benefit, should be closely scrutinized.

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Demographic Data Tool

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All information is confidential and will only be known to the investigator. The identity and information about specific individuals will not be disclosed.

1. Telephone number: _____	Code: (To be assigned by investigator): _____
2. Your Age Today	In years only: _____
3. Gender: Please circle one.	(a) Male (b) Female
4. Marital Status: Please circle one.	(a) Married (b) Unmarried
5. Income: Please circle one	(a) 0-10,000 (b) 10,001-20,000 (c) 21,000-35,000 (d) 35,001-50,000 (e) 50,001-65,000 (f) 65,001-80,000 (g) 80,001-100,000 (h) over 100,000
6. Race/Ethnicity PLEASE FILL-IN	_____
7. Education: please circle one.	(a) Less than 12 years completed (b) 12 to 14 years completed (c) 15 to 16 years completed (d) Post graduate education
8. Employment: please circle one	(a) Unemployed (b) Leave of absence (c) Full-time (d) Part-time (e) Unemployed, but not retired (f) Retired and not working

Demographic Data Tool

	(g) Uncompensated Volunteer Other: _____
9. Living arrangements: please circle	(a) Live alone (b) Live with at least one other person, who is not dependent on my care (c) I am responsible for at least one person(s) living with me Other: _____
10. Month and year of diagnosis	Month _____ Year _____
11. Site of Primary Cancer: Please circle one or write in your response under Other. If you do not know, circle here: "I do not know".	(A) lung; (b) breast (c) prostate (d) colon (e) skin/melanoma (f) brain (g) liver (h) bone (i) thyroid (j) lymphoma (k) other _____
12. Please circle the stage of your cancer disease today: If you do not know, circle here: "I do not know".	(a) Stage I (b) Stage II (c) Stage III (d) Stage IV
13. Circle the therapies that have been used to treat you and your cancer in the last 18 months	(a) Surgery: for treatment, not for diagnosis or staging of your cancer disease (b) Chemotherapy only (c) Radio-therapy (radiation) only (d) Chemotherapy and radiotherapy (e) Surgery and Chemotherapy (f) Surgery and Radiotherapy (g) Surgery, Chemotherapy and Radiotherapy Other: _____

Demographic Data Tool

<p>14. There are other services persons with cancer may use to help them such as relaxation therapy, music therapy, exercise therapy, meditation among others. In the box to the right, please indicate if you have used these services in the last 24 months. Also indicate what these are and if you are still using these services.</p>	<p>(a) I am not using any other support service now____ (Check here if you are not).</p> <p>(b) I am attending _____(which service)</p> <p>(c) I did use _____therapy for _____(how much time, days weeks, months), but no longer use this service.</p>
<p>15. If you are involved in any other support group other than the one stated at the bottom of this form, please write it in.</p>	<p>Are you involved in any other support group now_____(yes/no)</p> <p>Have you participated in any support group in the last 24 months? _____(yes/no)</p>
<p>16. I would like your permission to contact your physician's office to verify the clinical information (such as cancer site, and stage of disease or treatment) requested on this form. If I have your permission, please sign and date the box to the right.</p>	<p>I give my consent to Joann Harper to further contact my physician for more information.</p> <p>Sign: _____</p> <p>Date: _____</p> <p>Physician's name: _____</p> <p>MD's tele no. _____</p>

If you plan to attend group support, please complete the following information:
The investigator will contact you during the study in order to monitor your participation in the study.

Name of Group _____ Day and Time: _____ Facilitator Name: _____
Name of Facilitator _____

Psychological General Well-Being Schedule

J. Dupuy

NAME: _____ SEX: M [] F [] AGE: _____
Last First Middle

READ: This section of the examination contains questions about how you feel and how things have been going with you. For each question, put an "X" in the [] by the answer which best applies to you.

1. How have you been feeling in general? (DURING THE PAST MONTH)
 - [] In excellent spirits
 - [] In very good spirits
 - [] In good spirits mostly
 - [] I have been up and down in spirits a lot
 - [] In low spirits mostly
 - [] In very low spirits
2. How often were you bothered by any illness, bodily disorder, aches, or pains? (DURING THE PAST MONTH)
 - [] Every day
 - [] Almost every day
 - [] About half of the time
 - [] Now and then, but less than half the time
 - [] Rarely
 - [] None of the time
3. Did you feel depressed? (DURING THE PAST MONTH)
 - [] Yes - to the point that I felt like taking my life
 - [] Yes - to the point that I did not care about anything
 - [] Yes - very depressed almost every day
 - [] Yes - quite depressed several times
 - [] Yes - a little depressed now and then
 - [] No - never felt depressed at all
4. Have you been in firm control of your behavior, thoughts, emotions, or feelings? (DURING THE PAST MONTH)
 - [] Yes, definitely so
 - [] Yes, for the most part
 - [] Generally no
 - [] Not too well
 - [] No, and I am somewhat disturbed
 - [] No, and I am very disturbed

5. Have you been bothered by nervousness or your "nerves"? (DURING THE PAST MONTH)
- ☐ Extremely so - to the point where I could not work or take care of things
 - ☐ Very much so
 - ☐ Quite a bit
 - ☐ Some - enough to bother me
 - ☐ A little
 - ☐ Not at all
6. How much energy, pep, or vitality did you have or feel? (DURING THE PAST MONTH)
- ☐ Very full of energy - lots of pep
 - ☐ Fairly energetic most of the time
 - ☐ My energy level varied quite a bit
 - ☐ Generally low in energy or pep
 - ☐ Very low in energy or pep most of the time
 - ☐ No energy or pep at all - I felt drained and sapped
7. I felt downhearted and blue DURING THE PAST MONTH.
- ☐ None of the time
 - ☐ A little of the time
 - ☐ Some of the time
 - ☐ A good bit of the time
 - ☐ Most of the time
 - ☐ All of the time
8. Were you generally tense or did you feel any tension? (DURING THE PAST MONTH)
- ☐ Yes - extremely tense, most or all of the time
 - ☐ Yes - very tense most of the time
 - ☐ Not generally tense, but did feel fairly tense several times
 - ☐ I felt a little tense a few times
 - ☐ My general tension level was quite low
 - ☐ I never felt tense or any tension at all
9. How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)
- ☐ Extremely happy - could not have been more satisfied or pleased
 - ☐ Very happy most of the time
 - ☐ Generally satisfied - pleased
 - ☐ Sometimes fairly happy, sometimes fairly unhappy
 - ☐ Generally dissatisfied, unhappy
 - ☐ Very dissatisfied or unhappy most or all of the time

10. Did you feel healthy enough to carry out the things you like to do or had to do? (CURING THE PAST MONTH)

- ☐ Yes - definitely no
- ☐ For the most part
- ☐ Health problems limited me in some important ways
- ☐ I was only healthy enough to take care of myself
- ☐ I needed some help in taking care of myself
- ☐ I needed someone to help me with most or all of the things I had to do

11. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile? (DURING THE PAST MONTH)

- ☐ Extremely so - to the point that I have just about given up
- ☐ Very much so
- ☐ Quite a bit
- ☐ Some - enough to bother me
- ☐ A little bit
- ☐ Not at all

12. I woke up feeling fresh and rested DURING THE PAST MONTH.

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time

13. Have you been concerned, worried, or had any fears about your health? (DURING THE PAST MONTH)

- ☐ Extremely so
- ☐ Very much so
- ☐ Quite a bit
- ☐ Some, but not a lot
- ☐ Practically never
- ☐ Not at all

14. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? (DURING THE PAST MONTH)

- ☐ Not at all
- ☐ Only a little
- ☐ Some - but not enough to be concerned or worried about
- ☐ Some and I have been a little concerned
- ☐ Some and I am quite concerned
- ☐ Yes, very much so and I am very concerned

15. My daily life was full of things that were interesting to me DURING THE PAST MONTH.

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time

16. Did you feel active, vigorous, or dull, sluggish? (DURING THE PAST MONTH)

- ☐ Very active, vigorous every day
- ☐ Mostly active, vigorous - never really dull, sluggish
- ☐ Fairly active, vigorous - seldom dull, sluggish
- ☐ Fairly dull, sluggish - seldom active, vigorous
- ☐ Mostly dull, sluggish - never really active, vigorous
- ☐ Very dull, sluggish every day

17. Have you been anxious, worried, or upset? (DURING THE PAST MONTH)

- ☐ Extremely so - to the point of being sick or almost sick
- ☐ Very much so
- ☐ Quite a bit
- ☐ Some - enough to bother me
- ☐ A little bit
- ☐ Not at all

18. I was emotionally stable and sure of myself DURING THE PAST MONTH.

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time

19. Did you feel relaxed, at ease or high strung, tight, or keyed-up? (DURING THE PAST MONTH)

- ☐ Felt relaxed and at ease the whole month
- ☐ Felt relaxed and at ease most of the time
- ☐ Generally felt relaxed but at times felt fairly high strung
- ☐ Generally felt high strung but at times felt fairly relaxed
- ☐ Felt high strung, tight, or keyed up most of the time
- ☐ Felt high strung, tight, or keyed up the whole month

20. I felt cheerful, lighthearted DURING THE PAST MONTH?

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time

21. I felt tired, worn out, used up, or exhausted DURING THE PAST MONTH.

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time

22. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)

- ☐ Yes - almost more than I could bear or stand
- ☐ Yes - quite a bit of pressure
- ☐ Yes, some - more than usual
- ☐ Yes, some - but about usual
- ☐ Yes - a little
- ☐ Not at all

September 13, 1981

RN
245 La Barrera Drive
Solana Beach, California 92075

Dear Mrs. Harper:

I am sending you, per your telephonic request of Sept 12, some materials about the Psychological General Well-Being (PGWB) assessment instrument.

I personally & on my own, as Psychological Advisor in the National Center for Health Statistics (NCHS), conceptualized and developed the PGWB as an instrument to be used as a Quality of Life measurement of the American adult population (ages 25-74 years). It was used in a national sample of one hundred (100) different locations on 6,713 adults in our National Health Examination Survey.

The PGWB has been translated into at least 14 European languages, plus Japanese, what I know of, as an instrument to be used in national & sub-group assessments of Quality of Life (MAPI, Lyon, France).

Since I was an employee of the U.S. Federal Government when I developed the PGWB Schedule, it is in the "Public Domain," and may be used freely, except it can not be copyrighted for exclusive use.

If I can be of any further assistance, please let me know. I have deep and kind regards for members of the Nursing Profession and am most willing to be helpful when I can.

With kind regards,
PHD

Harold J. Dupuy PhD
Phone (804) 922-7467
253 Alto Road
Vesuvius, VA 24483-9410

1. Code:(to be assigned by investigator)

2. What is the nature of the TWC Session(s) to which you are assigned (participant group support for cancer clients, bereavement, family)?

3. What is your formal educational preparation?

4. Please designate credentials, licenses and certifications you hold:

5. Describe any special facilitator training you have received outside of TWC (please indicate the length and the nature of the training)

6. Please indicate specific TWC Facilitator training you have received including length and content _____
7. Please indicate any specific training you have had in order to conduct specific group sessions, such as bereavement, family or children sessions: _____
8. How long have you conducted group support facilitation_____ and how long have you been a facilitator at TWC _____? (months and years)
9. May I have your contact number? _____

If you have any questions about the study, please contact the investigator, Joann Harper at 760.599.3617.

Code number _____

Treatment Group _____

Non- Treatment Group _____

Variables

Age _____

Date: _____ Pretest score _____

Site of Disease: _____ New _____ Recurrent _____

Date of Diagnosis _____

Stage of Disease _____ Date: _____ Verified by: _____ (Medical record, physician or physician representative)

Date: _____ Posttest Score _____

Treatment Group: _____ **Date** _____

Group name _____ Facilitator _____

Dates of contact: _____

Attendance:

All dates of attendance: _____ OR number of weeks attended _____

Date started attendance _____ Date completed or stopped attending: _____ -

Alternative Therapy:

Alternative Therapy _____ yes _____ no _____ If yes: What
Therapies? _____

When initiated therapies? _____

Intervening event(s):

According to the participant: Please describe any event(s) that has occurred in the last three months that may have caused you to change how you feel about your life (your health, functioning, emotional, social status)?

Response: _____

Notes: _____

Monitoring record

Date of contact: _____
Date started attendance _____ Date completed or stopped attending: _____ -
How many times have you attended your group support session? Weekly? Bi weekly

Alternative Therapy:

Alternative Therapy _____ yes _____ no _____ If yes: What
Therapies? _____

When did you start going to alternative therapies? _____

When initiated therapies? _____

Intervening event(s):

According to the participant: Please describe any event(s) that has occurred in the last three months that may have caused you to change how you feel about your life (your health, functioning, emotional, social status)?

Response: _____

Notes: _____

Non-Treatment Group

Date of Contact: _____

Attendance group support: _____ yes _____ no _____ If yes, when: _____ Where: _____

Alternative Therapy:

Alternative Therapy: _____ yes _____ no _____ If yes: What
Therapies? _____

When did you start attending other therapies? _____

Intervening event(s):

According to the participant: Please describe any event(s) that has occurred in the last three months that may have caused you to change how you feel about your life (health physical, emotional or in any other way?

Response: _____

Notes: _____

--

Monitoring Record

Date of Contact: _____

Attendance group support: yes no If yes, when: Where: _____

Alternative Therapy:

Alternative Therapy: yes no If yes: What

Therapies? _____

When did you start attending other therapies?

Intervening event(s):

According to the participant: Please describe any event(s) that has occurred in the last three months that have caused you to change how you feel about your life (health physical, emotional or in any other way?

Response: _____

Notes: _____

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Name and Title of Authorized Person: _____

Signature: _____

11/26/01

Ph.D.

Date: _____

8555 Aero Drive, Suite 340
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April 2002

The Wellness Community® San Diego (TWCS) is a not for profit organization to support persons who have been diagnosed with cancer. One of the primary services TWCS offers is professionally-facilitated group support.

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TWCS grants permission to Joann Harper to conduct the study with our clients, or work with the TWCS staff to help conduct the study under the following circumstances:

1. A flyer is produced and approved for distribution by TWCS that announces the study and its criteria for participation.
2. An informed consent form outlining the purpose and procedures for the study is signed by each participant in the study. The study is absolutely voluntary for each participant. The informed consent includes explicit information about each person's right to refuse to participate, without any disruption of the services they receive from TWCS. Each person at any time can withdraw from the study.
3. Participants are given information about how the study will be conducted, and any information that will be requested of them during the study.
4. Joann Harper as the principal investigator is available to each person to respond to any questions about the study.

Based on the self-selection approach to the study and the intervention, which examines the outcome of group support on those who participate in it, the study is considered minimal risk to those who consent to the study. TWCS acknowledges that the study will be conducted for about twelve weeks, during which time Ms. Harper will need the cooperation of our support staff and the professional staff that facilitate group support.

While TWCS recognizes the potential benefit which may eventually be derived from its participation in the study, it must at all times be mindful of the well-being of those it serves. By authorizing Mr. Harper access to TWCS participants and operations, TWCS in no way represents that this is a binding agreement with Ms. Harper. TWCS reserves the right to terminate the arrangement with Ms. Harper, without notice, if at any time the well-being of TWCS participants or the integrity of TWCS operations is felt to be compromised by its participation in the study.

Jan R. Barnes, Chief Executive Officer

4-15-02
Date

Holly Hall, M.A., MFT, Program Director

4-16-02
Date

Cancer Support • Education • Hope

April 23, 2002

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To Whom This May Concern:

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Name and Title of Authorized Person: _____

Signature: _____

Date: 4/23/02

cancer support • education • hope

109 West Torrance Blvd., Redondo Beach, CA 90277 • Phone 310/376-3550 • Fax 310/372-2094
website: www.wellnessandcancer.org • e-mail: twcsbc@aol.com

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Name and Title of Authorized Person: Marty Nason, R.N., M.N., Program Director

Signature: _____ Date: June 10, 2002

Please remember The Wellness Community Valley/Ventura in your will.

530 Hampshire Road, Westlake Village, CA 91361 (805) 379-4777 fax (805) 371-6231
www.wellnesscommunityhope.org twcinfo@wellnesscommunityhope.org

Informed Consent Form

Informed Consent: Group Support Study Participant

The effect of professionally-facilitated group support on psychological well-being among clients with cancer

I HAVE BEEN INVITED BY JOANN HARPER, A REGISTERED NURSE AND A DOCTORAL CANDIDATE IN THE PHILIP Y. HAHN SCHOOL OF NURSING AND HEALTH SCIENCE AT THE UNIVERSITY OF SAN DIEGO TO PARTICIPATE IN A RESEARCH STUDY. BEFORE I GAVE MY CONSENT FOR PARTICIPATION, I READ AND UNDERSTOOD THE FOLLOWING:

PURPOSE OF THE STUDY

The purpose of this research study is to examine the differences between groups of persons who participate and who do not participate in group support by learning about group support's influence on psychological well-being.

Procedure

First, if I agree to be in the study, I will decide whether I will attend a support group on a regular basis (a **Participant** of group support) or whether I will not (a **Non-Participant**). Both **participants** and **non-participants** are considered in the study. If I decide to attend group support, my choice will be a professionally-facilitated support group. I understand professionally-facilitated means a group facilitator, who has the professionally preparation for, or is credentialed to provide, psycho-therapeutic sessions and who is assigned to the group by The Wellness Community. The study is designed to continue for twelve weeks. If my choice is to participate in group support, a **Participant**, I will try to attend the support sessions on a regular basis for the twelve weeks. If my choice is not to participate, a **Non-Participant**, I will not plan to attend support sessions during the twelve weeks of the study.

All persons who have agreed to the study will complete three forms. Therefore, whether I decide to be a **Participant** or a **Non-Participant**, as part of this study, I will complete three forms. One form is an information sheet about myself, (education, age, site of cancer, stage of cancer, if known, and other information) that takes about 20 minutes to complete. A second form is a brief questionnaire of 22 multiple choice questions. Some of these questions are about my feelings toward my health, and others are mostly about how I feel emotionally. This form takes about 8 to 15 minutes to complete. These two forms will be completed at the beginning of the twelve week period and before **Participants** start a professionally-facilitated support group. About twelve weeks later, I will complete a third form. This form again takes about 8 to 15 minutes to complete.

Informed consent for the participation in the study of the effect of professionally-facilitated group support on psychological well-being

Procedure continued

In addition, I will be asked to respond to a telephone inquiry midway through the study and at the completion of the study in order to obtain information about attendance, use of alternative therapies and one question about events that may have impacted my life during the study.

Risks

There are minimal risks to me by agreeing to and participating in the study as it is described under the procedure section. There may be uncomfortable feelings aroused in **Participants** of group support. Because persons who attend group support may experience varied feelings as they share their own thoughts and feelings and listen to the thoughts and feelings of others, the group support experience may arouse feelings of anxiety, and an array of emotions that may be uncomfortable. A referral telephone number will be provided for me to call a licensed mental health professional, should I wish to do so.

Benefits

I have been told there is no direct benefit foreseen for my participation in this study. I may benefit from a positive feeling that emerges as a result of my contribution to a study designed to look at ways by which other persons with cancer might benefit.

Participant's Rights

My participation in this study is completely voluntary. I can refuse to agree to participate in this study or withdraw after I have given written consent. Any decision I make, not to participate or to withdraw, shall not influence my rights or privileges to receive any kind of care or service now or in the future. I understand there is no other agreement beyond what has been expressed in this consent form.

Confidentiality

I understand my identity in this study is absolutely confidential and will not be disclosed. Any published document that results from this study will not reveal or disclose my identity in any way. All materials will be kept in a locked file available only to the investigator. All materials will be destroyed three years following completion of the study.

Informed consent for the participation in the study of the effect of professionally-facilitated group support on psychological well-being

Cost

I understand there is no cost to me for participating in the study. If I decide to be a **Participant** of group support, it is of my own choosing, and I will bear or arrange for the cost of transportation or other personal expenses for my attendance. If I choose to mail in any or all of the forms required, I understand, the researcher, Joann Harper will provide a self-addressed, pre-stamped envelope for these forms to be returned to her.

Reimbursement

I understand there will be no reimbursement to me for my agreement to take part in this study.

Informed Consent Statement

I have read and understood the contents of this form. Joann Harper has and will continue to be available to answer any questions I have about the study. If I had questions about the study, they have been answered to my satisfaction. I hereby give my voluntary consent to participate in this study. Signing this consent does not waive any rights nor does it release the investigator or any sponsor from their responsibilities.

I understand I may call Joann Harper at 760.599.3617, the investigator, at any time to respond to any questions or concerns I may have, or Dr. Jane Georges at 619. 260.4566

I understand I will be given a copy of this informed consent form.

"I, the undersigned, understand the above explanations and on that basis, I give consent to my voluntary participation in the study".

Printed Name of Study Participant: _____

Signature of Study Participant

Location

Date

Study's Participant's Address (for mailing if needed)

Signature of Witness

Date

Signature of Investigator

Date

Telephone Number

Risks and Benefits

The risks to study participation are considered minimal, although the completion of forms may be tiresome.

The investigator will take every precaution to secure and safeguard study participants records so confidentiality may be maintained. And, no identifying information regarding individual records will be discussed or reported. Each record will be sanitized, kept under lock and key, and properly disposed at the prescribed time period.

You will decide whether you will or you will not attend group support sessions offered by The Wellness Community. The investigator will not decide for you.

There are not any benefits anticipated for those who decide to participate in the study other than the possibility of feeling good about helping in a study.

Volunteers Needed for Group Support Study
Two kinds of *study* participants are needed:

- ☐ Those persons with cancer who plan to attend group support AND
- ☐ Those persons who do not plan to attend group support

For more information, please contact Joann Harper, RN, Ph.D(c) at 760-599-3617

Investigator:
Joann Harper, RN, Ph.D(c)
Phone: 760-599-3617

Volunteers Needed For Group Support Study

*to find out more about how group support may
be effective in helping persons with cancer.*

Investigator:
Joann Harper, RN, Ph.D(c)
Phone: 760-599-3617

About the Study

What is the study's purpose?

The purpose of this research study is to examine the differences between groups of persons who participate and who do not participate in group support by learning about group support's influence on psychological well-being.

What is group support for this study?

Group support for this study means persons with cancer who assemble under the guidance of a professionally trained person who facilitates scheduled sessions that focus on the concerns and the dialogue of persons within the group. If you decide to volunteer for the study, the session you attend must be at The Wellmen Community (TWC).

What sort of persons are you recruiting for the study?

The study is looking for persons who plan to participate in group support as defined above **or** persons who do not plan to participate in group support.

Is there a particular kind of cancer that is being studied?

No, there are no particular site or type of cancer, nor does treatment or stage of cancer matter for participants. However persons must be:

- 21 years of age or older;
- Must have been diagnosed with new or recurrent cancer within the last 18 months AND;
- Not attended group support sessions in the last two years.

Study Requirements

What are other requirements for the study?

1. You will be asked to complete two forms at the beginning of the study; each takes about 8 to 10 minutes to complete. You will be required to give consent to obtain verifiable information about your stage of cancer. Other medical record information is not required.
2. You will be asked to be available by telephone or in person (your preference) about midway through the study and again at the end of the study. This should take about ten minutes each time. This is mostly to ask you about your attendance, access to other therapies and any events that has happened that you think has made a difference in how you feel physically or emotionally.
3. At the end of the study you will be asked to complete another form; this is estimated to take about 8 to 15 minutes to complete.
4. If you plan to attend group support sessions, you will be asked to attend 12 sessions.
5. The study period is estimated at about 13 weeks to account for recruitment and the contact required for each study participant. Most of the time is the 12 weeks for which one group of participants in the study is attending group support sessions on their own schedule. Persons in the other group, non attendees of group support, will be contacted for their scheduled option not to attend.

About the Investigator

All study participants will be asked to complete the forms as those are described. These can be mailed to you if you prefer with a prepaid return envelope to the investigator.

An important requirement is that study participants regardless of their decision to attend or not attend group support must consent to the study by signing an informed consent form. Information about the study will be conveyed by the investigator either in person or by telephone to each potential study participant. The content of the consent form represents much of the same information written in this brochure.

Who is the investigator?

The investigator is Joann Hueper who is a doctoral candidate from the School of Nursing at the University of San Diego. Joann has been a registered nurse for the last thirty years. She believes this study is important to discover more about how group support may be effective in helping persons with cancer.

The investigator is not one of the facilitators in the group support sessions, but is the one who has designed the study, will collect data, will analyze and then report the data.

How do I contact the investigator?

The investigator may be contacted at 760-594-3517. To answer your questions about the study. Should you decide to participate in the study, you may contact her during the study at this same telephone number.

Dear Study Participant:

Thank you for your consideration in this study. As stated in the study's brochure, I hope to find out more about how group support may affect individuals. To understand more about the study, please read the brochure or contact me at 760-599-3617 (a San Diego number) and leave a message telling me when I may return the call. This way our conversation will not be at your expense.

If you have decided to participate in the study about group support, you need to complete the forms in this packet. The packet contains three separate documents. Each has a different purpose and must be completed by you to be considered in the study's results. The three documents are:

- ❑ An informed consent form that must be signed by you if you intend to participate in the study. Please note that although you may decide not to attend group support, you are still a participant in the study.
- ❑ A two-page form called a demographic data tool requesting basic information about you. This takes about 10 to 20 minutes to complete, often less time is needed.
- ❑ A questionnaire that asks about how you are feeling. This takes about 8 to 15 minutes to complete. If you note a few typographical errors, continue to complete the form as is. Because it is a standardized measurement tool, I have been advised not to modify it. If at anytime you are uncomfortable or you are unclear about what is being asked of you, please do not hesitate to consult with me at 760-599-3617.

You may mail the documents to me in the prepaid self-addressed envelope available to you or you may return them directly to me.

I am available to you either in person or by telephone at 760-599-3617. I invite your inquiry and an opportunity to speak with you. If you decide to attend group support sessions, it is very important to tell me when you start attending, AND complete the forms before you start attending. I will contact you midway through the study and at the close of the study to ask a few questions. At the close of the study, there will also be another questionnaire to complete; this takes about 8 to 15 minutes to complete.

I truly appreciate your willingness to help in this study. Again, I am eager to hear from you, so do not hesitate to contact me.

Best wishes,

Joann Harper, RN, Ph.D(c)
Investigator for this study

Informed Consent Form

Informed Consent: Facilitator Study Participant

The effect of professionally-facilitated group support on psychological well-being among clients with cancer

I HAVE BEEN INVITED BY JOANN HARPER, A REGISTERED NURSE AND A DOCTORAL CANDIDATE IN THE PHILIP Y. HAHN SCHOOL OF NURSING AND HEALTH SCIENCE AT THE UNIVERSITY OF SAN DIEGO TO PARTICIPATE IN A RESEARCH STUDY. BEFORE I GAVE MY CONSENT FOR PARTICIPATION, I READ AND UNDERSTOOD THE FOLLOWING:

PURPOSE OF THE STUDY

The purpose of this research study is to examine the differences between groups of persons who participate and who do not participate in group support by learning about group support's influence on psychological well-being. Facilitators have a role in the study because one condition of the study is that group support is "professionally-facilitated". In order to establish how uniformly that condition has been met, information about facilitators and their training will be collected.

Procedure

I understand professionally-facilitated means a group facilitator, who has the professionally preparation for, or is credentialed to provide, psycho-therapeutic sessions as assigned by The Wellness Community (TWC). I have an arrangement with TWC to conduct group support. I understand the TWC has provided their consent to the study and has agreed to cooperate with the goals of the study. First, if I agree to be in the study, at the beginning of the study, I will complete what is called a "Facilitator Questionnaire". The Questionnaire is a brief "fill in the blank" form asking information about my professional background and what credentials I have earned in order to provide a description of facilitators and their training for the investigator. The form is estimated to take about 10 minutes to complete. Second, I will be available to the investigator to respond to questions about my responses and other general questions about the sessions that may emanate during the study. Information about individual facilitators will not be discussed or reported. Therefore, my information will only be represented as it contributes to a collective description. I will not be asked to provide any information about individual participants in the study. The study is designed to continue for twelve weeks.

Informed consent for the participation in the study of the effect of professionally-facilitated group support on psychological well-being

Risks

There are minimal risks to me by agreeing to and participating in the study as it is described under the procedure section. Some anxiety may be aroused in completing information about myself.

Benefits

I have been told there is no direct benefit foreseen for my participation in this study. I may benefit from a positive feeling that emerges as a result of my contribution to a study designed to look at ways by which other persons with cancer might benefit.

Participant's Rights

My participation in this study is completely voluntary. I can refuse to agree to participate in this study or withdraw after I have given written consent. Any decision I make, not to participate or to withdraw, shall not influence my rights or privileges. I understand there is no other agreement beyond what has been expressed in this consent form.

Confidentiality

I understand my identity in this study is absolutely confidential and will not be disclosed. Any published document that results from this study will not reveal or disclose my identity in any way. All materials will be kept in a locked file available only to the investigator. All materials will be destroyed three years following completion of the study.

Cost

I understand there is no cost to me for participating in the study. I will bear or arrange for the cost of transportation or other personal expenses for my agreement to the study. If I choose to mail in any or all of the forms required, I understand, the researcher, Joann Harper will provide a self-addressed, pre-stamped envelope for these forms to be returned to her.

Reimbursement

I understand there will be no reimbursement to me by the investigator for my agreement to take part in this study. The investigator has no knowledge or control over the conditions of employment or any other arrangement I may have with TWC.

Informed consent for the participation in the study of the effect of professionally-facilitated group support on psychological well-being

Informed Consent Statement

I have read and understood the contents of this form. Joann Harper has and will continue to be available to answer any questions I have about the study. If I had questions about the study, they have been answered to my satisfaction. I hereby give my voluntary consent to participate in this study. Signing this consent does not waive any rights nor does it release the investigator or any sponsor from their responsibilities.

I understand I may call Joann Harper at 760.599.3617, the investigator, at any time to respond to any questions or concerns I may have, or Dr. Jane Georges at 619. 260.4566

I understand I will be given a copy of this informed consent form.

"I, the undersigned, understand the above explanations and on that basis, I give consent to my voluntary participation in the study".

Printed Name of Study Participant: _____

Signature of Study Participant Location Date

Study's Participant's Address (for mailing if needed)

Signature of Witness Date

Signature of Investigator Date Telephone Number

Date

Dear M,

Enclosed is a 22-item questionnaire that represents your last step in the group support study for which you have kindly agreed to participate. Please complete it as promptly as your time and health permits. Ignore typographical errors you may notice and complete the questionnaire as is. As a copyrighted document, I was advised not to correct or modify it. A prepaid envelope addressed to me has been included for the questionnaire's return.

The data collection period ends when each participant of the study returns the questionnaire to me. I may share the results with you after the study is presented to, and approved by, the committee from the University of San Diego, with all edits completed as required. If you are interested in hearing about the study's outcome, please do not hesitate to call me at 760-599-3617, or write to me at the same address on the enclosed envelope: Joann Harper, 991 Lomas Santa Fe Dr., Suite C429, Solana Beach, CA, 92075. However, I anticipate that allowable disclosure of the study will probably not take place until the early months of the year 2003.

The sole reason for the study's beginning, and hopefully its successful closure, is because of you, and each person like you, who gave and continues to give so graciously of their precious time and energy. It is with great gratitude and appreciation that I extend my very best wishes to you. You are welcome to contact me at any time.

My sincerest thanks to you.

Very truly yours,

Joann Harper, Ph.D(c), RN