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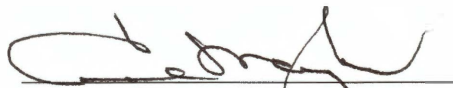


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Thesis
2007b
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**Hope, Coping Style, and Dietary Behaviors of Early and Late Phase Postgastrectomy
Stomach Cancer Patients**

**A Dissertation Proposal Presented for the
Doctor of Philosophy Degree**

The University of Tennessee, Knoxville

**Cynthia S. Collins
August 2007**

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Dedication

This dissertation is dedicated to all those cancer patients and other chronically and terminally ill patients who through their indomitable spirit and tenacity of hope have used their courage to face mortality and teach the rest of us about life.

A special dedication is extended to my parents without whom I would not have had this opportunity: to my mother whose premature death has not allowed her to see that I did follow her favorite piece of motherly advice (“take charge”) and to my father for his relentless belief in me and with whom I still love to engage in the nature versus nurture debate.

Finally, I extend dedication to my most unique supporter, Reese Patterson who has understood and promoted my quest to study body-mind, to honor the individual experience in adaptation to illness and who has taught me to see everyone as a potential ally.

Acknowledgments

I would like to take this opportunity to recognize the effort and willingness to share on the part of the study participants in this study. In addition, a variety of health care professionals have given of their time to facilitate the success of participant recruitment. I am very grateful to my committee members and other academic mentors who used their own experience and their confidence in me to provide exactly what I needed. I am indebted to all those researchers from whom I have attempted to build on their previous work and insights into this field of study. Finally, I express my appreciation to my friends and family who have accompanied me on this journey to date, which I hope has only just begun.

Abstract

Stomach cancer is the second leading cause of all cancer deaths worldwide and will increase yearly as the population increases (Lambert, 2000). Psychosocial interventions to promote optimal adaptation to stomach cancer and the special circumstances of gastrectomy should be guided by research on personality characteristics, other psychological factors and the health behaviors which characterize phases of recovery. Although coping styles of gastrectomy patients had been examined in an earlier study, no study had been conducted from a biopsychosocial perspective. In the present study, a group of stomach cancer patients (15) surviving less than five years postsurgery were compared to a group of stomach cancer patients (10) surviving five or more years postsurgery on personality traits of goal-based hope, coping style, knowledge about cancer, quality of life, and health-related behaviors.

Findings revealed that early phase survivors used a predominant coping style of anxious preoccupation, whereas long term survivors used a predominant style of fatalism. Both early and late survivors reported an average quality of life which was positively associated with goal-oriented hope, the coping style fatalism, and negatively associated with the coping style hopelessness/ helplessness. Long term stomach cancer survivors are at special risk for nutrient deficiencies that can lead to severe muscle wasting, osteoporosis and anemia. Both early and late phase patients consumed deficient levels of calcium, and vitamin D and had a substandard status of Body Mass Index (BMI). The strongest predictive factors for time since surgery for this study population of cancer patients were coping styles of anxious preoccupation, fighting spirit, and cognitive

avoidance; BMI; and knowledge about cancer. This study was not designed to measure the influence of factors on survival. It provides a description of patients who were in different phases of postgastrectomy surgery and offers suggestions as to how the findings can be used by clinicians to select appropriate interventions.

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Chapter 1: Introduction

Health and Senior Adults

The proportion of persons over age eighty-five is growing at a rate six times faster than the population as a whole (Nesse & Williams, 1994). The average life expectancy in the U.S. has increased from 69.7 to 75.2 years over the last three decades. Accordingly, medicine has slowly changed its focus from the acute diseases of childhood and younger adults to the chronic diseases of the older population (Nesse & Williams, 1994). Often stomach cancer survivors are left with ongoing physical effects that leave them in a state of chronic disease.

Approximately 80% of all cancers are diagnosed in persons ages fifty-five and older (American Cancer Society, 2001). The probability of developing an invasive cancer from age 60 to 79 is 22% for females and 33 % for males. Although cancer is the second leading cause of death in the United States, the current combined cancer five-year survival rate is 60%. Therefore, a large proportion of the 1.2 million new cancer cases which were predicted for the year 2001 are comprised of older adults. The five-year survival rate represents persons who are living five years after diagnosis. The rate is adjusted for normal life expectancy, including factors of dying of heart disease (the primary cause of death), accidents and other diseases of older age. Those included in the five-year survival rate may be in remission from cancer, disease-free, or undergoing treatment for cancer, but not those persons who are permanently cured, since cancer can affect survival more than five years after diagnosis (American Cancer Society, 2001).

Incidence of Gastric Cancer

The estimated new cases of gastric (stomach) cancer in the United States for the year 2001 is 8,300 for females and 13,400 for males, or an overall 21,700 cases (American Cancer Society, 2001). Until 1988, adenocarcinoma of the stomach was the leading cause of cancer deaths worldwide (Alexander, Kelsen, & Tepper, 1993). The five-year survival rate for cancer of the stomach rose significantly in the U.S. from 15% in 1974-1976 to a level of 21% in 1989-1996 (American Cancer Society, 2001). Prior to the 1960s, many gastric surgeries, especially partial gastrectomies (partial removal of the stomach) were performed for stomach ulcers. At the time, these were relatively young patients but they now make up part of the elderly population. "It is important for clinicians to be aware that these people are at risk of having developed metabolic disorders as a result of the operation." (Tovey, Hall, Ell, & Hobsley, 1992). In stomach cancer, surgery is the only curative treatment and it is also the major palliative (to alleviate without curing) approach (Bernhard & Hurny, 1998). Both partial removal of the stomach (partial gastrectomy) and total removal of the stomach (total gastrectomy) are performed, depending on the extent of the cancerous growth in the stomach. There is a projected overall 15% five year survival rate with gastric cancer, and a 50% chance for cure in gastrointestinal cancer patients who are considered potentially cured by their surgery (all local cancerous tissue removed) (Nordin & Glimelius, 1998). These statistics explain the increase in numbers of persons surviving for longer periods of time after undergoing gastrectomy for gastric cancer.

The generally held view is that although the diagnosis and treatment for cancer patients can cause significant emotional trauma, those who are surviving disease-free

often resume their usual life patterns (Andersen, 1994). The exception would be those cancer patients for whom the disease or treatment has late psychologic or physiologic effects. For gastrectomy patients, both partial and total, those effects can be various and significantly debilitating (Bernhard & Hurny, 1998; Harju, 1990). For this reason it may be useful to study the influence of psychologic variables at the time of cancer diagnosis or the early phases of treatment, and again during the survival phase (Andersen, 1994).

Andersen (1994) recommends employing a biobehavioral model of cancer which includes stable individual (personality) differences in cognition and coping style as opposed to fluctuating mood variables. She further suggests that including health behaviors with psychologic measures may enhance the dynamics and possible interventions provided for cancer patients.

Personality and Cancer

Research on the relationship between psychosocial factors and cancer has begun to include analyses of the long term impact of cancer on survivors (Redd & Jacobsen, 1988). Personality traits or coping styles are one of the major types of psychosocial risk factors studied. One type of research determines the association between personality factors measured at the time of diagnosis and disease outcome, as measured by time-to-relapse or length of disease-free survival.

The idea that personality and stress may contribute to, predict, or even influence the onset and progression of cancer has become a focus of intense research (Temoshok, 1991). It follows that psychological intervention with individuals may affect any of three areas: vulnerability to the onset of disease, success in coping with or overcoming cancer

and its treatments, and the quality of life. There are a number of critical studies that have established and reinforced the need to conduct research on the biological and psychosocial relationships in cancer. This is necessary in order to identify the actual physiological mechanisms by which psychosocial factors and thus psychological interventions may affect the outcome for cancer patients (Temoshok, 1991).

Adaptation, hope and knowledge. Cunningham (1995) reviewed the current status of clinical/anecdotal and experimental evidence for the influence of psychological events on the progression of cancer. He suggested that adjunctive approaches to cancer treatment are warranted. In doing so he emphasized that the “psyche must fluctuate in concert with the pathology of cancer.” This leads us to ask whether and how these psychic fluctuations can be detected and then whether they can be affected by therapeutic intervention.

Research that has demonstrated a relationship between personality and disease outcome has generally indicated that a more confrontive style on the part of the patient may predict slower disease progression (Nordin & Glimelius, 1998); whereas a personality style that is unassertive, unexpressive of negative emotions, and socially compliant (Temoshok, 1985) may be associated with poorer prognosis. Studies in which there seems to be very little relationship between psychological factors and disease outcome may have used measures of distress rather than the purported personality constructs of a active versus a passive coping style (Classen, Sephton, Diamond & Spiegel, 1998).

To that end, the dispositional Hope scale (Snyder, 1991) has been chosen as a cognitive personality measure of coping for the postgastrectomy patients who participated in the

present study. The Hope scale measures the components of a cognitive construct that indicates, in part, the degree of an active goal-seeking versus a passive stance.

Snyder (1994) developed the theory and measure (Hope scale) of both dispositional and state hope. He defines hope as a cognitive set of two goal-related factors: agency and pathways. The perception an individual has about his/her ability to initiate and sustain movement along a chosen pathway corresponds with agency; the individual's belief that he/she can generate routes for attaining goals is represented by pathways. Agency and pathways are related, yet distinct constructs (Babyak, Snyder, & Yoshinobu, 1993). More succinctly, agency cognition supplies the determination to use the pathways in order to attain the goals, and pathways cognition provides the strategies through which goals are successfully attained. Irving and coworkers (1998) found that college women presented with a hypothetical situation about breast cancer had high hope levels that were associated with a superior knowledge about cancer than their low hope counterparts.

Coping style. Research has also revealed a relationship between a patient's coping style and the degree of disease progression and mortality (Classen, Sephton, Diamond and Spiegel, 1998). Greer, et al. (1989) found that an attitude of "fighting spirit" versus that of denial and "hopelessness/helplessness" was associated with a slowed progression of disease in patients with breast cancer. Nordin and Glimelius (1998) examined the adjustment over time for gastrointestinal patients who were potentially cured (all cancerous tissue removed by surgery) or non-cured, doubtful cases (all cancerous tissue not removed with surgery or current metastasis). As a group, potentially cured patients

with gastrointestinal cancer had a predominant coping style of “fighting spirit” at diagnosis and also at twelve months; non-cured patients had no predominant coping style at diagnosis, but a predominant coping style of “fighting spirit” at six months (Nordin & Glimelius, 1998).

Nutrition and Gastric Cancer

Gastrointestinal cancer presents the patient with a special set of distressing physical symptoms (Bernhard & Hurny, 1998). The common consequences include severe eating disorders, nausea and vomiting, abdominal discomfort, and diarrhea or constipation. Gastrectomy (partial or total) for stomach cancer patients in particular often results in these symptoms with the addition of regurgitation of stomach contents (partial gastrectomy), and abdominal pain (Bernhard & Hurny, 1998). In patients who have had a total gastrectomy, there are the added frequent symptoms of hyper- and reactive hypoglycemia, alkaline reflux gastritis, dumping syndrome and steatorrhea (Harju, 1990). These symptoms put gastrectomy patients at risk for multiple nutrient deficiencies, including vitamin B-12, calcium, vitamin D, and iron, kilocalories, and protein (Gennari, Martini, & Nuti, 1998; Leidman, 1999; Mellstrom et al., 1993; Tovey, Hall, Ell, & Hobsley, 1991, 1992), for which osteoporosis is just one of the more serious consequences along with severe life-threatening anemia.

Quality of Life and Gastric Cancer

In stomach cancer, postgastrectomy nutrition and body weight are strongly associated with quality of life (Buhl, Schlag, & Herfarth, 1990; Habu, Saito, Sato, Takeshita, Sunagawa, & Endo, 1988). Although stomach cancer patients report having

gastrointestinal complaints prior to surgery, their scores on questionnaires for these same symptoms worsen overall after the surgery (Leidman, 1999). Scales for quality of life after gastrectomy have commonly concentrated on objective gastrointestinal symptoms (Leidman, 1999) and need to be expanded in terms of the patient's subjective experience and feeling of well-being (Bernhard & Hurny, 1998). The improvements in survival from cancer have led researchers to explore interventions that may improve the overall functioning and quality of life for survivors (Pinto, Eakin, & Maruyama, 2000).

Recent developments in quality of life measures have allowed for the construction of a universal measure of quality of life that applies to psychologic and medical situations and measures both satisfactions and dissatisfactions, and for several domains (Frisch, 1999). This tool enables researchers to measure more than symptom reduction. Instead a measure of happiness, satisfaction with life, those emotions that are significant in adapting to life from the patient's perspective is achieved (Frisch, 1999).

In summary, research has established that psychosocial interventions can alleviate the various adjustment difficulties experienced by patients with cancer as described by Classen, Sephton, Diamond and Spiegel, 1998. The effect of these interventions in the course of cancer, and specifically, stomach cancer, is less certain. As outlined by the above authors, those studies that have demonstrated increased survival in cancer patients appear to encompass one of four factors: a) a supportive environment, b) use of groups homogeneous for cancer type and stage, c) education, and d) teaching of coping strategies. These authors recommend that future research should explore the employment of these factors in intervention and include its effect on patients' health-related behaviors.

Need for This Study

Before interventions for stomach cancer patients can be developed, additional research needs to be conducted on the psychosocial behaviors of these patients. Previous research (Nordin & Glimelius, 1998; Morris, 1997) has examined adaptation to cancer as measured by change in coping style. However, only one study to date (Nordin & Glimelius, 1998) has included gastrectomy patients. In addition, as these authors state, complementary measures of additional personality factors as well as health behaviors are needed. This study attempts to further enumerate the characteristics of the experience with stomach cancer in patients who are in early stages as well as long term survival.

Comparisons between these two groups may help to describe adaptation to cancer over time. Assessment of personality as described by the complementary measures of cognition (Hope scale), coping style (Mini-MAC scale), of knowledge about cancer, and patient's perceived quality of life (QOLI) will provide information which may be useful in developing psychosocial interventions. In addition, the analysis of dietary intake, BMI and level of activity will enhance our knowledge about the health-related behaviors of this group and provide a measure of one type of behavioral implementation that characterizes survival efforts. A review of the literature detailing the psychological and physiological factors experienced by patients who have undergone partial and total gastrectomy is presented in Chapter Two.

Theoretical Bases

Researchers began to actively study the psychological and social issues related to cancer during the last two decades (Holland, 1998). This was followed by the emergence

of a subspecialty within the field of oncology, characteristically termed psycho-oncology, psychosocial oncology, or behavioral oncology. According to Holland (1998), cancer research is approached within this subspecialty from two related perspectives: a) the psychosocial perspective which entails the psychological responses of cancer patients at all stages during their disease process, and b) the psychobiological perspective which involves psychological, social and behavioral issues that influence morbidity and mortality (Holland, 1998).

Andersen (1994) employs an approach that integrates the two perspectives outlined by Holland (1998). The biobehavioral model of cancer includes the psychologic factors of stress and quality of life, the behavioral factors of compliance and health behaviors, and the biologic pathways associated with cancer stressors to disease course. It is these factors and their influence on the cancer patient's adaptation to the diagnosis which may then affect disease progression that are of primary interest. In Andersen's (1994) model the factors of stress, quality of life, health behaviors and compliance are areas involved in the adjustment to the cancer stressor that are prime targets for intervention.

Holland (1998) describes three factors that are the primary influences on the psychological adaptation to cancer. The first factor is society-derived and includes attitudes such as openness versus secretiveness about a cancer diagnosis, knowledge about treatment options, prognosis of the type of cancer, as well as popular beliefs about cancer. The second factor is patient-derived and consists of personal attributes such as coping ability, philosophic or religious beliefs and social relationships. The third factor is cancer-

derived and includes the medical facts and physical symptoms of cancer types, stage, treatment required and both the immediate and delayed sequelae of the cancer and cancer treatment.

Cunningham (1995) proposes a model of psychological adaptation to cancer that emphasizes the dynamic nature of psychological and biological responses to cancer in both the short and long term. In other words, the psychological status of the cancer patient fluctuates in concert with the progression of their disease. This makes it important to study the interactions of psychological, social and biological factors in adaptation at various stages during the progression of the disease.

Other researchers theorize that adaptation to cancer not only occurs over time after the diagnosis, but also does not end when treatment is complete (Spencer, Carver, & Price, 1998). The adaptation to stomach cancer involves chronic complications (Harju, 1990) and late-occurring nutritional complications which may require major physical and psychological adaptations over time (Nordin & Glimelius, 1998).

Measures of personality in cancer patients provide information about the patient-derived factor in the adaptation to cancer. One measure of personality is hopeful cognition (Snyder, 1995). Hopeful cognition as equated with goal-oriented thinking is defined by the Hope theory (Snyder, 1995) and must be accompanied by motivation and planning. As the theory proposes, there are three ingredients to this type of thinking: goals, agency (the motivational component) and pathways (the planning component) (Snyder, 2000).

Agentic thoughts are thoughts that reflect an individual's willpower to pursue a goal.

Pathways cognition reflects the perception that there are available routes to secure the

goal. Hope theory is similar to theories of self-efficacy in that agency corresponds to efficacy expectancies and pathways are analogous to outcome expectancies (Snyder, 1995). It differs from self-efficacy theories in two ways. First, Hope theory maintains that both agency and pathways are required and are iterative on the process of goal-directed thinking. In addition, in contrast to self-efficacy, by this definition hope is a cognitive orientation that is cross-situational. Hope theory predicts that positive pathways and agentic thinking will translate into greater success in dealing with cancer diagnosis and treatment (Irving, Snyder, & Crowson, 1998).

Another measure of personality in the adaptation to cancer is the mental adjustment to cancer, also termed coping style (Watson, 1994). Coping style has been of interest to cancer researchers for two reasons. The first is simply as a measure of the morbidity associated with the cancer diagnosis. The second is its possible role as a response to cancer that may then influence its progression. That is, coping style may be a prognostic indicator and thus could be a vital factor for intervention in promoting survival (Watson et al., 1988). Coping, or mental adjustment to cancer, has been described as incorporating three domains: cognitive, emotional and behavioral (Nordin & Glimelius, 1998). More specifically, a style of coping is considered an important attribute in the mediation between the stressful event (cancer and its effects) and both the psychological and physical adaptation (Nordin & Glimelius, 1997). Coping style may explain the psychological adaptation over time seen with many cancer patients (Nordin & Glimelius, 1998).

The impact of coping can be assessed by measurements of health-related behaviors such as dietary intake. The stomach has long been considered the recipient of the physical effects of emotional stress (Gray, 1954). Cancer of the gastrointestinal tract, including the stomach, is theorized to pose special problems in psychosocial adjustment (Bernhard & Hurny, 1998). Severely disordered eating, symptoms of weight loss and other physical discomforts are difficult to manage and require attention to the psychological component that often accompanies them. Theories of nutrition include the importance of interpersonal relationships and emotional well-being in aspects of eating and gastrointestinal function from an early age (Bernhard & Hurny, 1998). An example is the close connection seen with lack of appetite or difficulty in eating that can result not only from the physical effects of the cancer, but also from the anxiety associated with the status of the disease. The theory of the impact of coping as a mediator for survival may be especially evidenced in the dietary behaviors of stomach cancer patients. Since there is a lowered intake and absorption of nutrients, this predisposes them to malnutrition with serious health implications (Nordin & Glimelius, 1998).

Theories of quality of life in medicine represent the trend toward a holistic view of the individual (Sullivan, 1992). Quality of life is a broad concept and not easily defined. Measures of quality of life usually include data on a continuum that imply a theoretical maxim of belief in optimal health. Measures of the quality of life generally consist of symptoms of functional status, physical and psychological stress, social role functions and the individual's perception of their own quality of life (Sullivan, 1992). In cancer research, inclusion of quality of life measures is promoted in order to enhance the

understanding of the patient's own perspective and how it may influence their choices in decisions about health behavior (Pinto, Eakin, & Maruyama, 2000).

Cancer is predominantly a disease of the senior population, and this makes the psychological and physical theories of aging critically important (Ferrel & Ferrel, 1998). Generally, impairments in physical function increase with increasing age and are often accompanied by psychological concerns, such as depression and anxiety. Theories of aging and cancer consider the need for symptom management and social support as especially crucial. Many of the conditions naturally associated with age are considered to be potentially worsened by cancer and cancer treatment. These include cognitive dysfunction, gait disturbances, falls, slow rehabilitation and malnutrition (Ferrel & Ferrel, 1998). Influences of culture and gender, such as the need for stoicism, are examples of the additional issues that aging brings to the psychosocial quality of life with cancer. The physical and psychological effects of cancer are especially challenging for the senior population. Research studies of cancer in seniors should therefore take into consideration theories of aging.

This study applies a biopsychosocial model of adaptation to survival from stomach cancer. The psychological and social parameters that influence adaptation include personality (Hope and Coping Style), psychological state (Knowledge about Cancer) and Quality of Life which assesses individual psychological state in relation to self-imposed measures as well as interactions with others. Whereas other models as reviewed above include a biological marker of risk or prognosis, the biological component of model used in this study is a measure of adaptation to the sequelae of the gastrectomy surgery. This

biological component was measured via levels of activity and dietary intake. It represents level of success in adaptation as a measure of morbidity and may also have influence on prognosis and mortality.

Hypotheses

The purpose of this study is to examine the relationships between hope, coping style, knowledge about cancer, perceived quality of life and health-related behaviors in gastric cancer patients in early versus long term survival phases. No distinction will be made between partial and total gastrectomy type patients. The research hypotheses are as follows:

1. There will be a significant difference in mean hope scores between the early phase group and the long term survivor group.
2. There will be a significant difference in mean agency and pathways scores between the early phase group and the long term survivor group.
3. There will be a significant difference in level of knowledge about cancer between the early phase patients and the long term survivor group.
4. There will be a significant difference in mean perceived quality of life between the early phase patients and the long term survivor group.
5. There will be no one predominant coping style in early phase patients; however, there will be predominant coping style of “fighting spirit” in long term survivors.
6. There will be a significant difference in mean dietary intake of calcium, vitamin D, iron, kilocalories and protein, BMI and activity level between the early phase patients and the long term survivor group.

7. There will be a significant difference in mean dietary intake of calcium, vitamin D, iron, kilocalories and protein, BMI and activity level in those patients with higher hope as compared to those with lower hope.
8. There will be a significant difference in mean hope level in patients who have a predominant coping style of “fighting spirit” as compared to that of patients with a coping style of “cognitive denial.”
9. There will be significant relationships between personality, knowledge, and health related behavior factors and quality of life.
10. There will be significant relationships between personality, knowledge, quality of life, and health related behaviors factors and time elapsed since diagnosis.

Definitions of Terms

Each of the following terms are defined as they are used in this study.

Gastrectomy - the surgical removal of stomach (gastric) tissue. This is the only available curative and the major palliative measure for stomach cancer (Bernhard & Hurny, 1998).

Palliative - “mitigating; reducing the severity of; denoting the alleviation of symptoms without curing the underlying disease”(Stedman’s Medical Dictionary, 1990).

Total gastrectomy - the removal of the entire stomach.

Partial (subtotal) gastrectomy - the removal of part of the stomach tissue.

Early phase gastrectomy patients - those patients who are less than 5 years postsurgery.

Long term survivors - patients who are at least five years post gastrectomy surgery. The five-year relative survival rate is defined by the American Cancer Society and used as a tool to monitor in the treatment of various cancers (American Cancer Society, 2001).

Positive lymph node status - evidence of the cancer having spread to the lymph nodes.

Metastasis - evidence of the same type of cancer that was found in their stomach now present in other tissue.

Other primary cancer - a cancer type that is different from that found in the stomach now found in another body tissue.

Hope - a cognitive entity of goal-directed thoughts with two major components, agency and pathways (Snyder, 1995).

Agency ("the will") - the motivational factor in hope, sometimes defined as the cognitive willpower to move toward a goal.

Pathways ("the way") - the component of hope that is the perception a person has of their ability to generate routes to achieve their goal.

Coping (mental adjustment to cancer) - the cognitive and behavioral responses made by cancer patients to the diagnosis and progression of cancer (Watson et al, 1988). The Mini-Mental Adjustment to Cancer (MAC) scale measures and types the various responses observed in cancer patients (Watson, 1994). The following are the basic descriptions of each coping style subscale (Watson & Greer, 1998):

Fighting Spirit - An active coping response defined by the patient's full acceptance of the diagnosis, adoption of an optimistic attitude, determination to fight the disease, and desire to participate in treatment decisions,

Fatalism - Also called stoic acceptance, this style refers to a patient's full acceptance of the diagnosis, but with resignation,

Anxious Preoccupation - With this style the patient is in a constant state of preoccupation with cancer, interprets much somatic pain as a cause for fear of recurrence, and actively seeks reassurance,

Hopelessness/Helplessness - A patient with this coping style feels engulfed by their diagnosis, feels hopeless, is pessimistic, and feels like giving up,

Cognitive Avoidance - Sometimes characterized as denial, this style is defined by the patient's rejection of the cancer diagnosis (rejection of the affective and cognitive impact of the diagnosis), or minimization of the serious nature of the diagnosis and avoidance of thoughts about it.

Knowledge about cancer - responses to a series of factual statements related to cancer in general and stomach cancer specifically.

Dietary behavior - the amount of dietary intake of calcium, vitamin D, iron, kilocalories and protein ingested on an average daily basis as measured by a three-day dietary record.

Quality of life - some level of excellence in living as compared to a reference provided by the general consensus in society. It is usually understood in terms of goodness beyond survival or in terms of meaning in life, and in contrast to quantity of life.

Limitations

A limitation of the study is the Knowledge About Cancer quiz. This quiz was developed for the study by forming true/false questions from information in patient pamphlets provided by the American Cancer Society. Irving, Snyder and Crowson (1998) used a similar method to design a quiz for patient's knowledge about breast cancer in order to examine the association of hope and level of cancer knowledge. To evaluate reliability the knowledge quiz for this study was piloted with a group of 37 college students enrolled in health professional courses to evaluate reliability. The quiz was not piloted with stomach cancer patients.

Another potential limitation of this study involved the low numbers of participants. Similar studies with this limitation as well as other contributing factors for this limitation are discussed in Chapter 5. Comparisons of psychological measures between partial and total gastrectomy patients, as well as for those whose surgery was described as potentially curative versus those for whom surgery is only palliative was not feasible. For this reason, the hypotheses were based on groups collapsed for partial and total gastrectomy as well as for curative and palliative surgery.

The information presented thus far outlines the need for a study which can help to elucidate the biopsychosocial model of postgastrectomy stomach cancer patients. Hypotheses designed to target specific features of this model have been identified. The following review of the literature examines studies that provided additional context and direction for the current research.

Chapter 2: Literature Review

A review of the literature begins with an explanation of the life expectancy and nature of the aging process as it relates to health in senior adults. The relationship of personality and health status, particularly as measured by coping style and a hopeful thinking is then explored and includes studies employing these measures in cancer patients, specifically gastric cancer patients. The consequences entailing various nutrient deficiencies which increase the risk of malnutrition in patients who have undergone a gastrectomy for stomach cancer are described. Finally, the importance of including a subjective measure of perceived quality of life is examined.

Aging and Risk of Disease

Life expectancy in the United States. Both the absolute and relative numbers of adults older than age sixty-five have grown tremendously in the United States. These numbers have been unprecedented since 1900 when life expectancy was 47 years and only 4% of the population was older than sixty-five years of age (Butler, 1991). Today the average life expectancy is age 75, and 12% of Americans are over 65. In absolute terms, the numbers have increased due to a lessened maternal, infant and childhood mortality rate as well as increased prevention and management of diseases of late adult onset, such as hypertension and diabetes. The relative increase in number of persons over age sixty-five is attributed to the increased birth rate of the 1920's coupled with the decline in birth rate of the 1960's. It is projected that the proportions of persons older than 65 will increase to 20% of the population by the year 2030.

The aging process. Two natural processes occur during aging: a decline in physiological function and an increase in disease. Each of these can influence the other once they have occurred; the decline in physiology, however, will occur independently of exposure to disease. For example, a natural phenomenon of aging is the weakened function of the immune system (Abrass, 1991; Keicolt-Glaser & Glaser, 2001). Aging is more than changes in physiology. It has psychological and social components as well.

One way to conceptualize psychosocial aging is as an interactive process, involving both environmental and physical factors that are often not under the control of the aging individual, but which influence their already developed personality and psychological make-up (Cath & Sadavoy, 1991). Studies of the psychological impact of aging have a recurring theme of loss, whether it be loss of a physical, psychological, sociological, or interpersonal nature. Thus aging is seen as a process that is depleting and challenging, a time of continual adaptation. With the adaptation to the changes in aging, there may be characteristics that bring balance and coping, such as resiliency and other strengths (Cath & Sadavoy, 1991).

The nature of illness in senior adults. Acute disease has become less frequent among seniors; chronic conditions, whether singular or multiple, have become more common. Almost two-thirds of the U.S. work force retire before the age of sixty-five although many then pursue part-time work, if they have a positive view of their health (Butler, 1991). Generally, older persons have a lower socioeconomic status than younger persons and tend to spend a greater proportion of their income on basic housing, food and medical care. While the decline in physical health predisposes seniors to medical and

situational hardships, many conditions such as senility and depression, once thought to occur naturally with aging have come to be recognized as preventable. Much of this prevention involves lifestyle factors such as activity and diet.(Butler, 1991).

Survivorship and gastric cancer. The increase in life expectancy for older adults has led to the assumption that the period of dependency on others will decrease (Butler, 1991). The evidence for this is conflicting and it is possible that a bimodal phenomenon is occurring where for one segment of persons there is an increase in health and activity, while for the other there is increased disability due to “survivorship” from fatal diseases. A current example of “survivorship” from fatal diseases is represented by those persons surviving cancer, specifically survivors of gastrectomy for stomach cancer. Although the incidence of gastric cancer is declining, it is currently the second largest cause of cancer in the world (Hill, 1990). In the U.S., the prognosis for gastric cancer in the Western world is poor; the overall curability rate rarely exceeds 20% (Leidman, 1999). The prevailing view, however, is that there are thousands of patients worldwide who will live out their lives suffering the consequences of such a severe surgical procedure as total gastrectomy (Leidman, 1999). There are not only the immediate dangers of postoperative morbidity and mortality, but in addition to these both partial and total gastrectomy patients have a host of nutritional and metabolic consequences that are a ‘result of the curative surgery’ (Leidman, 1999). It is assumed that these consequences may lead to a deterioration of the quality of life.

Psychological Factors Associated With Health

Several researchers have explored the ability to cope with changing circumstances, whether these circumstances are internal (health status) or external (living situation). It appears that losses due to social (deaths) and aging factors, as well as to transitions like retirement, are met with successful adaptation by many seniors (Gove, Ortega, and Style, 1989). Overall, surveys show seniors reporting a higher level of symptoms of depression (Mirowsky & Ross, 1992). However, apparently there is an age difference in coping especially as it relates to locus of control (Blanchard-Fields & Irion, 1988).

Catanzaro, Horaney, & Creasay (1995) proposed that the expectancy for negative mood regulation is a predictor for coping in seniors. They defined coping as attempts made to feel better. Those seniors who have a personality characterized by high expectancy for regulating their negative moods would in turn be more likely to try to solve problems. That is, individuals with high expectancy have a stronger belief that their attempts will be successful (lead to feeling better). They are less likely to avoid stressors (since they expect their coping to work), and finally, expect negative moods to dissipate soon after their coping response. When the level of expectancy is the same, active coping attempts would not relieve depression. It was concluded that perhaps an individual's belief in his/her ability to cope may be more influential on mood as well as success in coping. Practical implications for counselors include placing a priority on intrapersonal stress management techniques for seniors who are dealing with changing life circumstances, in order to enhance expectancy and successful adaptation.

Personality in Health Research

An increase in the number of measurement occasions can increase the reliability of measures of longitudinal studies linking psyche and health (Segerstrom, 2000). Because personality is likely consistent over time, measurements involving psychology and health that are personality measures can be collapsed over time and considered valid (Segerstrom, 2000). Personality by definition describes enduring, characteristic feelings, thoughts, behaviors and ways of relating to others that are fairly stable over time. It is the consistency of personality that renders it potentially influential in matters of chronic health problems (Segerstrom, 2000). That is not to say that personality is not in some sense malleable and cannot be influenced by interventions (Monte, 1999).

Watson and Greer (1998) provide additional definitions of personality: a) “ the integrated and dynamic organization of the physical, mental, moral, and social qualities of the individual, as that which manifests itself to other people,” and b) “ the natural and acquired impulses and complexes and the habits of the person as these are manifested, within our social interactions.” They note that attempts to establish a clear link between health and a cancer-prone personality have been difficult due primarily to methodological challenges. However, they point out that it is intriguing at least that the Type C (cancer-prone) personality pattern has been more frequently observed among persons with cancer (Watson and Greer, 1998). Type C personality was elucidated by Temoshok (1985) and is characterized by behavior that is appeasing, unassertive, unexpressive of negative emotions (particularly anger), social compliance, and overly conscientious.

Personality Measures in Different Cancer Phases

Andersen (1994) describes a biobehavioral model of stress in cancer research that incorporates psychological measures of stable individual differences. In addition, she recommends measuring these variables at two time points, diagnosis and early phases of treatment, and again during the survival phase. The first time point allows for an understanding of the personality factor as it intervenes between the stressful event (diagnosis and anticipation of treatment) and the patient's stressful reaction. For example, if a patient has a personal view that one can anticipate good outcomes in life (optimistic view), the early event may be experienced as less stressful. Additionally, the second time point would enable a measurement of how a stable factor of personality moderates the outcomes of increased psychologic or behavioral morbidity. For example, it might be expected that one type of coping style will moderate further morbidity more successfully. Finally, Andersen (1994) suggests that the personality variable (in this case, an optimistic outlook) will likely covary with the stable coping style.

Hope as a Personality Measure

Individual differences in personality can be expected to relate to a successful adaptation to cancer (Spencer, Carver, & Price, 1998). Studies of optimism indicate that persons with a positive outlook and who are willing to take on challenges can be expected to adapt more successfully to the cancer challenge. A similar yet distinct personality factor is hope (Snyder, 1995). The Hope Scale allows for the measurement of the cognitive process of coping (Snyder, 1993). Snyder (1995) defines hope as a cognitive entity with two components. His definition is based on the belief that individuals are fundamentally

goal-directed. The first component represents the cognitive willpower to move toward a goal and is termed agency. The second component is the perceived ability to generate routes to this goal, and is thus termed pathways.

A level of hope that is enduring and cross-situational is a measure of dispositional hope. For example, a person of high hope has an enhanced sense of agency and pathways in general and is likely to approach a particular goal with positive emotions, a sense of challenge, and a focus on success. On the other hand, a person of low hope whose personal sense of agency and pathways is deficient, is likely to approach a goal with negative emotions, ambivalence, and a focus on failure (Snyder, 1995).

Some advantages of higher hope seen in outcome studies include having more goals, more difficult goals, more success in achieving goals, generally greater happiness and less distress, and better recovery from injury (Snyder, 1995). These outcomes are seen even when controlling for optimism, locus of control, positive and negative affect, and level of intelligence. This differentiates hope from two traits often subjectively associated with it, intelligence and optimism.

In general, higher hope persons demonstrate the following qualities: a) an overall sense of optimism about outcomes in life, b) a perception that they have more control in their lives and that they are more facile at problem solving, c) a higher sense of self-esteem, positive affect; lower reported depression and negative affect, d) a tendency to reflect on events around them with a positive bias, and e) the use of humor in coping with stressful events (Snyder, 1993).

For counselors, the use of Hope theory would be beneficial in therapy as an intervention for illness. Counseling for hope, when it is defined as a cognitive set, in no way dismisses the emotional component of psychological change (Snyder, 1995). In Hope theory emotions are viewed as the byproduct of the level of effectiveness that can be currently demonstrated in pursuing goals. That is, a reflection of having the perception that goals are attainable or have been reached, is a positive emotion. Conversely, the perception of having goals unmet or unmeetable results in negative emotions. The component of hope represented by agency can be likened to the expectancy for success as described earlier, according to Cantanzaro, Horaney, & Creasay (1995).

Hope in cancer patients. Few studies have employed this cognitive definition of hope (the State or Dispositional Hope Scale) in the arena of health-related issues. Irving and coworkers (1998) examined the influence of a superior knowledge base and coping skills in high hope people in health matters. They found a difference between high and low hope college women in regard to cancer-related activities. They administered the dispositional Hope scale to 115 college women, enrolled in an introductory psychology class. Participants were divided into high and low hope groups based on scoring one or more standard deviations from the mean hope score in either direction. Knowledge about cancer was measured using a 20-item "Cancer Facts and Fiction" quiz. This quiz is derived from the National Cancer Institute's (1986) "Cancer Prevention Awareness Survey" and a number of educational pamphlets provided by the National Cancer Institute and American Cancer Society. Scores on the quiz were a sum of the correct responses via "true," "false," and "Do not know the correct answer" options. Hopeful coping responses

to cancer were evaluated via a questionnaire entailing a choice of a specific strategy regarding cancer risk, detection, course and impact.

As predicted, those women with high hope levels were more knowledgeable about cancer. There was also a significantly positive relationship between high dispositional hope and grade point average. Furthermore, high hope women had more hope-related coping responses to imagined cancer phases (prevention/risk, detection, temporal course, and impact). They tended to be more aware of cancer yet saw it as occurring less frequently in the population as compared to their lower hope counterparts. A coping advantage of a high-hope person is the ability to apply a generally hopeful way of thinking to imagined circumstances. In effect, hope is providing a template for goal-directed thought which can be applied to imagined and not yet experienced coping situations.

As Snyder (2000) suggests, future research using the Hope scale would enable an examination of how high hope people can apply their high hope thinking to goals or obstacles related to physical illnesses. The physical and emotional benefits of employing a coping style of “fighting spirit” have been demonstrated (Nordin & Glimelius, 1998). It may be of benefit in the future to ascertain whether the essence of “fighting spirit” is hope (Irving, Snyder, Crowson, 1998).

Irving and coworkers (1998) have illustrated how, in the context of cancer, the analysis for both components of hope (agency and pathways) is necessary. Specifically, in the case of receiving a diagnosis of cancer, an individual who has no belief in the availability of strategies (pathways) for coping with cancer and achieving a goal, (e.g. of following medical advice, of surviving), may have high levels of motivation or agency but

could not apply them. Alternatively, an individual receiving a diagnosis of cancer who may be aware of and believes in strategies (pathways) to handle the treatment of cancer with the help of medical personnel and others; but if he/she lacks determination to apply those strategies (agency), then they may not follow through on known pathways. Hope theory would predict that the individual who has both high agency and pathways thinking could apply his/her sense of agency to goal-directed thoughts and deal successfully with cancer treatment.

Hope and cancer survivors. Cancer survivors have an ongoing effort to cope with cancer treatment and its consequences in order to maintain survival and a high quality of life. In an approach to apply the hope process to a larger view, Snyder (1993) offers a schematic of self-representation and goal-directed cognitions. As he relates, having a representation of ourselves and the world around us may be what makes us unique as humans. As such, we also have a linear sense of time (past, present, and future) which is especially salient to us because we have a tendency for goal-directed behaviors. Snyder was particularly inspired to develop the Hope theory after reading about survivors of very difficult circumstances. He noticed that even in the face of serious losses, these people had the common ability to maintain a goal-oriented perspective (Snyder, 1993). There are special questions to be answered in understanding how cancer survivors, who basically 'start time over' after facing the realization of the end of their lives, are able to resume goal-directed cognitions and behaviors.

The losses incurred from surviving with cancer must certainly affect the patient's level of hope. In other words, as Snyder (1993) describes, the understanding of loss

requires not only recognition of what is missing or unobtainable, but also insight into the effects of the loss (or goal removal) on the agency and pathways thinking. Specifically, the interruption and loss of usual and sometimes routine ways of achieving goals may be experienced (pathways). In addition, as concerns agency, a sense of frustration, anger and eventual draining of mental energy may result from blocked or lost goals. The sense of loss that was originally incurred, may be compounded by the fact that thinking about one component of the loss (the lost object, the agency, or the pathways) will likely bring a reminder of the other two (Snyder, 1993).

One of the common characteristics of high hope people is that they have been confronted by many losses (Snyder, 1993). It turns out that they are hopeful in their losses. For example, high hope people generally expect failure 50% of the time in achieving their goals. They have a built-in expectation which prepares them for the loss. In relation to pathways, high hope people commonly infer that they did not employ the best strategy when they experience a failure. Therefore they are more likely to consider and employ a new strategy. Often high hope people have alternative goals already in mind. They can switch to another of multiple goals without becoming demoralized about the loss of one. After a profound loss persons often experience a decrease in “agentic thinking.” Either the learning of new skills (pathways) or the renewal of agentic thought will allow one to hope again after loss (Snyder, 1993). An understanding of this process may be enhanced by a measurement of the components of hope in cancer survivors.

Coping Style and Cancer

The broader qualities of personality can be linked to coping processes (Spencer, Carver, & Price, 1998). In other word, the manner with which one copes becomes crucial. A review of studies indicates that cancer patients who remain engaged in the struggle to overcome cancer and its consequences fare better than those who cannot accept the reality of the diagnosis (denial) or who face the diagnosis with a sense of helplessness or hopelessness (Spencer, Carver, & Price, 1998).

Denial and coping: Denial is common in cancer patients and can be found in the various stages leading from diagnosis to the terminal phases (Kreitler, 1999). The frequency with which denial has been observed in cancer patients has given rise to the assumption that the tendency for denial may influence the course of disease and even survival. Denial is sometimes labeled as escape, repression, avoidance, suppression, disavowal, or defensiveness; furthermore, it is generally described as a type of cognitive strategy commonly applied in a partial or selective manner as part of the overall coping effort.

It appears that the activation of denial depends on the stage of disease as well as the patient's personality (Kreitler, 1999). A review of studies employing measures of denial in patients with various types of cancer indicates that the effects of denial on coping can be categorized according to the phase of disease, the kind of denial, and the affected domain of life (work, home, medical care). In each of these categories there are circumstances where denial appears to have positive effects, and others in which it is negative. Differences in types of denial illustrate this well. Denial of emotions tends to

provide relief from distress. This may produce the positive results of temporary decreased anxiety which may allow patients to follow medical advice, manage their affairs, and have an increased quality of life. On the other hand, denial of information may hinder a patient's adjustment to illness. This may result in a delay in seeking treatment as well as a decrease in medical compliance, and thus cause distancing from interpersonal relationships. This could explain why very often the general impact of denial may be positive in the short term in the early stages after diagnosis. However, in the long term avoidant strategies become a disadvantage.

Coping strategies and personality factors. The tendency for denial may be influenced by family and cultural background, coping strategies available to the patient, and personality factors such as beliefs, attitudes, and cognitive styles (Kreitler, 1999). Coping strategies and personality factors such as cognitive style have been a focus of ongoing research involving cancer patients and their adjustment to their disease. Coping is considered a dynamic process and is defined by Lazarus (193, p.237) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." In defining the mental adjustment to cancer, there are three major domains: cognitive, emotional, and behavioral (Nordin & Glimelius, 1998). Categories of these domains are defined and are often referred to as coping strategies (Greer, 1989).

A measurement of coping in cancer patients. Watson and coworkers (Watson et al, 1988) suggested a conceptualization of coping strategies into five dimensions of mental response to cancer: "fighting spirit", "fatalism", "hopeless/helplessness", "anxious

preoccupation”, and “avoidance.” The Mental Adjustment to Cancer (MAC) scale is a measure of these five dimensions (Watson et al, 1988). “Fighting spirit”, “fatalism”, and “avoidance” are considered cognitive and behavioral in nature; whereas “hopeless/helplessness” and “anxious preoccupation” are seen as measures of the emotional component of mental response to cancer. As recommended by Schwartz, et al. (1992), many researchers do not report the results obtained on the subscale “avoidance” due to its poor psychometric properties. The MAC scale has been refined by its original author (Watson et al., 1994) in order to correct this deficiency. The new version is termed the Mini-MAC scale. The subscales are basically identical to the original version, with the exception of the “avoidance” subscale, now labeled “cognitive avoidance,” to denote the denial of thoughts about cancer as opposed to emotions about the cancer diagnosis (Watson et al., 1994).

Studies employing the MAC with breast cancer patients have revealed changes in response to cancer over a period time, yet with varying patterns (Nordin & Glimelius, 1998). Studies of cancer patients in general have indicated a lessening of distress symptoms over time suggesting psychological adaptation, possibly due to adequate coping strategies (Cassileth et al, 1984). The usual length of time for follow up in these studies has been three months. In contrast, studies following cancer patients including patients with gastrointestinal cancer for up to twelve months, indicate an increase in emotional distress compared to that at diagnosis (Parle et al, 1996; Nordin & Glimelius, 1999). This may be a function of the initial high level of distress at diagnosis.

Coping and cancer phase. In an effort to answer the question of whether or not coping strategies and emotional well-being change over the course of an illness, Nordin and Glimelius (1998) studied 139 consecutive and newly diagnosed gastrointestinal cancer patients for a maximum of twelve months. Sixty-six of these patients were considered cured by complete removal of cancerous tissue during surgery. The remaining seventy-three patients were considered doubtful (non-cured) cases. Scores on the MAC scale revealed that a generally more confronting reaction to cancer diagnosis was associated with better emotional well-being, as measured by the Hospital Anxiety and Depression (HAD) scale.

As a group, potentially cured patients scored higher than non-cured patients on the “fighting spirit” subscale. The average values for the coping strategies subscales (MAC) remained relatively stable over twelve months for the potentially cured patients. The predominant coping strategy was “fighting spirit,” as determined by standardization of individual scores as recommended by Greer et al (1989). Unlike the other subscales, patients for whom “fighting spirit” was the predominant coping style at diagnosis, continued to have this predominant style at twelve months. This was true even though the total number of patients with “fighting spirit” as a predominant coping style had decreased over time through attrition (death, drop-outs, or other complications).

The average values for coping strategy subscales in the non-cured patients did not change over time as measured at either six months or twelve months (a total of six patients remained living). All coping styles were equally predominant at diagnosis in these non-cured patients. After six months in this group, 11 out of 25 surviving patients

had a predominant coping style of “fighting spirit.” “Fighting spirit” was the most common coping strategy for this group at six months. The authors warn against an interpretation of this result as a definite link between coping style and survival.

This study additionally found a relationship between coping strategy and emotional well-being. Patients with a more confronting attitude towards their diagnosis reported better emotional functioning. On the other hand, patients who avoided reminders of or had more intrusive thoughts about their disease reported more emotional distress.

When it was first developed it was not determined clearly if the measure of coping style by the MAC scale is a state or a trait measure. The stability of coping style over time seen in this study may be related to the fact that a trait measure is being made. The authors recommend that the addition of complementary scales to assess daily coping and rapid fluctuations in style may broaden our knowledge about coping, especially when defined as the mental attitudes and reactions to the process of having cancer.

Perhaps additional measures of personality and of behavioral outcome would also make this contribution. Coping is generally conceptualized as an important factor mediating the relationship between stressful events and both physical and psychological adaptation (Nordin & Glimelius, 1997). To that end this study assessed hope (defined as a cognitive aspect of personality) as complementary to coping style. Also dietary intake was analyzed as a measure of the impact of coping and hope on health-related behavior.

Coping style in gastric cancer. Of the total 139 patients in the above study who had gastrointestinal cancer, 32 patients had stomach cancer (gastric cancer) of which 72% were males. In this group 11 were considered cured by surgery and 21 were not. The mean

age was 67 years. Measures were administered at three months for 14 non-cured gastric cancer patients, and at 12 months for 3 cured and 4 non-cured gastric cancer patients. The decrease in patient numbers is attributed to death, poor physical condition, relapse, or withdrawal. The pattern and predominance of coping styles specifically for gastric cancer patients were reported elsewhere (Nordin & Glimelius, 1997). The results indicate that gastric patients scored highest on the “fighting spirit” subscale than any other subscale. In order of decreasing frequency the other subscales were represented in the gastric patient group as follows: “fatalistic”, “anxious preoccupation”, “hopeless/helplessness”, and “avoidance.”

Change in coping strategy was studied for a longer period of time by Morris (1997) who conducted follow up measures at two years post-diagnosis. The results are in agreement with those of Nordin and Glimelius (1998) in that the number of patients with a predominant coping style of “fighting spirit” decreased over time. However, the study group consisted of breast cancer patients and researchers did not distinguish between cured and non-cured. Additionally, each individual’s changes over time were not analyzed as they were in Nordin and Glimelius (1998).

The question of coping and adaptation to cancer treatment concerns the pattern of stress over time (Spencer, Carver, & Price, 1998). It would be interesting to know the periods of greatest distress and the length of phases of distress. It is important to note that stress and the adaptation process for a cancer patient often do not end when the treatment is complete. The success of gastrectomy for stomach cancer has resulted in an increasing number of survivors. Extended follow up is necessary in order to adequately assess their

adaptation to the special challenges incurred by the treatment itself. Complementary personality and coping measures such as hope and coping style may enhance our understanding. Also, the examination of behavioral measures, such as dietary intake, which is directly related to the unique challenges of living after gastrectomy will provide information about the active implementation of personality styles and coping ability.

Stress and the Stomach

The interplay of emotions and physiology relative to the gastrointestinal tract has long been recognized by even traditional medicine. As stated by Gray (1954), “the gastrointestinal tract has often been referred to as the ‘sounding board’ of the emotions, and as such is subject to a host of neurogenic, secretory, motor, hormonal, endocrine, and vascular influences. It must, in addition, contend with the daily bombardment of exogenous irritants, thermal and bacterial variants, and mechanical factors”(p.1531). Regardless of the emotional and environmental factors that may have led to a disease of the gastrointestinal tract and to gastric cancer specifically, the practical implications of a gastrectomy are of a potentially serious nature and can predispose the patient to states of serious malnutrition with both short and long term consequences.

Malnutrition in the Postgastrectomy Patient

Vitamin B-12 deficiency in postgastrectomy patients. Progressive malnutrition has been reported as a consequence of both partial gastrectomy (PG) and total gastrectomy (TG) in several studies (Bragelmann et al., 1996; Gennari, Martini, & Nuti, 1998; Liedman, 1999; Mellstrom et al., 1993); Schmeidl, Schwille, Stuhler, Gohl, & Rumenapf, 1999; Stael von Holstein, Ibrahimbegovic, Walther, & Akesson, 1992; Tovey, Hall, Ell, &

Hobsley, 1991, 1992). Patients who have had gastric surgery have a high prevalence of vitamin B-12 deficiencies (Sumner et al., 1996), decreased calcium and phosphate absorption (Tovey et al., 1992), significant deficiencies in vitamin D and iron (Tovey, Godfrey, & Lewin, 1990), and decreased total kilocalorie and protein status (Leidman, 1999). Vitamin B-12 deficiencies are best remedied by injections of this vitamin since the intrinsic factor necessary for absorption of dietary B-12, normally synthesized in the stomach, is unavailable to a gastrectomy patient (Sumner et al., 1996).

Calcium and vitamin D deficiency in postgastrectomy patients. Decreased calcium, phosphate, magnesium and vitamin D absorption, with or without steatorrhea has been demonstrated in gastrectomy patients (Gennari, Martini, & Nuti, 1998; Tovey, Hall, Ell, Hobsley, 1992). Steatorrhea, or intestinal fat malabsorption, is often responsible for the loss to feces and decreased absorption of other fat-soluble vitamins, such as vitamin D. In addition, the rapid transit of food through the gastrointestinal tract in the absence of a stomach means that less time is provided for the absorption of nutrients.

The lowered absorption of fat soluble nutrients in turn causes the production of calcium soaps, which may further inhibit calcium absorption (Maier, Kreis, Zittel, & Becker, 1997). Gastric acid is presumed to enhance both calcium and iron absorption; the lack of acid after gastrectomy is likely to further inhibit calcium absorption, although the evidence for this factor has been contradictory (Gennari, Martini, & Nuti, 1998). Calcium absorption is also decreased by the loss of its primary absorption sites in the duodenum and jejunum due to common surgical reconstructions after gastrectomy (Maier, Kreis, Zittel, & Becker, 1997).

For these reasons, gastrectomy is a secondary risk factor for osteoporosis, and the increased rates of bone loss are demonstrated at the radius and lumbar spine (Gennari, Martini, & Nuti, 1998; Mellstrom et al., 1993). Alhava and coworkers (1975) reported 63 male and 23 female postgastrectomy patients with low bone mineral content of the distal radius. Nishimura, et al. (1987) found a 25% incidence of low bone mineral content in postgastrectomy patients associated with a rising incidence (including female predominance) and an acceleration with aging in both sexes.

The term “postgastrectomy bone disease” was coined in order to describe bone disorders observed after gastrectomy surgeries (Maier, Kreis, Zittel, & Becker, 1997). Postgastrectomy bone disease may take the form of osteomalacia (bone softening), or osteoporosis in excess of normal aging or a combination of both. Osteoporosis is a bigger problem and its prevention and treatment is currently unsatisfactory (Tovey, Hall, Ell, & Hobsley, 1992).

Osteoporosis currently represents a wide group of conditions with many different causes and mechanisms. It is characterized by the reduced volume of cortical and trabecular bone and results in the reduction of either the area or the volume density of the bone. Once developed, the changes in bone seem irreversible by calcium supplementation (Tovey, Hall, Ell, & Hobsley, 1992). The term “secondary” is applied to all patients with osteoporosis in whom the identifiable causal factors are other than menopause and aging.

Many times, postgastrectomy patients have lowered serum calcium levels compared to those of controls, but not serum calcium levels that would be considered in the deficient range (Maier, Kreis, Zittel, & Becker, 1997). This is probably due to the

efficient counter regulation of the body where serum calcium levels are maintained, often due to the drawing on bone calcium stores and thus leading to bone calcium losses. A narrow range of serum calcium homeostasis is necessary for survival (Maier, Kreis, Zittel, & Becker, 1997).

There is a close relationship between calcium absorption, serum levels of vitamin D, and bone metabolism (Alhava, Aukee, Karjalainen, Kettunen, & Junti, 1975; Nilsen, 1975). In addition to vitamin D absorbed from food, in the body vitamin D can be formed from cholesterol by photobiogenesis in the skin. Impaired absorption, insufficient intake, or both have been suggested as the cause of low levels of the active form of vitamin D in postgastrectomy patients (Gertner, 1977; Tovey, Hall, Ell, & Hobsley, 1992).

Based on their results with a pig model, Maier, Kreis, Zittel, and Becker (1997) propose a mechanism for bone loss in postgastrectomy patients that is fundamentally caused by a decreased intake of dietary calcium. The low circulating levels of calcium are then counter regulated by parathyroid hormone and calcium homeostasis. After the counter regulation takes place the net result is increased bone resorption and decreased bone formation, which incur a risk of fractures. The study by Maier and coworkers (1997) is the first involving gastrectomized and control groups employing the pig as a study model. The results of their research supports their suggestion for calcium and vitamin D supplementation in postgastrectomy patients. They also point out, however, that there is little convincing evidence that calcium and vitamin D supplementation prevents bone disease in postgastrectomy patients. These authors call for future investigations of

exogenous sources of calcium and vitamin D in order to prevent postgastrectomy bone disease.

Mellstrom, et al. (1993) performed an age-controlled (mean age 72 years), community-based, case-control study of 129 men and confirmed that partial gastrectomy leads to reduced bone mineral density and an increased incidence of vertebral fractures. Mean time since surgery was 28.5 years. The incidence of vertebral fractures in postgastrectomy patients was 19% as compared to controls who had a 4% incidence. Bone mineral density was 20% lower as measured in the heel bone of men with gastrectomy as compared to controls. However, in contrast to other studies, low serum calcium concentration and vitamin D deficiency were not seen in this group possibly due to the presumed high intake of vitamin D-fortified milk and margarine intake in this Swedish population.

A recent study of 11 male, total gastrectomy patients (mean age 62 years) likewise revealed decreased bone mineral density in the lumbar spine on seven patients (Schmiedl, Schwille, Stuhler, Gohl, & Rumenapf, 1999). All eleven patients had undergone a total gastrectomy for treatment of stomach cancer and varied within the range of 3-18 years (mean year 8.9) postsurgery. Food composition, as measured by a questionnaire assessing long term intake, indicated the patients were consuming their usual 5-6 meals per day with low intakes of milk and other dairy products. Their calculated daily calcium intake was in the range of 6.25 to 17.5 mmol (mean 10 mmol), well below the recommended intake of 25 mmol. None of the patients took a vitamin or mineral supplement with the exception of vitamin B-12. These authors support the proposed mechanism by Maier and coworkers

(1997) whereby homeostatic mechanisms for calcium restore serum calcium at the expense of bone mineralization.

Iron deficiency in postgastrectomy patients. A frequent late complication of gastrectomy is iron deficiency (Green, 1996). Mellstrom, et al. (1993) also measured iron status and demonstrated a low transferrin saturation in 17% of postgastrectomy patients versus only 6% of controls. Transferrin is the transport protein which carries iron in the bloodstream. A low transferrin saturation indicates a lack of available iron to bind with the transferrin transport protein for circulation. It is an early sign of iron deficiency. Iron deficiency not only causes an anemia of its own, but it may also mask a vitamin B-12 deficiency which can potentially lead to pernicious anemia, characterized by irreversible neurological symptoms (Green, 1996; Pennypacker et al., 1992; Sumner et al., 1996).

In fact, when Tovey and coworkers (1990) followed 227 patients (62 females and 165 males) who had undergone partial gastrectomy for an average of twenty years, they found that iron deficiency was the commonest problem by the end of the first decade. At the end of the second decade of follow up, vitamin B-12 deficiency was more prevalent. In the third decade, iron and vitamin B-12 deficiency reached equal prevalence and were found in 90% of females and 70% of males. Iron deficiency was defined as an iron saturation of less than 16%, from which the patients became anemic within several months. In other words, employing the measure of iron saturation, the iron deficiency was detected several months before the patients became anemic. Women had an earlier and a higher incidence of iron deficiency, especially in the pre-menopausal group. These authors

attributed iron deficiency to low gastric acid and rapid transit of food over intestinal absorption sites for iron.

Bragelmann, et al. (1996) studied 174 consecutive total gastrectomy patients (63 females and 111 males, mean age 57.6) who were potentially cured for gastric cancer. The incidence of iron deficiency anemia increased with time after surgery to an eventual 46%.

Longitudinal studies of malnutrition in postgastrectomy patients. This longitudinal, cohort study (Tovey, Godfrey, & Lewin, 1990) allowed for the extent of nutritional problems with the passage of time to be thoroughly examined. The incidence of osteoporosis was 24% in the first decade, 20% in the second decade, and 22% in the third decade. There were 52 of 227 patients remaining in the third decade. In addition, a dietary survey was completed and they reported only a few patients who had severe deficiencies; however, the data are not published. In conclusion, Tovey and coworkers (1990) recommend continual screening in anticipation of severe deficiencies and recognizing that the importance of this increases with the passing years.

Dietary intake and nutritional markers were measured in 20 patients who had undergone partial gastrectomy (n = 10; one female, nine males) or a total gastrectomy (n=10; four females, six males) (von Holstein, Ibrahimbegovic, Walther, & Akesson, 1992). Minimum length of time since surgery was four years; range of 9-16 for PG and 4-17 years for TG). Four-day dietary records, assessed according to food tables of the Swedish Food Administration, revealed the following mean distribution of macronutrients: protein 13-14%, carbohydrate 46-48%, and fat 37-38%. The intake for total intake and macronutrients was similar for the PG and TG groups and were close to

those reported for healthy subjects of the same age in Sweden. The intake of vitamin D was within normal range. By the end of 20-25 years follow-up, the prevalence of iron deficiency was 92% in females and 67% in males. The major differences in nutritional status as measure by blood test were seen for vitamins E and A. The results of this study were used to make the recommendation that total gastrectomy should not be avoided in fear of increased morbidity as compared to partial gastrectomy, especially in cases of gastric cancer.

Calorie and protein deficiency in postgastrectomy patients. Bragelmann, et al. (1996) assessed dietary intake in their study of total gastrectomy patients. Dietary intake analysis revealed that 75% of patients ate at least five meals per day. Food intolerance was present in 62% of patients, most frequently for milk. The caloric intake for half of the patients was 2347 kilocalories (kcal) (median 37.8 kilocalories per kilogram (kg) of body weight) per day. Twenty-five percent of the patients consumed more than 43.1 kcal/kg body weight per day. This diet was a controlled diet supplied by the hospital with allowances of unlimited intake in quantity. The macronutrient distribution is as follows: 17% protein, 35% carbohydrates, and 48% fat. In cases where patients are eating ad lib, reduced food intake is usually explained by loss of the gastric reservoir, lack of appetite, dysphagia, dyspepsia, and altered intestinal motility (Leidman, 1999).

Furthermore, the patients in Bragelmann, et al. (1996) with a body mass index (BMI) of less than 20 kg/m², as measured in kilograms of body weight per height in squared meters, suffered more symptoms. The symptom list included abdominal complaints such as frequency of fecal elimination, early satiety, nausea, vomiting,

dumping, and dyspepsia (epigastric burning). Mellstrom, et al. (1993) also found a significantly decreased BMI for gastrectomy patients as compared to controls. In addition, a low BMI of less than 25 kg/m² was indicated as a risk factor for osteoporosis.

Decreased kilocalorie and protein intake or absorption and the resultant general malnutrition may also be a factor in health complications for postgastrectomy patients.

Protein intake and serum albumin (a circulating transport protein) have shown to have a positive correlation with bone mass. Protein metabolism plays an important role in forming the collagen matrix of bone. Impaired protein absorption resulting from reduced intake, rapid intestinal transit or poor mixing with pancreatic enzymes, as evidenced by an increase in fecal nitrogen output can have deleterious consequences (Tovey, Hall, Ell, & Hobsley, 1992). There is some disagreement about which component of body composition (body fat versus body muscle) is responsible for the loss of body weight in postgastrectomy patients. Some studies show a loss of the body fat component while sparing lean body mass (body muscle protein); others indicate a loss of the lean body mass component (Leidman, 1999).

In any event, adequate protein consumption, digestion and absorption are necessary to offset body weight loss. Probably the most important factor in impaired protein nutrition is reduced dietary intake (Nilsen, 1975). It is likely that decreases in body weight seen in postgastrectomy patients are due mostly to losses of body fat as the body adapts with selective wasting of body fat in order to spare lean body mass (body protein)(Leidman, 1999). This is an adaptive survival mechanism the body has to spare vital protein (antibodies, enzymes, heart muscle) while using body fat for calories. The

loss of body weight begins to slow down when the body initiates another survival mechanism of lowering the overall metabolic rate. This decreases the need for calories (energy).

There are other possible causes of body weight loss. In many gastrectomy patients, diarrhea which usually declines with time but has the potential to incur losses of 50 kcal/day or 10 kg of body fat in five years (Leidman, 1999). In light of the association between low BMI and decreased bone density, preservation of body weight could have a positive influence on bone health (Leidman, 1999; Schmeidl, Schwille, Stuhler, Gohl, & Rumenapf, 1999).

Level of physical activity may have an influence on BMI as well as body weight due to its energy use. Activity level was not measured in other studies of gastrectomy patients (Brägelmann et al., 1997; Liedman, 1999; Mellstrom et al., 1995; Nordin & Glimelius, 1998). Paffenbarger, Hyde, Wing and Hsieh (1986) performed a prospective study of 16,936 Harvard alumni to assess the relationship of physical activity and other lifestyle factors with all-cause mortality. Exercise was reported in terms of walking, stair climbing and sports playing. Exercise was translated into kilocalorie usage based on estimated values of average energy expenditure for the various activities reported. Exercise was inversely related to mortality, particularly as concerns cardiovascular causes of mortality, and partly independent of other factors associated with cardiovascular disease. This study offers support for the hypothesis that exercise can positively influence longevity. Exercise levels in gastrectomy patients may influence their prognosis,

especially in light of the evident need for balance in calories and probable association of BMI with morbidity.

The subjective experience of the postgastrectomy patient. Data for both partial and total gastrectomy patients has been presented in the above review. Recent series of studies indicate that there is no difference in postoperative morbidity between these two surgeries (Bozzetti et al., 1997). Reported subjective symptoms may appear differently as outlined by Harju, 1990. For patients with a total gastrectomy, food enters the small intestine directly and will tax the system in its coordination of digestion and absorption. The diet of most total gastrectomy patients is best described as a compromise between the limited volume they can tolerate and the reduced time for digestion and absorption (due to increased transit rate). This compromise is an attempt to avoid the pain and other abdominal discomfort produced by a large meal and other food intolerances. Often this results in the need to eat several small meals per day, separating liquid intake from mostly solid meals, and a host of limitations in food type selection.

Quality of Life in Postgastrectomy Patients

Pinto, Eakin, & Maruyama (2000) recommend including psychological quality of life measures along with health-related outcome variables in studies involving cancer patients. This may enhance our understanding of how patient's perceive their quality of life and how that in turn may influence decisions to engage in health behavior changes.

For postgastrectomy patients, traditional postsurgical quality of life measures have focused on physical symptoms (Alexander, Kelsin, & Tepper, 1993). The physical symptoms can be very distressful for these patients. The entry of food directly from the

esophagus into the small intestine experienced by many postgastrectomy patients is termed the dumping syndrome. The symptoms of dumping include epigastric pain and distension, sweating, increased heart rate, faintness, dizziness, nausea, vomiting, diarrhea, disorientation, and even unconsciousness (Harju, 1990). Also, symptoms from the fast entry of glucose from the small intestine into the blood stream which induce hyperglycemia (high blood sugar), reactive hypoglycemia (low blood sugar), and alkaline reflux gastritis or esophagitis (inflammation of the stomach or esophageal tissue) are commonly experienced by these patients. There appears to be a large variance in reports of these symptoms by postgastrectomy patients (Harju, 1990). However, the final consequence of nearly any level of the pain and other discomforts they cause usually encompasses a response of lack of appetite and decreased dietary intake. Harju (1990) agrees that quality of life measures should include psychological factors associated with these physical symptoms.

The Quality of Life Inventory (QOLI), was developed as an alternative to quality of life measures that focus on physical symptoms (Frisch, 1993). It is a measure of both satisfaction and dissatisfaction of sixteen areas in life, including love, work and health. It is not a disease-specific measure and because of that is deemed useful as a universal measure of life satisfaction which will make comparisons with other study populations possible. The QOLI has been promoted as useful outcome measure for medical treatments in cancer (Frisch, 1999). This inventory is currently in use in an NIH-funded study of age-related changes in health and quality of life, and has been used in research for a variety of

other conditions, including depression (M. Frisch, personal communication, March 21, 2001). The QOLI was used in the current study and is discussed in detail in Chapter 3.

In summary, postgastrectomy patients represent a population at particular risk for malnutrition and late phase consequences such as osteoporosis and severe anemia (Tovey, Hall, Ell, & Hobsley, 1991). The number of patients surviving gastric cancer in the future will continue to increase due to earlier diagnosis and improved surgical techniques. This makes the long term problems that potentially arise from gastrectomy of great clinical importance (Bragelmann et al., 1996).

A currently unsolved question in the pathophysiology of total gastrectomy bone disease includes the role played by nutritional status (Schmiedl, Schwille, Stuhler, Gohl, & Rumenapf, 1999). The consequences of iron deficiency anemia require continued screening and very often iron supplementation (Nilsen, 1975). The variability with which various nutrients are consumed in the diet and the possible complications that may result from uncontrolled nutritional influences has led some researchers to choose an animal model for studies of postgastrectomy effects (Maier, Kreis, Zittel, Becker, 1997). However, in lieu of an animal model, clinical studies of postgastrectomy patients make investigation of recorded dietary intakes a necessary component of postgastrectomy research. Furthermore, because some of the consequences of postgastrectomy, namely bone disease, are not apparent until several years after surgery, studies of gastrectomy survivors in these later years is required.

Conclusion

Aging is often met with a decline in physiological functioning and an increase in disease, along with changes in psychological and social functioning. The older population is faced with more chronic conditions and disease states. One example of this is the surgical procedure, gastrectomy, which is performed on stomach cancer patients.

Coping with gastrectomy requires successful adaptation on a variety of levels. The biopsychosocial model provides information about methods of coping with the components of personality and psychological measures, social aspects, and health behaviors. Stable factors of personality can moderate the coping behaviors that are likely to change during different phases of an illness. For example, a stable level of goal-directed hope may influence how a postgastrectomy patient adjusts to changes in dietary needs and difficulties with eating. The level of knowledge about an illness may affect how well a patient copes. These factors in turn may affect the overall quality of life as perceived by the postgastrectomy patient. At some phases of an illness, certain forms of denial, either emotional or cognitive, have been proposed to have short term benefit.

In short, patients adjust to cancer in three domains: cognitive, emotional, and behavioral. The biopsychosocial model attempts to describe the various components and their interplay in adjustment to chronic disease. Successful adaptation may require psychosocial interventions that target specific personality, psychological and health behavior components. In addition, these may need to be addressed differently at various phases of the illness.

Finally, adaptation for postgastrectomy patients requires that certain daily and tangible needs be met and often on an urgent basis. In response to the now recognized nutritional complications and often severe discomfort with eating process that postgastrectomy patients experience, Harju (1990) suggests a general recommendation of obtaining food with increased nutrients and which will cause fewer symptoms. This is the obvious goal for every postgastrectomy patient.

However, achieving this goal as well as maintaining an adequate nutritional status would require a certain amount of psychological adaptation for these patients. As attributed previously to Andersen (1994) stable personality traits may influence in a psychological factors and behaviors involved in successful adaptation. The biopsychosocial model employed in this study attempted to identify those personality and psychological factors that had significant influence on moderating health behaviors that are necessary to survive as a postgastrectomy stomach cancer patient.

Chapter 3: Method

In order to compare the relationship of personality, knowledge about cancer, quality of life, and health-related behaviors between early phase and long term survival postgastrectomy patients, the following methods were used.

Sample and Procedure

Approval to recruit postgastrectomy stomach cancer patients was obtained from the University of Tennessee Compliance Office of the Institutional Review Board and the Covenant Health Institutional Review Board. All participants who volunteered for this study were given two copies of the Informed Consent form which is shown in Appendix C. One copy was retained by the participant, the other was retained by the investigator. The study sample was a sample of convenience recruited from local oncology medical practices and through a web page posted on the Internet. Twenty-five (25) participants were recruited during the period which began in May 2001 and extended through March 2002. Participants were stomach cancer patients who were postsurgical for gastrectomy. Fifteen (15) were in early phase postsurgery (four weeks to five years), and ten (10) were in long term survival phase postsurgery (five years or more). Patients with a total esophagectomy and re-attached stomach which renders the stomach non-functional were also included as total gastrectomy patients. Patients who were presumed cured by surgery (all cancerous tissue removed and no metastasis) as well as those for whom surgery was palliative (metastasis including positive lymph node status) were included in the study. Patients presumed cured have undergone a partial or total gastrectomy and have no lymph node or other evidence of metastasis. Patients for whom surgery was palliative may have

undergone either a partial or a total gastrectomy. Additional demographics on patients are presented in Results. Participants were solicited from local oncology and surgical practices, and by the Internet via a constructed web page. All patients elected to receive the study questionnaires by mail and return them to the principal investigator in a pre-addressed and stamped envelope. Informed consent was obtained in the packet. Every participant was asked to keep a copy of the informed consent for their personal records.

Demographics

Participants were asked to complete a questionnaire detailing general demographics of age, educational level, marital status, health status, surgery type, and physical symptoms including pain, nausea, abdominal discomfort, and other gastrointestinal difficulties.

Personality Measures

Hope. The Hope scale was used to assess overall hope, and the subscales of agency and pathways. The Hope scale (Snyder et al., 1991) consists of four agency items (e.g. "I energetically pursue my goals"), four pathways items (e.g. "There are lots of ways around any problem"), and four distracter items. Respondents rate how accurately each item describes them on a scale of 1 (Definitely false) to 4 (Definitely true). The final score for the Hope scale reflects the sum of the agency and pathways items. At the suggestion of the author, the scale was presented as a "goals" questionnaire, as shown in Appendix D.

Previous studies using this scale demonstrate internal consistency and test-retest reliability (Snyder et al., 1991). Cronbach's alpha for the total scale ranged from .74 to .84. For the subscales, Agency and Pathways, Cronbach's alpha ranged from .71 to .76

and from .63 to .80, respectively. Test-retest correlations, taken from studies of four samples of undergraduate students at the University of Kansas were .85 ($p < .001$) over a three week interval, .73 ($p < .001$) over an eight week interval, and .76 and .82 ($p < .001$) over a ten week interval in two samples. These numbers support the temporal stability of the Hope scale scores. Confirmatory factor analysis indicated that agency and pathways are related, yet distinct constructs of the of the hope construct (Babyak et al., 1995). Concurrent construct validity has been demonstrated by correlations with other related measures; and, it further has discriminant utility in predicting goal-related outcomes beyond the variance attributable to other measures (Snyder et al., 1991).

The Hope scale has concurrent validity with measures of self-esteem, perceived problem-solving capabilities, perceptions of control in life, optimism, positive affectivity, and positive outcome expectancies (Snyder, 1995). Its validation also included negative correlations with social introversion, depression, negative affectivity, and anxiety (Snyder, 1995). Discriminant validity has indicated that the Hope scale measures account for additional variance beyond measures of anxiety, positive and negative affectivity, optimism, positive outcome expectancies, and locus of control (Snyder, 1995).

Coping style. The Mini-Mental Adjustment to Cancer (Mini-MAC) scale (Watson et al., 1994) was administered in order to assess coping style, as shown in Appendix E. The prototype of this scale, the MAC scale (Watson et al., 1988) consists of 40 items constituting five subscales which represent coping styles: Fighting Spirit, Fatalistic, Anxious Preoccupation, Hopelessness/Helplessness, and Avoidance. Except for Avoidance, these subscales showed good psychometric properties (Greer et al., 1989;

Watson, 1988). The normative sample contained sixteen patients, out of a total of four hundred patients, who had cancer of the gastrointestinal tract. Further development of the MAC scale employed factor analysis (Kaiser-Meyer-Olkin measure = .91), refined original subscales, corrected the deficiencies of the Avoidance subscale, and resulted in a new subscale, Cognitive Avoidance. Reliability for the Mini-MAC subscales is expressed with the following alpha coefficients: Fighting Spirit (.76), Fatalism (.62), Anxious Preoccupation (.88), Hopelessness/Helplessness (.87), and Cognitive Avoidance (.74). The Mini-MAC is less lengthy (29 items) and its measurements are strongly related to the previous scale. Comparison of scores from previous studies using the MAC scale with new studies using the Mini-MAC scale are considered valid. Additional validity was ascertained by Schwartz, Daltroy, Brandt, Freidman, & Stolbach, 1992). Measures of construct validity indicated a negative correlation between anxiety and depression and the coping style fighting spirit; alternatively they were positively correlated with the coping styles of anxious preoccupation, fatalism, and hopelessness/helplessness.

Health-Related Dietary Behavior Measures

Participants were asked to complete a dietary record of all items consumed for three average days. A three-day average analysis was performed to assess the representative dietary intake. Analysis for kilocalories, protein, iron, calcium, and vitamin D was completed using the Nutritionist Pro software (2001) published by First Data Bank, Inc. The Body Mass Index (BMI) was calculated from the current weight and height recorded by participants as weight per height-squared. See Appendix F for a sample report of a three day average diet analysis. Physical activity was assessed with the method

established by Paffenberger, Hyde, Wing and Hsieh (1986). This method consists of answering four questions to determine activity from walking, stair climbing, and sports playing. Each activity was translated into kilocalorie amounts according to the following values: walking = 56 kilocalories/.94 kilometer or 7/12 mile or 7 city blocks; stair climbing = 28 kilocalories/ 70 stairs; light sports activity = 5 kilocalories/minute; vigorous sports activity = 10 kilocalories/minute; mixed sports activity = 7.5 kilocalories/minute. The physical activity questionnaire was included with questions pertaining to demographics and gastrointestinal symptoms, as shown in Appendix G.

Knowledge About Cancer

A cancer knowledge quiz, as shown in Appendix H, derived in a similar fashion to that used by Irving, Snyder, and Crowson (1998) on cancer prevention was administered to participants. Information from educational pamphlets available to the public from the National Cancer Institute and the American Cancer Society regarding both cancer in general and stomach cancer was extrapolated to a twenty question quiz format. Response options include “True,” “False,” and “Do not know the correct answer.” Scores are computed by summing the number of correct answers. Reliability for this measure was obtained before its use with this study population. The test group consisted of 37 college students in science courses, the majority majoring in pre-nursing and other health-related fields. Internal consistency for time 1 was .8 ($p < .001$) and for time 2 was .9 ($p < .001$). Cronbach’s alpha for test-retest reliability was .8 ($p = .008$).

Quality of Life

The Quality of Life Inventory (QOLI) (Frisch, 1993)(see address in Appendix I) was administered in order to assess life satisfaction in sixteen different domains: health, self-esteem, goals-and-values or philosophy of life, money or standard of living, work, play or recreation, learning, creativity, helping or social service, love or love relationship, friends or friendships, relationships with children, relationships with relatives, home, neighborhood, and community (Frisch, 1999). Reliability has been measured with samples from the general population ($\alpha = .77$), a University Counseling Center ($\alpha = .83$) and Veterans inpatients ($\alpha = .86$) and recovered patients ($\alpha = .89$). Test-retest reliability was performed on a subset of the normative sample over a two week interval ($\alpha = .73$). The QOLI has convergent validity with two other measures of quality of life, the Satisfaction With Life Scale and the Quality of Life Inventory ($r = .56$ and $r = .75$, respectively).

This inventory is brief (ten minutes) and is written on the 6th grade level to insure comprehension of most adult participants. Respondents rate the importance of each of the sixteen domains in their overall happiness, ranging from 0 (“not at all important”) to 2 (“very important”). They then rate how satisfied they are in that domain, with answers ranging from -3 (“very dissatisfied”) to +3 (“very satisfied”). Weighted satisfaction ratings ranging from -6 to +6 are calculated by multiplying the importance rating by the satisfaction rating for each domain. The resultant “weighted satisfaction profile” provides a comprehensive view of the respondents strengths and problems in these sixteen domains of life. An average of all of the weighted satisfaction (non-zero) ratings provides a score

of overall life satisfaction. Thus the total score reflects satisfaction in the life domains that the respondent considers important.

Design and Statistical Analysis

This research was designed as a comparison study of two groups of postgastrectomy cancer patients (early phase and long term survivors). Comparative analysis included independent t-tests and MANOVA. Additional correlational analysis was performed in order to analyze relationships. For the purpose of this research, group 1 = early phase postgastrectomy patients (0-5 years), and group 2 = long term survivors of gastrectomy (5 years and greater). Both group 1 and group 2 consists of patients who have undergone partial and total gastrectomy. Also, both group 1 and group 2 consists of patients who are considered cured and those for whom surgery was palliative. Alpha level was set at 0.05 and all analyses were performed with SPSS version 10.0 for Windows.

Chapter 4: Results

Please refer to Appendix A for all tables and Appendix B for figures. In addition, an example of a three day diet analysis and report can be found in Appendix C.

Basic Demographics

A total of twenty five (25) postsurgical cancer patients volunteered for the study: group 1 consisted of fifteen (15) persons surviving less than five (5) years postsurgery; group 2 consisted of ten (10) persons surviving five or more (≥ 5) years postsurgery. Overall there were eighteen (18) males and seven (7) females. In this group, fifteen (15) persons underwent total gastrectomy and ten (10) persons underwent subtotal gastrectomy. Two patients had a variation on total gastrectomy that involves a total esophagectomy and reattachment which renders the stomach completely nonfunctional. In group 1, the surgery type included nine (9) total and six (6) subtotal gastrectomy patients; in group 2, the surgery type included six (6) total and four (4) subtotal gastrectomy patients. The gender breakdown for groups was nine (9) males and six (6) females in group 1 and nine (9) males and one (1) female in group 2. Group 1 had a mean age of 67, with a range of 46 to 82. Group 2 had a mean age of 69, with a range of 54 to 78. Age did not vary with time since surgery ($r = .302$, $p = .142$). For the total study population, the majority of patients had an educational level of 12 to 18 years. Educational level did not vary with time since surgery ($r = .205$, $p = .326$). Most of the patients (twenty-one) were married; four patients were either never married, widowed or divorced. A variety of physical symptoms were reported as experienced with eating, the most frequent being

diarrhea, nausea, pain above stomach line, cramping in abdomen, reflux, indigestion, bloating and racing heart.

Hypothesis Testing

Hypothesis 1. There will be a significant difference in mean hope scores between group 1 and group 2. This difference was tested with an independent t-test. The independent variable (IV) is phase in recovery; the dependent variable (DV) is hope. The mean hope score for group 1 was 24.3, (SD=4.0); and for group 2 was 26.0 (SD=3.2). T-test found that hope scores for these two groups were not significantly different ($t(23)=-1.099$, $p=.283$).

Hypothesis 2. There will be a significant difference in mean agency and pathways scores between group 1 and group 2. This difference was tested by a one way MANOVA. The IV is phase in recovery; the DV are agency and pathways. The mean agency score for group 1 was 12.0, (SD= 1.9); and for group 2 was 13.3, (SD= 1.7). The mean pathways score for group 1 was 12.3, (SD= 2.6); and for group 2 was 12.7, (SD= 2.1). MANOVA found that neither agency nor pathways differed significantly by group ($F(2,22)=1.607$, $p=(.223)$).

Hypothesis 3. There will be a significant difference in level of knowledge about cancer between group 1 and group 2. This difference was tested with an independent t-test. The IV is phase in recovery; the DV is knowledge about cancer. The mean knowledge about cancer score for group 1 was 11.3, (SD=1.1); and for group 2 was 13.2 (SD=1.1). T-test found that knowledge about cancer scores for these two groups were not significantly different ($t(23)=-1.193$, $p=.245$).

Hypothesis 4. There will be a significant difference in mean perceived quality of life group 1 and group 2. This difference was tested with an independent t-test. The IV is phase in recovery; the DV is perceived quality of life. The mean quality of life score for group 1 was 2.6, (SD= 1.4); and for group 2 was 3.3 (SD= .84). T-test found that quality of life for these two groups was not significantly different ($t(22) = -1.426$, $p = .168$).

Hypothesis 5. There will be no one predominant coping style in early phase patients (group 1); however, there will be a predominant coping style of “fighting spirit” in long term survivors (group 2). The mean scores and standard deviations for the five different coping styles for groups 1 and 2 respectively are listed in Table 1 of Appendix A. Within subjects repeated -measures analysis of variance indicated an interaction between styles and group ($p = .007$). First t-tests were performed to see how styles differed between groups. It was found that there was a significant difference for “hopelessness/helplessness” ($t(23) = 2.83$, $p = .009$) and “anxious preoccupation” ($t(23) = 2.57$, $p = .017$), but no significant difference for “fighting spirit” ($t(23) = -1.56$, $p = .133$), “cognitive avoidance” ($t(23) = 1.106$, $p = .280$), or “fatalism” ($t(23) = -.829$, $p = .416$) (Figure A of Appendix B). A Chi-Square analysis indicated the possibility of a characteristically predominant style for each group, $X^2(5, N = 25) = 3.7$, $p = .054$). Next, within each group pairwise comparisons indicated that group 1 had predominant coping styles of “anxious preoccupation” and “fatalism” ($p = .000$), whereas group 2 had predominant coping styles of “fighting spirit” and “fatalism” ($p = .003$). The style with the highest score was then listed as the predominant style for that subject. Further analysis indicated that 73% of patients in group 1 have a “predominant” coping style of “anxious preoccupation” and

67% of patients in group 2 have a predominant coping style of “fatalism”. Patients with a predominant coping style of “anxious preoccupation” had a mean time of survival since surgery of 41 months; patients with a predominant coping style of “fatalism” had a mean time of survival since surgery of 88 months. A t-test was performed and indicated that the time since surgery between these two groups was significantly different ($t(22) = -2.13$, $p = .045$). (Please see Figure B of Appendix B). Correlational analysis across both groups revealed a negative correlation between both “hopelessness/helplessness” ($r = -.568$, $p = .003$) and “anxious preoccupation” ($r = -.592$, $p = .002$) with time since surgery. (Please see Table 4 of Appendix A). In addition, correlational analysis indicated a negative association between age and “anxious preoccupation” ($r = -.445$, $p = .026$).

Hypothesis 6. There will be a significant difference in mean dietary intake of calcium, vitamin D, iron, kilocalories and protein, BMI, and activity level between the group 1 and group 2. This difference was tested with a one-way MANOVA. The IV is phase of recovery; the DV are calcium, vitamin D, iron, kilocalories, and protein, BMI and activity level. The mean dietary intake for group 1 was as follows: kilocalories ($M = 2172$, $SD = 631$), protein ($M = 88$ grams, $SD = 20$), calcium ($M = 1003$ milligrams, $SD = 384$), vitamin D ($M = 4.3$ micrograms, $SD = 5.4$), and iron ($M = 18.9$ milligrams, $SD = 7.6$). The mean dietary intake for group 2 was as follows: kilocalories ($M = 2421$, $SD = 833$), protein ($M = 99$ grams, $SD = 34$), calcium ($M = 955$ milligrams, $SD = 483$), vitamin D ($M = 2.8$ micrograms, $SD = 2.3$), and iron ($M = 20$ milligrams, $SD = 7.5$). MANOVA indicated that there were no significant differences for these nutrients between groups ($F(1,24) = .981$, $p = .478$). The mean dietary intake for macronutrients when expressed as a

percentage of need as suggested by the United States Recommended Dietary Allowances, for group 1 is as follows: kilocalories ($\underline{M} = 128\%$, $\underline{SD} = 41$), carbohydrate ($\underline{M} = 118\%$, $\underline{SD} = 49$), protein ($\underline{M} = 131\%$, $\underline{SD} = 37$) and fat ($\underline{M} = 151\%$, $\underline{SD} = 53$). The mean dietary intake when expressed as this percentage for group 2 is as follows: kilocalories ($\underline{M} = 131\%$, $\underline{SD} = 39$), carbohydrate ($\underline{M} = 125$, $\underline{SD} = 40$), protein ($\underline{M} = 145\%$, $\underline{SD} = 46$) and fat ($\underline{M} = 137$, $\underline{SD} = 55$). MANOVA for kilocalories, carbohydrate, protein and fat intake expressed as a level of percentage of dietary need indicated no significant differences between groups ($F(1.24) = .938$, $p = .463$). Analysis by t-test indicated that neither BMI ($t(22) = .458$, $p = .651$) nor activity ($t(23) = .818$, $p = .422$) differed significantly between the two groups.

Hypothesis 7. There will be a significant difference in mean dietary intake of calcium, vitamin D, iron, kilocalories, and protein, BMI, and activity level in those patients with higher hope compared to those patients with lower hope. Correlational analysis indicated no significant relationship in mean dietary intake of calcium ($r = -.038$, $p = .862$), vitamin D ($r = -.300$, $p = .154$), iron ($r = .373$, $p = .073$), kilocalories ($r = .348$, $p = .096$), protein ($r = .308$, $p = .143$), BMI ($r = .112$, $p = .601$) and activity level ($r = .184$, $p = .380$) in those patients with higher hope compared to those with lower hope.

Hypothesis 8. There will be a significant difference in mean hope level in patients who have a predominant coping style of “fighting spirit” as compared to those patients with a predominant coping style of “cognitive denial.” This difference was tested with an independent t-test. The IV is coping style and the DV is hope. Because neither “fighting spirit” nor “cognitive avoidance” were predominant coping styles, this

hypothesis was corrected to determine if coping style varied according to level of hope. Correlational analysis indicated that level of hope was negatively correlated with “hopelessness/helplessness” ($r = -.612, p = .001$) and positively correlated with both “fighting spirit” ($r = .460, p = .021$) and “fatalism” ($r = .468, p = .018$). When tested for the two subsets of hope, which are agency and pathways, agency was negatively correlated with “hopelessness/helplessness” ($r = -.487, p = .014$) and positively correlated with “fighting spirit” ($r = .484, p = .014$) and “fatalism” ($r = .476, p = .016$). Pathways was negatively correlated with “hopelessness/helplessness” ($r = -.561, p = .004$).

Hypothesis 9. There will be significant relationships between the personality, knowledge, health behavior factors and quality of life. Correlational analysis revealed relationships where quality of life varied with personality measures: positively with hope ($r = .448, p = .036$), positively with agency ($r = .490, p = .020$), positively with “fatalism” ($r = .447, p = .037$), and negatively with “hopelessness/helplessness” ($r = -.508, p = .016$). Quality of life was also associated with kilocalorie intake ($r = .918, p = .000$), carbohydrate intake ($r = .472, p = .026$), calcium intake ($r = .567, p = .006$), iron ($r = .483, p = .023$), and percent carbohydrate ($r = .440, p = .040$). Quality of life was not significantly correlated with pathways ($r = .321, p = .146$), “anxious preoccupation” ($r = -.320, p = .146$), “fighting spirit” ($r = .324, p = .142$), “cognitive avoidance” ($r = -.034, p = .882$), knowledge about cancer ($r = -.203, p = .365$), BMI ($r = .012, p = .957$) or activity ($r = .250, p = .238$), (see Table 2, Appendix A).

Hypothesis 10. There will be significant relationships between the personality, knowledge, quality of life, and health behavior factors and time elapsed

since diagnosis. These relationships were tested with regression analysis. Table 3 (Appendix A) presents the significant results of multivariate stepwise regression. An entry allowance of $p \leq .1$ was used to examine associations between demographic, personality and health behavior characteristics. Significant factors in the regression equation in descending order were “anxious preoccupation”, “fighting spirit”, BMI, knowledge about cancer and “cognitive avoidance”. “Anxious preoccupation” and BMI were negative factors, the remaining factors were positive. In summary, analyses of the data indicated that group 1 did not differ significantly on the measures of hope, agency, pathways, knowledge about cancer, or quality of life. Group 1 did differ from group 2 significantly on the measure of coping styles for “hopelessness/helplessness,” and “anxious preoccupation,” but not for “fighting spirit,” “cognitive avoidance,” or “fatalism.” The predominant coping styles for group 1 were “anxious preoccupation,” and “fatalism.” The predominant coping styles for group 2 were “fighting spirit,” and “fatalism.” When comparing those patients with a predominant coping style of “anxious preoccupation” versus “fatalism,” there was a significant difference in time since surgery of 41 versus 88 months. Correlational analysis indicated negative covariance between “hopelessness/helplessness,” “anxious preoccupation,” and time since surgery and again for age and “anxious preoccupation.” Group 1 did not differ significantly from group 2 for dietary measures, BMI, or activity level. There were no significant differences between dietary measures, BMI, or activity level for low versus high hope persons. Level of hope covaried positively with “fighting spirit” and “fatalism”

and negatively with “hopelessness/helplessness.” Agency covaried positively with “fighting spirit” and “fatalism” and negatively with “hopelessness/helplessness”. Pathways covaried negatively with “hopelessness/helplessness.” Quality of life covaried positively with hope, agency, “fatalism,” kilocalorie intake, carbohydrate intake, calcium intake, iron intake, and percent carbohydrate and negatively with “hopelessness/helplessness.” Quality of life did not vary with pathways, “anxious preoccupation”, “fighting spirit”, “cognitive avoidance,” knowledge about cancer, BMI, or activity. Finally the model for time since surgery indicated significant factors of “anxious preoccupation”, “fighting spirit”, BMI, knowledge about cancer, and “cognitive avoidance.”

Overall, analysis of the study hypotheses revealed group differences in predominance of coping style. Interrelationships among the psychological, personality, and health behavior factors were revealed with correlational analysis. Some of these factors varied with time since surgery and provided a preliminary model for this endpoint. These results and their implications for psychosocial interventions as well as for future research follow in Chapter 5.

Chapter 5: Discussion

This study examined the relationships between personality factors (hope and coping style), psychological factors (quality of life and knowledge about cancer) and health behaviors (activity and dietary intake) with time since stomach cancer surgery. In addition, the influence of demographic variables of age, marital status and education level were analyzed.

Incidence and Survival

Ten of twenty five patients in the current research population were drawn from three local surgical or oncology offices, each associated with a separate hospital. The remaining fifteen patients were obtained by word of mouth through one of the original patients who had developed a personal network with other stomach cancer patients. Of the fifteen patients, one was from Canada, two were from England, and the remainder lived in the United States.

The incidence and survival rates for the largest of the three local hospitals from which patients were drawn indicated there were 137 patients diagnosed with stomach cancer since 1992; the overall relative survival was 23.7% for five years and 12.3% for ten years (University of Tennessee Medical Center Knoxville Tumor Registry, 2002). These rates include all types of stomach cancers with or without surgery. This compares similarly with the 0% - 30% five-year survival rate reported by Eiseman (1980), and the 21% predicted survival rate for the United States via the statistics of the American Cancer Society (American Cancer Society, 2001). The reported national incidence is 6.9/100,000 for men and 2.9/100,000 for women (Lambert et al., 2002). This national incidence

represents a decline from 1975 to 1995 of 2.6 and 1.4 per 100,000 men and women, respectively. The age-adjusted mortality rate for stomach cancer in the United States is 4.7/100,000 for men and 2.3/100,000 for women (Lambert, 2002). Although the overall five-year survival rate has seen an increase from 15% to 21% from 1976 to 1996, the specific prognosis depends on the stage of cancer, the cell type and its spread. The current study design compared early phase to late phase patients with both of these groups including patients who underwent subtotal and total gastrectomies. No distinction in analysis between patients who underwent subtotal versus total gastrectomy was made. In addition, the participants were asked if they were lymph node positive which would indicate dissemination of their disease. The prognosis for stomach cancer patients ranges from a five-year survival rate of 10-30% for patients who had a partial gastrectomy/esophagogastrectomy/ total gastrectomy for localized (non-metastasis) cancer, to 0% for patients who had a total gastrectomy for disseminated cancer (Eiseman, 1980). The current study population consisted of five patients with disseminated gastric cancer who underwent total gastrectomy, one of which has survived five or more years.

Research and patient organizations such as the American Cancer Society Cancer Survivors Network, the National Coalition for Cancer Survivors, the National Wellness Community, the Oncology Nutrition Dietetic Practice Group, the Coalition of National Cancer Cooperative Groups, Coping magazine and others were contacted for potential recruitment. In addition, a web page entitled Hope for Stomach Cancer Survivors was developed. No participants were recruited from these sources. The lack of response may be related to the lowered incidence as reported above combined with the poor survival rate for

stomach cancer patients in general. In addition, some organizations expressed a reluctance to assume liability for endorsing a scientific endeavor for which they did not have the appropriate expertise to evaluate.

A review of the literature produced studies that indicate similar limitations with participant recruitment. For example, some research conducted on postgastrectomy cancer patients contained 32 patients at outset and 7 patients in 12 months (Nordin and Glimelius, 1998). Another study analyzed data from 11 males only (Schmeidl et al., 1999). Tovey et al. (1990) began a longitudinal study with 227 patients and had only 52 remaining after twenty years. Also, von Holstein et al. (1992) conducted a study of only 20 patients of both gastrectomy types. Bragelmann (1991) accrued 174 patients from three hospitals over a period of three years and studied them without followup. Finally, Saito (2001) reported data on forty patients of both gastrectomy types, also without followup.

Basic Demographics

The average age for both of the current study groups (67 and 69 years) is not surprising, given the fact that 80% of all cancers are diagnosed in persons greater than age fifty-five (American Cancer Society, 2001). This probability is greater for males according to the American Cancer Society and the current study population reflects this with eighteen males and seven females.

Personality Measures

A review of the literature indicates that there are no comparative studies to date that examine hope, or its subsets of agency and pathways in stomach cancer patients or in other types of cancer, comparing early and late-phase survivors. The Hope scale, which is a

measure of goal-directed thinking, seemed an appropriate measure for our comparison. Knowledge about cancer did not vary for early and late phase survivors. These results suggest that knowledge and goal-related cognitions are not the discriminating personality features for early and late stomach cancer survivors. It may be that overall hopeful cognition (Snyder's measure of goal-directed hope) is less influential on actual time since surgery and that a variety of other factors, including hope as an emotional construct are more influential. Although goal-directed hope was not influential on time since surgery time, the coping style of "hopelessness/helplessness" decreased with time since surgery. Examples of statements from the Mini-MAC that describe the "hopelessness/helplessness" coping style follow: "I feel like giving up," "I can't handle it," "I feel that life is hopeless" (Watson et al., 1994).

Scheier and Carver (2001) apply a model of self-regulation to coping with cancer where maintaining an engaged attitude toward goals is critical. They propose that survival may be related to the ability to shift from an unattainable goal (in this case, due to the illness) to a new goal, or to find another path to meet the original goal. Thus, surviving patients maintain goal-directed and therefore hopeful, they may choose a different or less ambitious goal.

In this current study, in measuring the mental adjustment to cancer, coping style varied according to level of goal-directed hope. Those who had higher levels of the coping style "hopelessness/helplessness" tended to have lower levels of goal-directed hope. Those patients with coping styles described as "fatalism" or "fighting spirit" had higher levels of goal-directed hope. Agency, or the will to achieve personal goals, was greater in patients

who had a coping style of “fighting spirit” and lower with those patients who tended to cope with thoughts of hopelessness and helplessness. Pathways, or the belief in the ability to find strategies to achieve goals, was lower in patients using a coping style of “hopelessness/helplessness.” These associations indicate a relationship between the emotional feelings that accompany coping styles and cognitive processes.

Coping style was a more influential factor on time since surgery as indicated by t-test, for the styles of “hopelessness/helplessness” and “anxious preoccupation.” Both early and late phase survivors had a predominant coping style of “fatalism”, however, those patients surviving less than five years since surgery were more likely to use a coping style of “anxious preoccupation.” Given the adjustment to receiving the diagnosis, making decisions about treatment and experiencing the current stressors as well as contemplating the impact on work, home, family and future, a predominant coping style of “anxious preoccupation” is understandable. Examples from the Mini-MAC of statements that express a coping style of “anxious preoccupation” follow: “I feel very angry about what has happened to me,” “I worry about the cancer returning or getting worse,” “I am upset about having cancer,” “I have difficulty in believing that this has happened to me” (Watson et al., 1994). This final statement may indicate an element of denial expected in early phases of survival, and often considered beneficial. It is important to note, however, that neither group expressed a predominant coping style of “cognitive avoidance.”

Those patients who have survived five or more years are using a coping style of “fatalism” and “fighting spirit”. The majority appear to use “fatalism.” Chi-square analysis indicates that on the whole the patients in the study population evolve from a predominant

coping style of “anxious preoccupation” after surviving 41 months (3 years, 5 months) on average, and by the time they have survived an average of 88 months (7 years, 4 months) they express a predominant style of “fatalism.” Examples from the Mini-MAC of statements that express a coping style of “fatalism” follow: “At the moment I take one day at a time,” “I’ve put myself in the hands of God,” “ I count my blessings,” “Since my cancer diagnosis I now realise how precious life is and I’m making the most of it” (Watson et al., 1994).

Older patients were less likely to express a coping style of “anxious preoccupation.” Although the age of the patients did not vary with time since surgery, the decrease in “anxious preoccupation” with age might indicate a developmental aspect of this coping style that is age related regardless of the time since surgery. In other words, although the older a patient was, the less likely they were to use this coping style, the lower likelihood of using this coping style later after surgery was not a function of the patient’s age.

Very little comparison data is available on coping style of gastrectomy patients as measured by the Mini-MAC scale. Nordin and Glimelius (1997) studied 32 patients who underwent gastrectomy for stomach cancer. Their average age and percentage of males in the study population approximates this current study (67 years and 72%, respectively). Measurements were made at diagnosis, three months and 12 months. At twelve months, seven patients remained. The pattern of coping was somewhat different than in the current study. The predominant coping style was “fighting spirit.” The remainder of coping styles used in order of decreasing predominance were “fatalism,” “anxious preoccupation,”

“hopelessness/helplessness,” and “avoidance.” At one year, the participants in this current study had a predominant coping style of “anxious preoccupation.” A confounding factor in comparing this current study with Nordin and Glimelius (1997) is the division of patients into “cured” and “non-cured” status, which was not performed with this current study.

Quality of Life

Early and late phase survivors report that they have a similar quality of life. Their scores indicate they fall into the classification of an average quality of life. This classification according to the author of the quality of life scale used (Frisch, 1999) describes generally well-functioning persons who are basically content, able to get their needs met and their goals achieved in most of the important areas of their lives (Frisch, 1999). This finding coincides with the lack of difference found between early and late-phase survivors in goal-directed hope. The average quality of life category also implies an ability to set realistic goals, and to de-emphasize uncontrollable areas in life (Frisch, 1999). Perhaps this is a level that allows for survival and is therefore maintained even in the late phase survival group. Patients who scored higher on the Quality of Life Inventory tended to have higher overall hope level and higher agency levels. The results have shown that there is no difference in the level of goal-directed hope between early phase and late phase patients. Snyder (1993), who authored the Hope Scale, developed it after noticing that persons who survived serious losses were able to maintain their goal-oriented perspective. This is consistent with the current results in that hope levels did not differ by time since surgery. It appears that the quality of life may have a relationship with this ability to maintain goals even in the face of significant loss. Snyder (1993) further proposes that

cancer survivors may experience a disruption of the usual routes they have used to achieve goals in the past. If there is a relationship between quality of life and the ability to maintain hope, it is not found in the aspect of pathways of the current patients. It is more likely attributable to the maintenance of agency, the belief that one can attain goals that are established. Snyder speaks of high hope people as having the ability to increase either their agentic thinking or learning of new pathways. With a higher quality of life, the current patients were able to increase their agentic thinking and have an overall higher hope level. Once again, these levels of hope were not different for the early and late phase patients.

Patients with a higher quality of life also scored higher on the coping style “fatalism.” It appears that an attitude of taking one day at a time, appreciating their lives, and counting their blessings is associated with a higher quality of life. On the other hand, coping with a style of hopelessness where the person feels “like giving up,” and “cannot handle it,” is not characteristic of an average quality of life and this hopelessness increases as quality of life decreases.

It has been suggested by some researchers, rather than reporting aggregate scores of quality of life, that perhaps measures of categories or dimensions may be more informative (Cella, 2001). The Quality of Life Inventory (Frisch, 1994) provides weighted satisfaction in a variety of dimensions: health, self-esteem, goals and values, money, work, play, learning, creativity, helping, love, friends, children, relatives, home, neighborhood and community. However, these dimensions have not yet undergone empirical validation; therefore, although useful in clinical settings, this eliminates their use in comparative research analysis.

Some studies have suggested that physical measures, which have traditionally been used by the medical profession to indicate standards or quality of life, should be included in psychological measures. This would require disease-specific scales of quality of life. As discussed, the current study patients expressed a variety of negative gastrointestinal symptoms which would be specific for stomach cancer. It is more feasible and more helpful to find validated general measures of quality of life and add on only the most pertinent or useful specific questions, retesting for validity and reliability (Cella, 2001; Cascinu, Labianca, Daniele, Beretta, & Salvagni, 2001). Fifteen patients followed for a mean of five years after total gastrectomy answered quality of life questionnaires that included specific questions regarding gastrointestinal symptoms in addition to those pertaining to emotional and social aspects of life (Liedman, Svedlund, Sullivan, Larsson, & Lundell, 2001). Measures of quality of life which corresponded to gastrointestinal symptoms correlated with changes in body cell mass (body weight attributed to non-fat, non-water components).

A higher quality of life translated to an improvement in some dietary measures in this current study. Dietary consumption of kilocalories, carbohydrate, calcium and iron were all higher. In addition, percentage of recommended values of carbohydrate intake for health were higher in persons with higher quality of life. The meaning of this latter finding is difficult to ascertain at this time.

Health-Related Dietary Behavior Measures

Previous studies found that total gastrectomy patients consume from 2347 kcal/day to 2672 kcal/day (Bragelmann et al., 1996). Patients in the current study have similar

intakes for early phase (2172 kcal/day) and late phase (2421 kcal/day). Calcium intake for total gastrectomy patients have been reported to range from 25% to 70% of the recommendation made for health (Schmiedl, Schwille, Stuhler, Gohl, & Rumenapf, 1999). Early phase patients in the current study consumed 84% and late phase patients consumed 80% of the 1200 milligrams of calcium stated as the Recommended Dietary Allowance in the United States.

Iron deficiency anemia is a risk for gastrectomy patients. Dietary intakes were no different between our early and late phase survival patients and were well above the Recommended Dietary Allowance for iron (18 milligrams). The anemia reported in other gastrectomy patients is likely due to differences in absorption of iron. The current study did not measure serum iron levels, therefore the difference in absorption for these patients is not known.

Total gastrectomy patients studied by Bragelmann, et al. (1996) had an average body mass index (BMI) of less than 20 kg/m², lower than the 25 kg/m² cutoff which serves as a predictor for osteoporosis (Mellstrom et al., 1993). Patients in both the early and late phase survival groups in the current study are at risk for osteoporosis based on their BMI (22 and 21 kg/m², respectively), in combination with their lowered intake of calcium as noted above. Consistent with the findings of others, the current study revealed deficient intake of vitamin D whose major source is milk and other dairy products (both groups demonstrated 40% or less of the Recommended Dietary Allowance of 10 micrograms). Because vitamin D functions to facilitate calcium absorption from the small intestine, this further increases the risk for osteoporosis.

Although not reported in the literature for gastrectomy patients to date, it is of interest to measure macronutrient (kilocalorie, carbohydrate, protein, and fat) intake as a percentage of what is recommended for the individual based on their gender, height, weight, and age. As reported in the Results section, the percentages of recommended kilocalories, carbohydrate, protein and fat consumed were not different between early and late phase survivors; all patients consumed at least 100% of their recommended levels. Caloric intake and activity are influential factors on BMI; the similarities between the early and late phase patients in overall caloric intake and BMI are consistent with their reports of overall similar activity levels.

Deficiencies in consumption of nutrients, especially those associated with osteoporosis (calcium and vitamin D) are critical in that they exacerbate the problems of malabsorption. This is especially true for patients who have undergone a total gastrectomy where the absence of gastric acid significantly hinders absorption. The previously mentioned reports of mineral and protein deficiencies are based on serum measurements and bone marrow studies and often do not include dietary records. Saito et al., 2001 confirmed the effect of malabsorption by measuring serum concentrations of amino acids. Whereas total serum concentrations were not significantly different between gastrectomy patients and controls, specific levels of essential amino acids were altered and significantly lower for gastrectomy patients. They hypothesize that differences in protein absorption alter skeletal muscle proteolysis. The result is an increase in protein catabolism within the body, caused originally by poor absorption of overall calories or the breakdown product of protein, amino acids. This study suggests that future studies of gastrectomy patients should

include dietary intake analysis, serum amino acid analysis and measures of enzyme activity and protein malabsorption.

Model for Time Since Surgery in Postgastrectomy Patients

The strongest predictors for the length of time since surgery for the study population, in order of decreasing influence, were the coping styles of “anxious preoccupation,” and “fighting spirit,” BMI, knowledge about cancer, and “cognitive avoidance.” “Anxious preoccupation” and BMI are negative predictors for length of time since surgery. This implies that when all other predictors are held constant, using a coping style where the patient is preoccupied with worry about the current diagnosis or about recurrence or worsening of the cancer is a good predictor of early phase survival, probably up to 3 years, 5 months with given variance. This does not mean that having a coping style of “anxious preoccupation” is a causal factor in decreasing the length of survival time. For the current study population, it is a negative predictor for the model, and can be interpreted to mean that the late phase survivors in the current study are surviving greater than five years without the use of this coping style, when all of the other predictive factors are the same. Given that all other factors are the same, it would be of benefit to adopt a coping style other than “anxious preoccupation” in order to survive. In the current model, the alternative coping style that is most supported is “fighting spirit.” Interestingly, in the study conducted by Nordin and Glimelius (1997), the predominant coping style for gastric cancer patients was “fighting spirit.” Additionally, in a study by Greer et al., (1989) the predominant style in the cured patients was “fighting spirit” and, those patients who had a predominant coping style at the outset maintained this style after 12 months.

Lowered caloric and protein intake, along with a decreased activity level can potentially lead to a lowered BMI. As a negative predictor for the model, the potential effect of these factors on survival time is inherent, given the constancy of all other predictors in the model. It is also possible that the early phase group had a number of patients who had significant weight loss from surgery which they had not yet regained. If this were so, then even though the average BMI did not differ significantly between the early and late phase groups, there may be a period of time where changes in BMI are particularly critical. Future investigation into the dynamic changes in BMI and its associated factors may point to phases that may be considered critical periods in survival where aggressive nutritional repletion may be warranted. The increased incidence of early stage stomach cancer and tendency to perform radical gastrectomy surgeries (total gastrectomy and removal of lymph nodes) in Japan has provided comparative research information for the effects on morbidity and mortality (Saito et al., 2001). The mortality rate has risen in Japan to a five-year survival of 50-60%. Studies of morbidity and in search of predictors for mortality include the primary factors of resumption of preoperative levels of dietary intake within one year of surgery, normal protein status as measured by serum albumin, and body weight loss that ceases within a few months postsurgery. Poor food tolerance and significant, continued weight loss are early markers of increased morbidity (Saito et al., 2001). Body mass index (BMI) is measure of body weight and body composition in that it is calculated as weight in kilograms per height in meters squared, thus indicating the percentage of body weight as fat versus lean body mass indirectly. The

predictive model for the current study adds further credence to the use of body weight/composition in measures of morbidity and relationships to time since surgery.

Knowledge about cancer was another predictive factor for time since surgery in the model for the postgastrectomy patient. Research shows that group interventions which have an educational component are more effective in enhancing adjustment to cancer as measured by a decrease in intrusive thoughts about the illness, increase in self-esteem and body image, lessened confusion about the illness and increased feelings of control over the illness (Helgeson et al., 2001). The finding that knowledge is associated with less intrusive thoughts about cancer coincides with the final predictor of the model discussed below, cognitive avoidance. The last predictive factor in the model for time since surgery in the postgastrectomy stomach cancer patient is the coping style of cognitive avoidance. This concurs with the reports in the literature regarding denial in cancer patients (Kreitler, 1999). Whether the patients in this study were practicing denial of information or emotion may influence the repercussions of their cognitive avoidance, the former leading to lack of compliance or healthy behaviors, the latter being protective for anxiety (Kreitler, 1999). Examples of statements representative of “cognitive avoidance” on the Mini-MAC scale include the following: “I distract myself when thoughts of illness come into my head,” “Not thinking about it helps me cope,” “I make a positive effort not to think about my illness,” and, “I deliberately push all thoughts of cancer out of my mind.” Based on these statements, it appears that thoughts which may lead to emotions as well as thoughts which pertain to information about their illness may be included in the type of denial these patients practice. Depending on the stage of illness, the effect of denial may vary. The

degree of harm from denial which leads to lessened emotions may also be beneficial due to lessened anxiety. But a form of denial that implies also a lack of knowledge and possibly poor compliance with follow through on medical concerns may be harmful. As a positive predictor and holding all other predictors in the model constant, the patients who have been surviving more time since their surgery are more likely to be in some form of avoidance of thoughts dealing with their cancer.

Implications for Counseling Interventions

Psychosocial interventions to promote optimal adaptation to stomach cancer and the special circumstances of gastrectomy patients should be guided by the personality and other psychological factors which characterize the phases of recovery. The results from this study indicate there are differences in some of these factors depending on the length of time since surgery. It appears that gastrectomy patients surviving in both phases are able to maintain goal-directed hope with a decrease in the use of the coping style of “hopelessness/helplessness” after more time passes since their surgery. Also, they use “fighting spirit” and “fatalism” to cope when goal-directed hope is higher. With higher agency, they use more “fighting spirit” and less “hopelessness/helplessness”; with higher pathways, they use less “hopelessness/helplessness.” It would appear to be beneficial to design support groups and individual therapies that would engender hope as engagement in goals. This might be accomplished by assisting the patient in either finding alternative pathways or by renewing the belief in the ability to choose less ambitious goals.

“Fatalism” is a coping style that predominates for early and late survivors and could be fostered by psychosocial interventions. This may be especially in assisting the early

survivors who are coping by “anxious preoccupation”, and to show them how to gradually emerge to a less anxious state by taking one day at a time and finding new appreciation in life. The secondary predominance of “fighting spirit” may be one way to transition from “anxious preoccupation” to “fatalism” since it is a predominant coping style for both early and late survivors. The average quality of life may be influenced by cognitive interventions designed to enhance hope, agency and “fatalism”, all of which were positively associated with quality of life. With an improved quality of life, knowledge can be increased and educational information regarding dietary needs and methods must be provided. Persons with enhanced quality of life tended to consume more of their necessary nutrients in spite of the physical limitations that accompany gastrectomy.

Generally, interventions that enhance quality of life and decrease distress after a diagnosis of cancer are shown to lead to better treatment outcomes and often lengthen survival (Baum & Andersen, 2001). Meaningful changes in the course of an illness are expected when interventions are designed to target groups of patients in various phases of disease and treatment (Baum & Andersen, 2001). The role of the health psychologist often becomes crucial to the overall adaptation for a gastrectomy patient. With an increased knowledge of the biopsychosocial components in the adjustment to gastrectomy, especially as this relates to the phase of illness, health psychologists can provide additional interventional tools to assist the patient. It seems obvious that for most patients, making health care and other life decisions, adjusting to changes in identity and psychosocial relationships must be very difficult when the predominant coping style is “anxious preoccupation.” As recently as 1954, medical textbooks were recommending the

withholding of information from cancer patients so as not to provide false hope: “As a general principle, it is advisable to withhold the diagnosis of gastric cancer from the patient, but it should be freely and openly discussed with the next of kin....Most patients eventually know they have cancer, but cling to the ray of hope that they may be mistaken. This reasonable doubt regarding the diagnosis exerts a sustaining influence in their attitude to the disease. The patient may repeatedly interrogate the physician and urge him outwardly to reveal the diagnosis, hoping fervently that the true facts will not be divulged. Cautious optimism on the part of the physician is necessary...” (Gray, 1954). We have come a long way in just fifty years from this attitude to one of the informed and proactive patients. Patients today are more likely to ask for the facts about their illness and will often search even into costly alternative and/or complementary means of treatment. However, there seems to be some reluctance on the part of much of the medical establishment in joining the patient in a team approach toward recovery. This is evidenced by anecdotal story after story by patients voicing their frustration with the patient-physician relationship and the lack of communication and information.

Studies like the current one offer an opportunity for the health care professional, the patient and the family members and other caregivers, to gain insight into the experiences and needs of gastric cancer patients in different phases of their illness and recovery. This becomes especially crucial when survival suddenly thrusts the patient into a position of chronic illness with daily mental and physical struggle and risk of severe concomitant illnesses. But it may be that we need to do more than just gather additional facts on the biological and psychological features of illness. Perhaps it is the application of these facts

that will begin to make the difference in successful and optimal adaptation through our life span. Once again we are in need of a paradigm shift: “We might say that at this movement, as in the time of Galileo, what we most urgently need is much less new facts (there are enough and even embarrassingly more than enough of these in every quarter) than a new way of looking at the facts and accepting them. A new way of seeing, combined with a new way of acting - that is what we need.”(deChardin, taken from Kearney, 1996). The Health Psychologist is in a unique position to be a motivator and a participant in this revolution that is now taking place in the health care system.

Implications for Future Research

It is worth emphasizing that this study compared a group of stomach cancer patients who were less than five years postgastrectomy to a group of stomach cancer patients who were five or more years postgastrectomy. This study did not measure the influence of factors on survival. It provides a description of patients who fall into these two groups and as such enhances insight into their experience as well as the choices on the part of the clinician into methods of intervention. It in no way provides predictive information for survival. The model derived from regression of the parameters studied suggests that there is value in conducting a longitudinal study. By following a cohort of patients over time and addressing these parameters, a dynamic view of responses to diagnosis, treatment and life changes during survival would emerge.

A possible limitation of this study is the fact that each study group contained patients who had undergone both subtotal and total gastrectomy. The potential negative gastrointestinal symptoms observed after total gastrectomy are often far more severe,

global, and potentially debilitating than those observed in patients after subtotal gastrectomy (Harju, 1990). A recent investigation by Leidman, et al. described a positive relationship between gastrointestinal symptom control and both body composition and quality of life. A recommendation for future studies includes the separation patients who have undergone subtotal and total gastrectomy for purposes of comparison.

Although the incidence rates are declining overall worldwide, stomach cancer remains the second leading cause of cancer deaths and will increase yearly as the population ages (Lambert et al., 2002). Unlike Japan, stomach cancer goes undetected until later stages in the United States because we lack early standard modes of screening (Lambert et al., 2002). In addition, the increased mortality due to radical surgeries seen in Japan, has not been confirmed in Western countries including the United States (Lambert et al., 2002). Possibly there are additional factors unaccounted for that influence mortality in the United States. These may be lifestyle factors that are influenced by personality traits and psychological states. This is supported by evidence in the current research population, where the personality trait of coping style was predictive of time since surgery. Furthermore, the psychological measure, quality of life, was associated with the predominant coping style of patients living more than five years postsurgery, fatalism.

Measures of personality and psychological factors that influence successful adaptation to cancer are most useful when they are standardized. Attention to consistent use of similar measures with longitudinal studies would make comparison studies much more informative.

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Appendices

Appendix A - Tables

Table 1

Mean Coping Style Scores

	Group 1 - Early Phase		Group 2 - Late Phase	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Helplessness/Hopelessness	13.2*	3.6	9.6 *	2.1
Anxious Preoccupation	19.2*	5.6	13.9*	4.0
Fighting Spirit	12.1	2.3	13.5	1.9
Cognitive Avoidance	10.1	3.1	8.7	3.2
Fatalism	15.3	2.6	16.2	2.4

Table 2

Significant Relationships with Quality of Life

Quality of Life		
	Correlation	Significance
Hope	.448	.036
Agency	.490	.020
Hopelessness/ Helplessness	-.508	.016
Fatalism	.447	.037
Carbohydrate	.472	.026
Calcium	.567	.006
Iron	.483	.023
Percent Goal -Carbohydrate	.440	.040

Table 3

Postgastrectomy for Cancer Syndrome Model - Associations Between Psychological Factors and Health Behaviors with Survival

Stepwise Regression	b	p	% variance	incremental
Anxious Preoccupation	- .467	.025	22	22
Fighting Spirit	.406	.037	37	15
BMI	- .308	.084	47	10
Knowledge	.337	.050	57	10
Cognitive Avoidance	.363	.048	66	9

Table 4

Significant Relationships with Time Since Surgery

Time Since Surgery		
	Correlation	Significance
Hopelessness/ Helplessness	-.568	.003
Anxious Preoccupation	-.592	.002
Fighting Spirit	.219	.294
Cognitive Avoidance	-.134	.524
Fatalism	.217	.297

Appendix B - Figures

Figure A. Coping Styles For Early Phase and Long Term Survivors

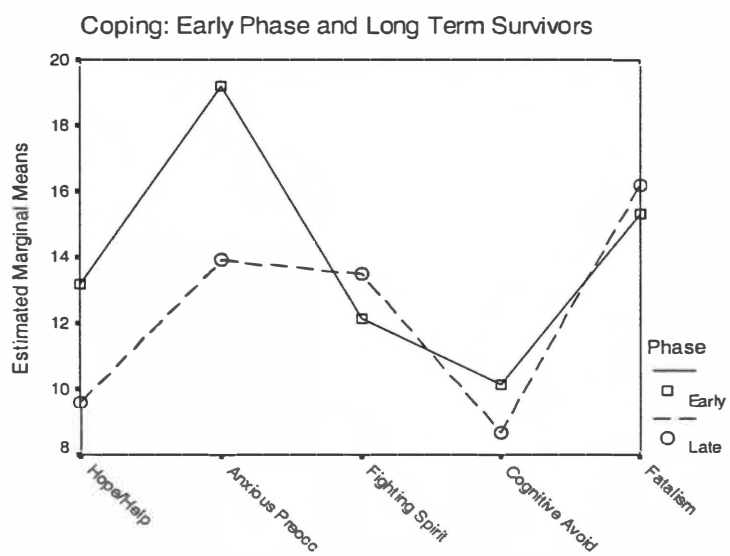
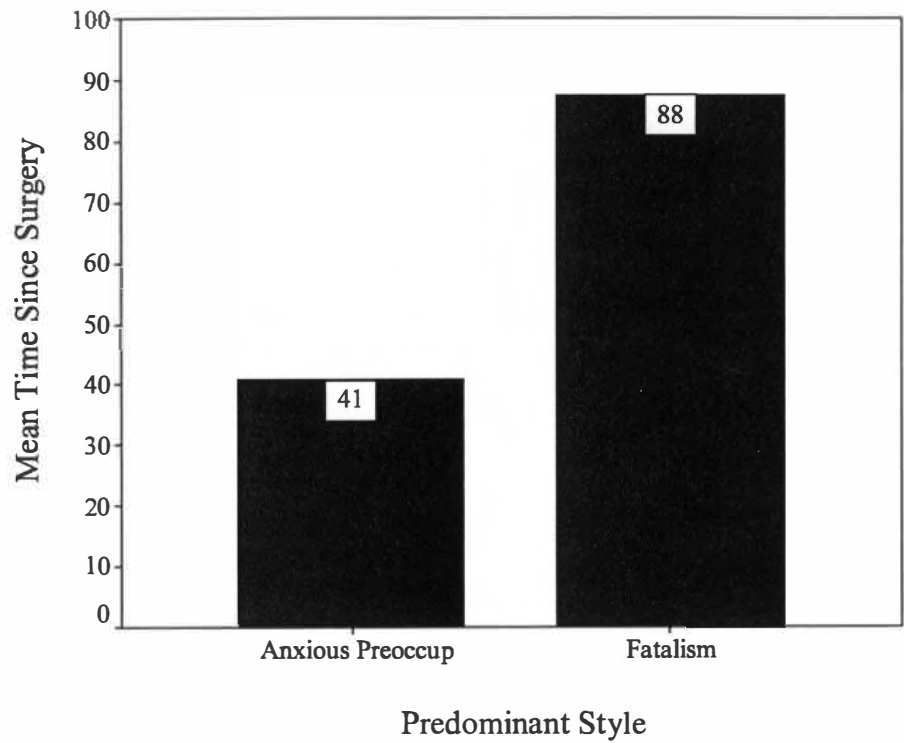


Figure B. Predominant Coping Style and Mean Time Since Surgery for Groups



Appendix C - Informed Consent

CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: Hope, Coping Style and Dietary Behaviors in Postgastrectomy Stomach Cancer Patients

1. PURPOSE OF THE STUDY:

You have been invited to participate in a research study because you have undergone a partial or total gastrectomy (removal of stomach tissue) for stomach cancer. You will be asked to complete psychological questionnaires which will provide information about your level of hope, style of coping, knowledge about cancer and your view of your quality of life. In addition, you will be asked to complete a record of the foods you consume for three typical days. The information you provide about these measurements will increase stomach cancer patients who have undergone a gastrectomy. You are giving your permission for this information to be used to make comparisons between recently our understanding of the psychological and dietary aspects and needs on the lives of diagnosed stomach cancer patients and long term survivors of stomach cancer. The information we gather will be shared with other scientists by publication in a professional journal or presentation without revealing your identity as a participant.

2. PROCEDURES TO BE FOLLOWED:

For doctor's office patients: If you choose to participate in this study, a packet of materials containing the psychological questionnaires and form for dietary records will be provided to you. These are written questionnaires which require your reading and writing the answers. The dietary record will be filled in for three days. You will return this packet

of materials to your doctor's office in person or by mail in the pre-addressed envelope provided. It is estimated that these questionnaires will take a total of 1.0 hour to complete.

You will also be provided a copy of this Informed Consent for your personal records.

or Web Page participants: If you choose to participate in this study, you will receive in the mail a packet with psychological questionnaires and form for dietary records. These are written questionnaires which require your reading and writing the answers. The dietary record will be filled in for three days. You will return this packet of materials to the principal investigator in the pre-addressed envelope provided. It is estimated that these questionnaires will take a total of 1.0 hour to complete. You will also be provided a copy of this Informed Consent for your personal records.

3. POTENTIAL RISKS:

The potential risks to you of participation in this study are deemed to be minimal risks, as defined by the University of Tennessee Institutional Review Board, in that there is no risk greater than that posed by daily life or routine psychological tests. The content of the psychological questionnaires has been chosen with the vulnerability of cancer patients in mind and therefore involves a minimum amount of emotional or stressful issues.

4. BENEFITS:

The information provided by you through the psychological questionnaires and dietary records will enhance the knowledge and understanding of persons researching the health issues of stomach cancer patients. This understanding in turn may be of practical benefit to health care providers in implementing programs to assist stomach cancer

patients. Study participants will receive feedback on their dietary records, including calorie, protein, iron, calcium and vitamin D content.

5. CONFIDENTIALITY:

All reasonable precautions will be taken to maintain confidentiality of the information provided by study participants. Participants are not required to provide their name or any other identifying information along with the questionnaires or dietary record. You will be given an opportunity to provide additional consent for follow up for future studies by providing your signature and method/location of contact. The data will be stored in a locked facility at the University of Tennessee. Data will be archived only for those participants who provide separate and additional permission. No references will be made in oral or written reports which could link participants to the study.

6. CONTACT INFORMATION:

If you have any questions at any time about the study or the procedures you may contact the researcher, Cynthia Collins, at The University of Tennessee, Counseling Psychology Program, (865)- 974-5131. If you have questions about your rights as a participant, contact the Compliance Section of the Office of Research at (865) - 974-3466.

7. PARTICIPATION:

Your participation in this study is voluntary. You may decline to participate without penalty. You may choose to withdraw at any time during the course of the study without penalty and without loss of the benefits (such as dietary feedback) to which you were otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed.

CONSENT

I have read the information above and received a copy of this form.

I agree to have my information archived (stored) for future analyses **without my name or other identification.**

Participant's signature _____

Date _____

I agree to have my information archived (stored) for future analyses in follow-up and longitudinal studies **with my name and other identifying information so that you may contact me in the future. Enter only the information you wish to provide below.**

Participant's signature _____

Date _____

I am providing **my name and other identifying information only for the purposes of receiving feedback on my dietary analysis. Enter only the information you wish to provide below.**

Participant's signature _____

Date _____

Street Address:

City: _____ State: _____ Zip Code: _____ Country:

_____ Phone: _____ E-mail: _____

KEEP ONE COPY FOR YOUR RECORDS/ RETURN THE COPY WITH YOUR SIGNATURES

Appendix D - The Goals Scale

The Goals Scale

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1= Definitely False

3= Mostly True

2= Mostly False

4= Definitely True

_____ 1.I can think of many ways to get out of a jam.

_____ 2.I energetically pursue my goals.

_____ 3.I feel tired most of the time.

_____ 4.There are lots of ways around any problem.

_____ 5.I am easily downed in an argument.

_____ 6.I can think of many ways to get the things in life that are most important to me.

_____ 7.I worry about my health.

_____ 8.Even when others get discouraged, I know I can find a way to solve the problem.

_____ 9.My past experiences have prepared me well for my future.

_____ 10.I've been pretty successful in my life.

_____ 11.I usually find myself worrying about something.

_____ 12.I meet the goals that I set for myself.

Appendix E - The Mini MAC

Coping Style A number of statements are given below which describe people's reactions to having cancer. Please check the box to the right of each statement, indicating how far it applies to you at present.

	<u>Definitely</u> does <u>not</u> apply to me	Does <u>not</u> apply to me	Applies to me	Definitely applies to me
1. At the moment I take one day time	☐	☐	☐	☐
2. I see my illness as a challenge	☐	☐	☐	☐
3. I've put myself in the hands of God	☐	☐	☐	☐
4. I feel like giving up	☐	☐	☐	☐
5. I feel very angry about what has happened to me	☐	☐	☐	☐
6. I feel completely at a loss about what to do	☐	☐	☐	☐
7. It is a devastating feeling	☐	☐	☐	☐
8. I count my blessings	☐	☐	☐	☐
9. I worry about the cancer returning or getting worse	☐	☐	☐	☐
10. I try to fight the illness	☐	☐	☐	☐
11. I distract myself when thoughts about my illness come into my head	☐	☐	☐	☐
12. I can't handle it	☐	☐	☐	☐
13. I am apprehensive	☐	☐	☐	☐
14. I am not very hopeful about the future	☐	☐	☐	☐
15. I feel there is nothing I can do to help myself	☐	☐	☐	☐
16. I think it is the end of the world	☐	☐	☐	☐

17. Not thinking about it helps me cope	☐	☐	☐	☐
18. I am very optimistic	☐	☐	☐	☐
19. I've had a good life what's left is a bonus	☐	☐	☐	☐
20. I feel that life is hopeless	☐	☐	☐	☐
21. I can't cope	☐	☐	☐	☐
22. I am upset about having cancer	☐	☐	☐	☐
23. I am determined to beat this disease	☐	☐	☐	☐
24. Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	☐	☐	☐	☐
25. I have difficulty in believing that this happened to me	☐	☐	☐	☐
26. I make a positive effort not to think about my illness	☐	☐	☐	☐
27. I deliberately push all thoughts of cancer out of my mind	☐	☐	☐	☐
28. I suffer great anxiety about it	☐	☐	☐	☐
29. I am a little frightened	☐	☐	☐	☐

Appendix F - Sample Diet Analysis



Client Diet Record Report

First:
Middle:
Last:
Company:

Female
Identification Number:
Date of Birth: 1/1/1920
Height: 5 ft. 2 in.

Weight: 110.00 lb.

Total Days: 3
Total Foods: 58
Avg. Daily Kcals: 1901.305

Diet Name: .DIET RECORD

Name	Amount Unit	Kcal kcal	Protein g	Carb g	Fat g	Sodium mg	Vit A (IU) IU	Vit C mg	Calcium mg	Diet Fiber g	Sugar g
DAY 1		1873.003	88.268	245.875	53.787	1878.122	2581.982	57.847	652.042	24.405	88.122
ALL DAY		1873.003	88.268	245.875	53.787	1878.122	2581.982	57.847	652.042	24.405	88.122
Half and Half Cream	0.500 c.	158.000	3.552	5.180	13.800	49.200	520.800	1.080	128.000	0.000	
POST GRAPE NUTS Cereal	0.500 c.	200.000	8.000	47.000	1.000	350.000	750.000	0.000	20.000	5.000	7.000
English Muffin, Toasted	0.500 Item	83.750	2.100	12.500	0.500	128.000	0.000	0.025	47.250	0.725	
Margarine	0.500 t.	18.897	0.021	0.021	1.892	22.181	83.919	0.005	0.705	0.000	0.000
White Bread	1.000 sl.	68.750	2.050	12.375	0.900	134.500	0.000	0.000	27.000	0.575	0.975
Peanut Butter, Smooth	2.000 T.	189.760	8.067	8.170	16.330	149.440	0.000	0.000	12.160	1.888	2.500
Grapes, European, Adherent Skin	20.000 Item	71.000	0.680	17.770	0.580	2.000	73.000	10.800	11.000	1.200	18.100
Banana	1.000 Item	108.580	1.215	27.847	0.568	1.180	95.580	10.738	7.080	2.832	18.425
Nonfat, Skim or Fat Free Milk	4.000 fl. oz.	42.875	4.177	5.941	0.221	83.700	249.900	1.225	150.875	0.000	5.400
Chicken Breast, Meat Only, Breaded, Baked or Fried	3.000 oz.	193.212	25.279	8.939	6.822	450.157	16.454	0.000	18.587	0.212	0.000
Lima Beans, Boiled, Drained	0.250 c.	52.275	2.894	10.047	0.136	7.225	157.250	4.293	13.800	2.253	1.248
Potatoes, Baked	0.500 Item	110.090	2.323	25.482	0.101	8.080	0.000	13.029	10.100	2.424	1.615
Watermelon	0.500 c.	24.320	0.471	5.457	0.327	1.520	278.180	7.298	8.080	0.380	6.840
Nonfat, Skim or Fat Free Milk	4.000 fl. oz.	42.875	4.177	5.941	0.221	83.700	249.900	1.225	150.875	0.000	5.400
Popcorn, Popped in Oil	2.000 c.	110.000	1.980	12.584	6.182	194.480	33.880	0.068	2.200	2.200	0.220
Saltine, Oyster, Soda or Soup Crackers,	11.000 Item	143.220	3.038	23.595	3.894	252.780	0.000	0.000	39.270	0.990	0.000
Unsalted Toppings											
Apple	1.000 Item	81.420	0.282	21.045	0.497	0.000	73.140	7.868	9.880	3.726	18.400
DAY 2		1792.388	67.417	285.195	55.695	1982.710	3641.741	48.895	785.254	22.387	93.587
ALL DAY		1792.388	67.417	285.195	55.695	1982.710	3641.741	48.895	785.254	22.387	93.587
Half and Half Cream	0.500 c.	158.000	3.552	5.180	13.800	49.200	520.800	1.080	128.000	0.000	
POST GRAPE NUTS Cereal	0.500 c.	200.000	8.000	47.000	1.000	350.000	750.000	0.000	20.000	5.000	7.000
English Muffin, Toasted	0.500 Item	83.750	2.100	12.500	0.500	128.000	0.000	0.025	47.250	0.725	
Margarine	0.500 t.	18.897	0.021	0.021	1.892	22.181	83.919	0.005	0.705	0.000	0.000
White Bread	2.000 sl.	133.500	4.100	24.750	1.800	269.000	0.000	0.000	54.000	1.150	1.950
Low Calorie Mayonnaise	0.500 t.	6.178	0.008	0.427	0.512	13.253	0.000	0.000	0.000	0.000	
Cucumber, Sliced	0.500 c.	8.780	0.359	1.435	0.088	1.040	111.800	2.758	7.280	0.418	1.195

Monday, March 18, 2002

1

First DataBank Nutritionist Pro™



Client Diet Record Nutrition Summary

First:
Middle:
Last:
Company:

Female
Identification Number:
Date of Birth: 1/1/1920
Height: 5 ft. 2 in. Weight: 110.00 lb.

Total Days: 3
Avg. Daily Kcal: 1901.305

Total Foods: 56
Diet Name:

DIET RECORD

Macronutrients			% Goal	Vitamins			% Goal
Kilocalories	1901.305	kcal	142 %	Vitamin A (RE)	831.402	RE	*
Protein	70.038	g	139 %	Beta-Carotene	799.816	µg	*
Carbohydrate	288.870	g	157 %	Vitamin C	51.970	mg	69 %
Fat, Total	58.597	g	%	Vitamin D (µg)	4.267	µg	28 %
Alcohol	0.000	g	*	Vitamin E (mg)	5.439	mg	36 %
Cholesterol	126.580	mg	*	Alpha-Tocopherol	0.924	mg	*
Saturated Fat	19.791	g	*	Thiamin	1.671	mg	152 %
Monounsaturated Fat	18.060	g	*	Riboflavin	2.162	mg	197 %
Polyunsaturated Fat	10.139	g	*	Niacin	24.602	mg	176 %
MFA 18:1, Oleic	13.075	g	*	Pyridoxine (Vitamin B6)	2.297	mg	153 %
PFA 18:2, Linoleic	6.502	g	*	Folate	354.299	µg	89 %
PFA 18:3, Linolenic	0.664	g	*	Cobalamin (Vitamin B12)	3.631	µg	151 %
PFA 20:5, EPA	0.003	g	*	Biotin	20.768	µg	69 %
PFA 22:6, DHA	0.006	g	*	Pantothenic Acid	3.432	mg	69 %
Dietary Fiber, Total	22.478	g	*	Vitamin K	35.443	µg	39 %
Sugar, Total	88.504	g	*				

Amino Acids			% Goal	Minerals			% Goal
Tryptophan	500.622	mg	*	Sodium	2795.809	mg	*
Threonine	1602.637	mg	*	Potassium	2807.860	mg	*
Isoleucine	2017.824	mg	*	Calcium	935.045	mg	78 %
Leucine	3304.538	mg	*	Iron	18.034	mg	225 %
Lysine	2604.321	mg	*	Phosphorus	1286.349	mg	184 %
Methionine	875.135	mg	*	Magnesium	321.643	mg	101 %
Cystine	520.880	mg	*	Zinc	7.806	mg	98 %
Phenylalanine	1820.409	mg	*	Copper	1.270	mg	141 %
Tyrosine	1534.792	mg	*	Manganese	1.465	mg	81 %
Valine	2217.802	mg	*	Selenium	36.630	µg	67 %
Histidine	1133.688	mg	*	Chromium	0.119	µg	595 %
				Molybdenum	28.812	µg	64 %

(* No Goal)



Client Diet Nutrient Deficiencies

First:
Middle:
Last:
Company:

Female
Identification Number:
Date of Birth: 1/1/1920
Height: 5 ft. 2 in. Weight: 110.00 lb.

Diet: DIET RECORD

A nutrient analysis revealed the following deficiencies in your diet. For each deficient nutrient, this report lists the nutrient name, the amount of the nutrient, the goal amount, the percentage of goal, followed by key sources.

Nutrient	Amount · Unit	Goal	% Goal	Key Sources
Vitamin C	51.970 mg	75.000	69 %	Collard greens, broccoli, brussels sprouts, orange juice, oranges, tangerines, grapefruit, spinach, white potatoes, strawberries, green peppers, tomatoes, cantaloupe, berries
Vitamin D (ug)	4.267 µg	15.000	28 %	Fortified milk products, fortified margarine, egg yolk, fish oil
Vitamin E (mg)	5.439 mg	15.000	36 %	Vegetable oils, wheat germ, leafy green vegetables, seeds, almonds, margarine, whole grain products
Biotin	20.768 µg	30.000	69 %	Liver, butter, eggs, rice, peas, soybeans, sunflower seeds, milk, brewer's yeast, mushrooms, bananas, tomatoes, whole grains
Pantothenic Acid	3.432 mg	5.000	69 %	Yeast, meats, salmon, eggs, cauliflower, broccoli, tomatoes, molasses, legumes, milk, liver, whole grain products
Vitamin K	35.443 µg	90.000	39 %	Kale, lettuce, spinach, cabbage, cauliflower, liver, egg yolk, soybeans
Selenium	36.630 µg	55.000	67 %	Seafood, kidney, liver, meat, grains
Fluoride	319.962 µg	3100.000	10 %	Fluoridated water
Molybdenum	28.812 µg	45.000	64 %	Milk, legumes, meat, grains

Appendix G - Patient Information

Participant Information

Please do not put your name on this form.

Part 1: Please circle the answer that applies to you

1) Gender: **male** **female**

2) Type of surgery: **partial gastrectomy** **total gastrectomy**
 removal of cardiac (esophageal) sphincter
 other organ or tissue removal _____
 lymph nodes: positive or negative

3) Marital status: **never married** **divorced**
 widowed **married**

4) Level of education: **8 years** **12 years** **18 years** **More than 18 years**

Please answer the following in the blank(s) that are provided:

5) My age is _____ years.

6) The approximate date of my surgery was _____ (month _____) (year).

7) Do you have any other chronic or terminal illness (es)?

If so, please list your illness (es). _____

8) What is your weight? _____ pounds What is your height? _____ feet _____ inches

9) Please circle all of the symptoms that you experience with eating:

diarrhea	pain above stomach line	sweating
constipation	cramping in abdomen	dizziness after eating
nausea	reflux	bloating
vomiting	indigestion	racing heart

10) Please provide your best estimate for the activities below. Report the **amount per week**.

Number of city blocks walked: _____ **OR** miles walked _____.

Number of stairs climbed: _____

What types of sports or other activities (gardening) in **amount of time per week:**

Activity _____	Time _____
Activity _____	Time _____
Activity _____	Time _____
Activity _____	Time _____
Activity _____	Time _____

Appendix H - Knowledge About Cancer Quiz

Knowledge About Stomach Cancer

Please check the box for the correct answer for each of the following questions.

	True	False	Do not know
1. Millions of people are living with cancer or have been cured of cancer.	☐	☐	☐
2. When cancer cells accumulate and lump together, this is called a tumor.	☐	☐	☐
3. When the cancer spreads to a new site, this is called metastasis.	☐	☐	☐
4. All tumors, including benign tumors are cancerous.	☐	☐	☐
5. When the cancer responds to treatment or is under control it is termed "remission."	☐	☐	☐
6. Most stomach cancers occur in people under the age of 60.	☐	☐	☐
7. All forms of cancer involve out-of-control growth and spread of abnormal cells.	☐	☐	☐
8. A risk factor increases a person's chance of getting cancer.	☐	☐	☐
9. One of the risk factors for stomach cancer is smoking.	☐	☐	☐
10. A bacteria called <i>Helicobacter pylori</i> is often present in patients with stomach cancer.	☐	☐	☐
11. Persons who have relatives with stomach cancer have no more risk of getting cancer of the stomach than any other person.	☐	☐	☐
12. More women than men get stomach cancer.	☐	☐	☐

- | | | | |
|---|--------------------------|--------------------------|--------------------------|
| 13. The goal of palliative treatment is to cure the cancer. | ☐ | ☐ | ☐ |
| 14. Having part or all of the stomach removed may require taking a non-food source of vitamin B-12. | ☐ | ☐ | ☐ |
| 15. After removal of the stomach, a patient is not at any greater risk of osteoporosis. | ☐ | ☐ | ☐ |
| 16. Most stomach cancers are of the type called adenocarcinoma. | ☐ | ☐ | ☐ |
| 17. A common result of surgery for stomach cancer is poor absorption of nutrients. | ☐ | ☐ | ☐ |
| 18. Stage 0 stomach cancers are in the lining only and are usually removed with surgery. | ☐ | ☐ | ☐ |
| 19. Persistent nausea, vomiting, heartburn and unintended weight loss are symptoms of stomach cancer. | ☐ | ☐ | ☐ |
| 20. Removal of the esophageal sphincter (the muscle at the top of the stomach) will make it less likely for a gastrectomy patient to have reflux. | ☐ | ☐ | ☐ |

Appendix I - Quality of Life Index

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Vita

Cynthia Susan Collins was born in Arlington, Texas on May 4, 1960. She was raised in West Palm Beach, Florida. She attended St. Clare grade school and Cardinal Newman High School. She graduated from the University of Florida, Gainesville in 1982 with a Bachelor of Science in Biology and complete her Master of Science in Nutritional Biochemistry in 1987. After completion of her doctorate in psychology, she plans to integrate her degrees and experiences in devoting herself to learning from and giving service to persons surviving chronic and terminal illnesses.

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