IDENTIFYING THE LEVEL OF PROGNOSTIC INFORMATION DESIRED BY PEOPLE WITH CANCER

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The study explored whether certain factors might be used to distinguish between people with cancer who do or do not want detailed information about their disease progress, do or do not want to be informed if their disease is no longer considered curable, and who do or do not want an estimation of life expectancy if their disease is no longer considered curable. The factors included whether an individual has an internal versus external locus of control, uses an active coping strategy or a planning coping strategy, the level of spirituality, and age. Participants consisted of 51 people with cancer from a cancer center in the state of Washington. Results indicated that 98% wanted detailed information about their disease progress, 94% wanted to be informed if their disease was no longer considered curable, and 78% wanted an estimation of life expectancy if their disease was no longer considered curable. Due to the majority of the participants endorsing the need for prognostic information none of the factors (e.g. coping strategies, locus of control, spirituality) were able to predict the information needs of the patients with cancer. Clinical implications of this study suggest that physicians have an ongoing, open dialogue with their patients about their prognostic information needs. The dialogue might be especially important for patients undergoing active treatment for cancer, since it could affect treatment decisions.

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INTRODUCTION

Life-Threatening Illnesses

A recent report issued by the Centers for Disease Control and Prevention (CDC) showed the top four leading causes of all deaths reported in the United States to be heart disease (26.6%), cancer (22.8%), stroke (5.9%), and chronic lower respiratory disease (5.3%) (Kung, Hoyert, Xu, & Murphy, 2008). The top two leading causes of death, heart disease and cancer, account for over one million deaths annually (Kung et al.). A life-threatening illness, such as cancer, poses many challenges and concerns to individuals with the illness and to their families.

A study by Heyland et al. (2006) revealed that a concern rated as extremely important by individuals with a life-threatening illness was the need to have trust and confidence in the doctors treating them (55.8%) and to have information about the illness given to them in an honest manner by the doctor (44.1%). Probably one of the most important factors concerning health care communication for people in America, especially those faced with life-threatening illness, is the widely accepted cultural belief in this country of autonomy and the right to participate in treatment decisions. In order for an individual to engage in autonomy and participate in treatment decisions the individual needs to have adequate information about the medical condition or disease that is affecting them. However, what is deemed adequate information? Furthermore, who determines what is adequate information, the doctor or the patient? Or is it a collaborative decision? A better understanding of the information sharing dilemma can perhaps be best understood with a look back in time to the history of information sharing with regards to disclosing the diagnosis of cancer.

Historical Overview on Disclosing Cancer Diagnosis

In the United States over the last 160 years there has been an evolution in the amount of information physicians disclose to patients with serious and potentially life-threatening illnesses such as cancer. As noted by Sokol (2006), physicians in 1847 were instructed by the American Medical Association's (AMA) first code of ethics not to make "gloomy prognostications" directly to patients but instead they should inform the patients' relatives and friends. The reason for the mandate according to the AMA was that the physician should be "the minister of hope and comfort" to their patients (Code of Ethics, AMA).

The mandate of AMA's first code of ethics set the standards of acceptable practice for many years in this country as demonstrated in a study conducted in 1953 which found that approximately 70% of physicians usually did not tell or never told their patients if they had cancer versus 30% who reported they always told or usually told their patients (Fitts & Ravdin, 1953). The questionnaire used in this study allowed for additional remarks to be added by the physicians and a frequent comment added was that although a patient should not be told, a family member should always be informed (Fitts & Ravdin). Other comments added by the physicians reflect the general attitude that a physician is irresponsible to the best interests of the patient if they disclose a cancer diagnosis directly to the patient (Fitts & Ravdin). This highlights the fact that non-disclosure of a cancer diagnosis was still in effect approximately 100 years after AMA's first Code of Ethics was adopted. Of note is that a study conducted by Kelly & Friesen in 1950 found that 89% of the patients with cancer they surveyed wanted to know their diagnosis.

A decade later a more in-depth survey was conducted to explore the underlying attitudes of physicians on what to disclose to cancer patients (Oken, 1961). The query of 219 physicians, of which 95% responded, indicated that almost 90% withheld the information of a cancer diagnosis from the patient, with the maintenance of a patient's hope as the major reason underlying the policy of nondisclosure (Oken). Interestingly, 60% of these same physicians agreed that if they were the patient with cancer they would want to be told. When asked if they thought their policy would change as to disclosing a cancer diagnosis, 46% answered either with “no possibility” or that it was “very unlikely” (Oken).

However, attitudes did change. In 1979 another study surveyed 264 physicians using the same questionnaire as Oken and found a pervasive change of policy with 97% endorsing that they would tell a patient the cancer diagnosis (Novack, Plumer, Smith, Ochitill, Morrow, & Bennett, 1979). What brought about the dramatic change of policy? Novack et al. proposed multiple factors were probably involved in the change. First, there was an increase in the general public's knowledge about cancer which was partially due to an education campaign to heighten peoples' awareness of the early warning signs of cancer. In addition, there had been an increase in public figures who shared their personal cancer stories, which Novack et al. thought had likely reduced the stigma of cancer. Perhaps most influential in the physicians' change of attitude were the medical advances in the treatment of cancer that extended survival rates, provided permanent cures, and improved the overall quality of life for patients with cancer (Novack et al.).

Physicians' attitudes toward delivering prognostic information and the actual practice of disclosing prognostic information seem to share striking similarities to the early controversy on disclosure of a cancer diagnosis.

Physicians' Attitudes on Prognostic Information

Currently it is generally accepted in the United States to disclose a terminal prognosis because it resonates with the general cultural belief of autonomy and a patient's right to participate in treatment decisions (Cristakis, 1999; Gordon & Daugherty, 2003). One descriptive study questioned oncologists using semi-structured interviews to elicit information on their attitudes and practice toward disclosure of prognosis to end-stage cancer patients (Gordon & Daugherty, 2003). The study found in general the oncologists were reluctant to discuss prognosis with patients under the basic premise that it would undermine the trust necessary to maintain a good doctor-patient relationship. Additionally, they believed patients most likely already knew their disease status as they had previously been under the care of a primary care physician before being referred to the oncologist. The oncologists also believed that most patients did not desire prognostic information (Gordon & Daugherty, 2003). The maintenance of hope and the desire to “do no harm” were cited as important considerations. Another dilemma cited by the doctors was their concern with making a prognostic statement that ultimately might be inaccurate. While these oncologists were reluctant to release prognostic information, they agreed they would do so if the patients specifically asked for the information and if they believed the patient was sufficiently psychologically stable to receive the information. The oncologists agreed that as treatment progressed, prognostic discussions often came about when current treatments were failing, the patient was in pain or having serious complications, and treatment decisions needed to be made. Of note is that this was a small sample of oncologists (*n* = 14) with the majority (86%) from an academic setting engaged in Phase I clinical drug trials (Gordon & Daugherty, 2003).

A qualitative study on physician practices of informing terminally ill patients about their disease was conducted at a major East coast teaching hospital (Miyaji, 1993). Terminal illnesses were not defined exclusively as cancer but, instead, referred to any patient with a 95% or greater chance of dying within 3 years. The study found that most of the physicians in their sample generally informed patients according to the informational wants and needs of each individual patient. How physicians determined a patient’s information needs varied among the sample. However, specific determinates cited by the physicians included current treatment availability, disease severity, the patient’s family and social responsibilities, financial arrangements, and the patient’s personality. Additionally, they found prognostic information was often modified if the physician felt the patient’s ability to cope necessitated it. Patients’ age, gender, personality and emotional state were factors taken into consideration when making the decision about their ability to cope. For example, 75% of the physicians would alter or restrict information if the patient appeared anxious and insecure. The problem with this approach is the potential difficulty for the physician to accurately assess the patient’s emotional state. Physicians in this sample also stated prognostic information was at times purposely indirect or vague. One physician stated he would never tell a patient “your prognosis is terrible.” Instead he would say “it might be difficult for us to control it.” Interestingly, 84% of the physicians questioned believed most patients were aware they were terminally ill; however, approximately 50% did not explicitly inform the patient they were dying (Miyaji). This study highlights the conundrum many physicians find themselves struggling with in delivering prognostic information. The physicians stated they were guided in the process by the desire to respect the truth while preserving hope and adhering to the medical-legal responsibility of honoring patients’ rights and their duty to inform (Miyaji).

In contrast to the general belief in honoring patients’ rights and the duty to inform were findings from another study that specifically queried 67 physicians asking them if within the last year they had withheld prognostic information at the request of family members (Anderlik, Pentz, & Hess, 2000). The results showed that 25% abided the family members request “most of the time,” 43% reported they “occasionally” abided by the request, and 4% stated they “always” honored the family’s request. One of the reasons many physicians (49%) endorsed for withholding information was concern over the patient’s fragile emotional state (Anderlik, Pentz, & Hess).

A study by Lamont & Christakis, 2001, further expands on the difficult task facing physicians on prognostications. Physicians of 326 cancer patients admitted to various hospice facilities were asked to estimate how long each patient had to live (formulated prognosis) and what estimate they would give to the patient if the patient requested the information (communicated prognosis). In 23% of the cases physicians stated they would not provide a time specific prognosis even if one was requested by the patient. However, when they did agree to give a time specific prognosis 40% would convey a different prognosis then their originally formulated estimation. In 70% of these cases the prognosis was readjusted to be more optimistic. The authors suggested perhaps the reason for more optimistic estimates was due to the physicians’ belief in the maintenance of hope. Only 37% of the time was the formulated prognosis the same as the communicated prognosis (Lamont & Christakis, 2001). If physicians would not disclose temporal prognosis in 23% of the cases, and these were hospice patients, how much more often might this occur with non-hospice end-stage cancer patients? Once again, the findings support the difficulty physicians encounter when it comes to deciding how much prognostic information they should convey to their patients.

One study provided an interesting comparison between medical versus law students' beliefs about disclosing a diagnosis and prognosis to a metastatic cancer patient with a less than one year life expectancy (Elger & Harding, 2002). The decision to use law students for the comparison was the researchers' belief that law students would generally represent society's values since they are educated in the application of society's laws. Not surprisingly, medical students were 100% in favor of informing the patient of the cancer diagnosis. However, only 29% of the medical students would "certainly" disclose the poor prognosis to the patient if it was requested, and 45% "probably" would disclose. In comparison, 54% of the law students would "certainly" recommend disclosing the prognosis, and 28% would "probably" recommend disclosure. Furthermore, if the patient specifically requested not to be told a prognosis, 26% of the law students still felt the obligation to disclose the poor prognosis, whereas only 7% of medical students endorsed disclosure (Elger & Harding, 2002). The findings suggest a difference in perception on prognostic truth telling and what is felt to be in the patients' best interest between future physicians and societal beliefs as represented by the law students.

Overall, physicians' disclosure of prognostic information to cancer patients reflects their desire to respect each patient's autonomy, provide hope, and preserve a good doctor-patient relationship. The problem confronting physicians is identifying the extent or level of prognostic information a patient desires.

Patients' Attitudes on Prognostic Information

There have been a fair amount of studies investigating the information needs of seriously ill patients and their caregivers. For example, one study explored what end-of-life issues were most important to seriously ill hospital patients and their families and found that 92% of the patients and 97% of the family members indicated it was “very” to “extremely” important that they be given adequate information about the disease, which included the risks and benefits of treatment (Heyland, Dodek, Rocker, Groll, Gafni, Pichora, et al., 2006). However, this study did not specifically ask about prognostic information (Heyland, et al.).

A study of 120 terminally ill patients with cancer explored what their most highly rated concerns were as they neared the end of their life. Ninety-three percent felt knowing their prognosis and being able to talk truthfully with the doctor about their prognosis was extremely or very important to them (Greisinger, Lorimor, Aday, Winn, & Baile, 1997). Similarly, another study questioned 67 patients who had been recently diagnosed with cancer and found 88% wanted information about their prognosis (Reynolds, Sanson-Fisher, Poole,Harker, & Byrne, 1981). However, there are people with cancer who do not want prognostic information. In fact research has shown 9% to 17% of people with cancer are not desirous of prognostic information (Meredith, Symonds, & Webster, 1996; Lobb, Kenny, Butow, & Tattersall, 2001).

In their review of the literature on this topic, Hagerty, Butow, Ellis, Dimitry, & Tattersall (2005) found agreement that most patients desire to be informed about their prognosis; however, there is variability in the type of prognostic information patients' desire. For example, a study involving older patients (mean age 73 years) found that 53% of cancer patients wanted information about life expectancy whereas 47% did not (Fried, Bradley, & O'Leary, 2003). A study by Kaplowitz, Campo, and Chiu (2002) found 80% of their sample of patients with cancer wanted a qualitative prognosis (i.e., whether or not they will die from the disease); however, only 50% wanted a quantitative prognosis (i.e., estimate on how long the patient might live). One study found 57% wanted life expectancy to be discussed (Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall, 1996). Another study found 61% wanted information on how cancer would affect their life expectancy, with another 10% being unsure (Schofield, Beeney, Thompson, Butow, Tattersall, & Dunn, 2001). One qualitative study described a specific example in which a patient felt it was too harsh when the physician informed her she had 6 months to live (Friedrichsen, Strang, Carlsson, 2000). These results highlight the possibility that some patients may want general information about prognosis but not specific quantitative information such as life expectancy.

In a qualitative study of information needs of patients with cancer receiving palliative care and their families, prognostic information was listed among the top two areas of information desired (Kirk, Kirk, & Kristjanson, 2004). Once again, however, the participants expressed mixed feelings about the specificity of information desired. For example, some patients stated they did not want to know the approximate length of time they had left, whereas others stated they did want to know because it allowed them the opportunity to “make plans”, “make the last little bit as good as possible”, and to “get their affairs in order” (Kirk, Kirk, & Kristjanson). Additionally, as their disease progressed many patients did not want as much detail about their prognosis as they had initially requested (Kirk, Kirk, & Kristjanson). Ambivalence toward detailed prognostic information was also found in another study on the information needs of patients with terminal illnesses. This study showed that patients felt conflicted between their need to know and their fear of receiving more bad news (Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999). A study of patients with metastatic cancer found that 40% of the patients wanted information about life expectancy and dying only if they specifically requested the information, whereas 30% wanted the doctor to tell them without asking them first (Hagerty, Butow, Ellis, Lobb, Pendlebury, & Leighl, 2004). Many patients desire to know if the physician believes the cancer is curable; however, survival rates were not necessarily desired or requested (Friis, Elverdam, & Schmidt, 2003).

The literature suggests the majority of patients want their physicians to disclose at least a general or qualitative description of prognostic information to them. However, as demonstrated in the aforementioned studies, the need for more detailed or quantitative information, such as life expectancy, reflects a certain degree of variability among patients (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurzeler, & Bradley, 2005; Kutner et al., 1999).

There is little doubt that physicians want to honor patients' autonomy and facilitate patients' informational needs with regards to prognosis (Anderlik, Pentz, & Hess, 2000; Christakis, 1999; Gordon & Daugherty, 2003; Miyaji, 1993). Likewise, research indicates greater patient satisfaction with their physicians when patient needs for specific prognostic information are met (Scofield, Butow, Thompson, Tattersall, Beeney & Dun, 2003). Knowing which patient wants qualitative, quantitative, or little to no prognostic information is the current challenge for physicians.

Demographic Factors Related to Patients' Prognostic Information Needs

Few studies have explored factors that might predict or be associated with the need for prognostic information or the level of information desired by patients with potentially life-threatening illnesses. In fact, information on this has generally been the result of exploring differences on demographic variables such as marital status or age. For example, a study conducted by Fried et al. (2003) revealed 63% of unmarried patients wanted to have information about their life expectancy versus 48% of married patients (Fried et al., 2003). Age has also been shown to be a factor, as demonstrated in a study that found older patients with cancer were less likely to want either a qualitative prognosis (i.e., whether or not they will they die from the disease) or quantitative prognosis (i.e., estimate on how long the patient might live) (Kaplowitz, Campo, & Chiu, 2002). Another study with cancer patients found younger patients were more likely to want detailed information about their disease and to want to participate in treatment decisions rather than leave the decisions to the doctor (Cassileth, Zupkis, Sutton-Smith, & March, 1980). An additional study, where the participants were older patients with serious illnesses, found that the largest factor associated with the desire for prognostic information was the patient's own belief about how long they thought they were going to live (Fried et al.). Eighty-three percent of patients who believed they had one year or less to live wanted to discuss their prognosis versus 53% of patients who believed they had two to five years to live (Fried et al.). Interestingly, another study reported that age, gender, and years of education were significantly associated with specific information needs; however, the study did not report detailed information on the results (Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999). Instead the researchers summarized the findings, stating that although a few significant associations were shown between patient characteristics and informational needs, there was no discernable set of patient characteristics that predicted informational needs of patients with terminal illness (Kutner et al.).

Once again, the challenge for physicians is determining the type or level of prognostic information desired by their patients with cancer. Variables that are mainly demographic in nature are not helpful to physicians except in the most general sense. Beyond demographic variables what factors might predict which patient would like detailed prognostic information? More specifically, what might predict which patient would want prognostic information such as to be told if their cancer was no longer considered curable? Which patients would desire an estimate of life-expectancy? Perhaps factors such as a person's use of particular coping strategies or one's general orientation and beliefs about life and death might be predictive of information seeking behaviors.

Coping with Illness

Psychosocial adjustment and adaptation to a chronic illness has been studied extensively (Livneh & Antonak, 1997). An important area of research within this domain is focused on understanding how chronically ill patients cope with their illness (De Ridder & Schreurs, 1996; Liveneh & Antonak).

Lazarus and Folkman (1984) defined coping as efforts, either cognitive and/or behavioral, that help people manage demands that are perceived as taxing or exceeding one's resources. Coping is a dynamic and situationally dependent process that begins with an initial appraisal of the situation and evolves into a continuing process of reappraisals to deal with the situation as it unfolds (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen,1986).

Certain concepts and theories have been generated about how people cope with various stressors. Two general categories of coping strategies have been identified: problem-focused and emotion-focused (Folkman, Lazarus, Dunken-Schetter, DeLongis, & Gruen,1986). Problem-focused coping refers to dealing with the stressor by taking steps to solve, manage, or improve the problem (Folkman, et al.). Examples of problem-focused coping strategies for a person with an illness might be to seek a second opinion before treatment decisions are made or to purchase vitamins to help improve overall health. Emotion-focused coping helps people regulate or manage emotions associated with a stressful event (Folkman et al.). For example, emotion-focused coping strategies for someone with a chronic illness might include cognitive positive reframing, such as thinking about people one knows who have the same illness and have managed quite well. Emotion-focused coping also includes avoidance strategies such as taking on more volunteer work to keep one busy and not dwell on their medical problem.

Theoretical models and measurements to capture and expand on the dimensions of each model have, of course, evolved over the years. Scales originally developed to measure the two broad categories of problem-focused and emotion-focused coping strategies/ factors and subscales have expanded into a more diverse collection of subscales encompassing a broader range of coping strategies. (Carver, Scheier, & Weintraub, 1989; Endler & Parker, 1994). For example, Carver et al. developed a multidimensional coping inventory with items to measure 13 different categories of specific coping strategies, such as active coping strategies, suppression of competing activities, focus and venting of emotions, behavioral disengagement, acceptance, denial, and seeking emotional social support, to name just a few. Other models and theories on coping have been proposed. For example, Taylor (1983) developed a theory of cognitive adaptation to threatening events, such as cancer, that focuses on three themes. The first theme is a persons' search for meaning in the experience which allows one to gain control over the event and their life (Taylor). Answers to questions such as what is the significance of the event to that person, what caused it to happen, what does life mean now, are examples of the cognitive process that occurs in adapting to the illness. Taylor's second theme is that people will attempt to regain mastery over the event. In other words, what can I do to manage the illness now and prevent further reoccurrences? The final theme is restoring self-esteem by self-enhancement mechanisms. Basically, this involves finding ways to feel good about oneself despite, or perhaps because, of the illness (Taylor). For example, Taylor found that people rated themselves as being emotionally better adjusted after their bout with cancer than before they had been diagnosed.

Coping Strategies as a Factor in Patients' Prognostic Information Needs

When demands are seen as taxing or exceeding one's personal resources, the situation is viewed as stressful (Endler, 1997). Certainly for most people, receiving a diagnosis of cancer is a stressful event, as are subsequent events related to the cancer such as surgery, chemotherapy or radiation treatment, change in body image, concerns over an unpredictable future and financial strain. A study by Felton & Revenson (1984) found that people with chronic illnesses that engaged in information seeking behaviors demonstrated better emotional adjustment to their illness.

Perhaps, seeking or avoiding prognostic information, or wanting a general qualitative versus a specific quantitative prognosis, is dependent upon which coping strategies an individual utilizes. Given that people use varying coping mechanisms to effectively handle stress, it seems plausible that one or more categories of coping strategies may be predictive of an individual's tendency to seek various levels of prognostic information or to avoid wanting this information at all.

Spirituality as a Factor in Patients' Prognostic Information Needs

Many people diagnosed with cancer draw on their spirituality to bring meaning to their illness and guide them through the experience (Greisinger, Lorimor, Aday, Winn, & Baile, 1997; Simon, Crowther, & Higgerson, 2007). For example, one study found spirituality ranked high in helping people deal with terminal cancer; 94% finding strength in their beliefs and 92% finding comfort in their faith (Greisinger et al., 1999). Kutner et al. (1999) found similar findings in their sample of terminally ill patients; 85% felt spirituality was of key importance to them. The importance of spirituality can also be seen from a quality of life study involving patients with end-stage cancer which found 55% felt it was very to extremely important to have their spiritual or religious needs met at that time in their lives (Heyland, Dodek, Rocker, Groll, Gafni, & Pichora et al., 2006).

Spirituality has been found to be associated with positive coping skills (Rowe & Allen, 2004). Rowe & Allen (2004) found people with chronic illness who scored high in spirituality also scored higher in overall coping scores. Spiritual well-being has also been linked to psychosocial adjustment and reduction in psychological distress in people with chronic illness (McNulty, Livneh, & Wilson, 2004), and specifically with people with cancer (Ell, Mantell, Hamovitch, & Nishimoto, 1989). A review of research findings on the effect of religious or spiritual coping strategies used by patients with cancer found in 7 of the17 studies that this form of coping reduced distress or provided an overall better adjustment to their illness (Thune-Boyle, Stygall, Keshtgar, & Newman, 2006).

Given the high degree of importance placed on spirituality by people with cancer, especially those with late stage cancer (Greisinger, Lorimor, Aday, Winn, & Baile, 1997)), one might wonder if it would guide their information seeking behaviors. One study found that prior to their consultation with a physician, patients at an oncology clinic, who endorsed items reflective of a belief that God was in control of the development and course of their disease were found to want less information and fewer details in general about their disease (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997). However, on subsequent reevaluation at the patients' next appointments 3 to 6 months later, this was no longer found to be true (Butow et al.).

Locus of Control as a Factor in Patients' Prognostic Information Needs

Julian Rotter (1966) proposed that future behavior was guided in part by one's past history of contingencies; specifically, if one perceives a reward is contingent on his own behavior, then he will have an internal locus of control of reinforcement. Conversely, if one perceives some outcome is not contingent on his behavior alone, but rather is due to luck, chance, fate, or the result of powerful others, he would be described as having an external locus of control (Rotter). Numerous studies were conducted on internal-external locus of control before the research expanded to include physical health related implications for treatment and outcome possibilities (Rotter). Discussions about future research possibilities for the locus of control variables prompted the development of the Health Locus of Control Scale (Wallston, Wallston, Kaplan, & Maides, 1976). Wallston et al. felt the Health Locus of Control Scale would be more precise in predicting health related behaviors since past behaviors in a specific venue (e.g. health/illness domain) should more accurately predict what an individual's future expectancies would be in the same domain. For example, one early study found that women who had a childhood history of poor health were more likely to have an external orientation towards health (Tolar, 1978). Another study with older Hispanic women found that women who were higher on internal health locus of control would participate in health related behaviors over which they had more control, such as breast self-examinations (Bundek, Marks, & Richardson, 1993). Interestingly, these same women were also more likely to seek health information when concerned about their own health and to watch or read more health related information in general (Bundek et al.).

Internal and external locus of control has also been linked to other information seeking behaviors. For example, during the development and validation of the Health Locus of Control Scale, healthy undergraduate students who highly valued health and also scored high in internal locus of control had higher levels of health related information seeking behavior (Wallston et al., 1976). Information provided to people can also have an effect on adjustment to surgical procedures, as seen in a study conducted with pre and post dental surgery patients. The study found that individuals who scored higher in internal locus of control did better in surgery if they watched a videotape prior to the surgery that provided them with specific information on the dental procedure (Auerbach, Kendall, Cuttler, & Levitt, 1976). Additionally, people high in external locus of control did not adjust well if they watched the videotape with specific information. Instead, individuals with an external locus of control did better in surgery if the video they watched was very general in nature (Auerbach et al.).

Due to the association between information seeking behaviors and the variables of internal and external locus of control, it might be predicted that people with cancer who have a more internal locus of control would choose not only to want prognostic information, but to prefer more specific quantitative information. Conversely, people with a more external locus of control might prefer a general qualitative prognosis or they may desire no prognostic information at all.

Proposed Variables that Might Predict Patients' Prognostic Information Needs

The literature shows physicians are motivated to respect and honor their cancer patients' rights to autonomy with regard to their prognostic information needs, while still maintaining hope. However, physicians are in the difficult position of determining not only which patient wants prognostic information, but more specifically, whether or not they desire general qualitative information or specific quantitative information. The literature also shows that although the majority of patients desire prognostic information to be disclosed, there are still some patients who do not want this information. Furthermore, within the population of patients desirous of prognostic information, the level of information desired consistently reveals a considerable amount of variability.

The literature has shown that spirituality is an important aspect in people's life when faced with a potentially life-threatening illness (Greisinger et al., 1997; Heyland et al., 2006; Kutner et al., 1999; Simon et al., 2007). Additionally, Butow et al. (1997) found that individuals with cancer who held the belief that God was in control over the course of their disease wanted less information and fewer details about the disease prior to an initial oncology consultation; although this effect was not seen on a return visit to the oncologist 3 to 6 months later.

Individuals also employ various coping strategies to deal with cancer related stress. In particular, one might engage in what is referred to as an active coping strategy in which the individual is taking action to improve his or her situation or to use a planning coping strategy such as coming up with specific steps to take when faced with a stressful situation (Carver, 1997).

Past studies have found that an individuals locus of control is associated with health related behaviors, including information seeking (Bundek et al.,1993;

Wallston, et al., 1976). Specifically, individuals higher on internal locus of control were more proactive information seekers (Bundek et al.; Wallston et al.).

Age also might be a factor in the level of information desired as one study indicated older patients wanted more general information about their prognosis versus specific details such as an estimate on how long they might live (Kaplowitz et al., 2002).

On the basis of the aforementioned literature, this study proposes that there are specific variables, including one’s level of spirituality, level of active coping and planning strategies, level of internal versus external locus of control, and one’s age, that might be used to identify and distinguish between people with cancer who do or do not want detailed information about their disease progress, who do or do not want to know if their disease is no longer curable, and those who would want an estimation of life expectancy if their disease was no longer curable.

Study Hypotheses

This study proposes the following hypotheses:

1. People with cancer who want detailed information about their disease progress will score higher in internal locus of control, score higher in active coping and planning, score lower in spirituality, and be younger.
2. People with cancer who have been told their disease is no longer curable and who want an estimation of life-expectancy will score higher in internal

locus of control, score higher in active coping and planning, score lower in spirituality, and be younger.

3. People with cancer who would want to know if their disease is no longer curable will score higher in internal locus of control, score higher in active coping and planning, score lower in spirituality, and be younger.
4. Females will be more likely than males to want detailed information about their disease progress, to be told if their disease is no longer considered curable, and to want an estimation of life-expectancy if their disease becomes no longer curable.

CHAPTER 2

METHODS

Participants

Participants were recruited from Northwest Medical Specialties, Oncology Clinic, in Tacoma, Washington. Participation in the study was limited to persons 18 years of age or older, who were able to complete the questionnaires which were in English, and had been diagnosed with cancer at some point in the past. The sample included 55 participants of which 4 were excluded due to incomplete questionnaires or failure to follow directions on the questionnaires. The remaining 51 participants included 40 women and 11 men. The participants ranged in age from 29 to 85 years, with a mean age of 56.51. The ethnic representation included only one participant from each ethnicity of African American, Asian American, Hispanic American, and Native American, with the remainder of the participants (*n* = 44, 86.3%) Caucasian American. Thirty-one (60.8%) of the participants were married, 9 (17.6%) were single, 7 (13.7%) divorced, 3 (5.9%) widowed, and 1 with no marital status disclosed. The educational level of the participants included 23.5% with a high school education, 33.3% with some college, 21.5% with an undergraduate degree, and 21.5% with a graduate level degree. Types of cancers represented include breast cancer (31%), lung cancer (14%), colon cancer (12%), ovarian cancer (8%), multiple myeloma (6%), Hodgkin’s lymphoma (4%), non-Hodgkin’s lymphoma (4%), bile duct cancer

(2%), lymphoma (2%), pancreatic cancer (2%), testicular cancer (2%), thymoma (2%), uterine cancer (2%), carcinoid (2%), and leukemia (2%) and type of cancer not disclosed (6%). Severity of the cancer included 6% with Stage I, 20% with Stage II, 26% with Stage III, 29% with Stage IV, and 20% who did not disclose the information.

Measures

Demographic information and prognostic information needs questionnaire. A general information form specifically designed for this study was used to collect demographic data on age, gender, marital status, educational level, ethnicity, number of children, and number of grandchildren. Questions pertaining to prognostic information needs and current status of their disease (i.e., type of cancer, stage of cancer) comprised the second part of the questionnaire. The questions, which required a yes or no response, are as follows:

1. Do you want detailed information about disease progress?
2. Would you want to know if the disease is no longer considered curable?
3. If disease is no longer considered curable, would you want to be given an estimation of life-expectancy (how long you had to live)?

Refer to Appendix A to review the questionnaire in its entirety.

Spirituality. Thune-Boyle et al. (2006) discussed problems with questionnaires used for measuring religious/spiritual coping. For example, some of the studies they reviewed produced positive findings associated with increased levels of religiosity. However, they stated that because of the measures utilized in these studies, findings might actually be due to increased social support provided by regular church attendance and more involvement in church activities rather than core spiritual beliefs. Basically, measurements of extrinsic religiousness (e.g. frequency of church attendance) may not adequately capture the essence of spirituality or be reflective of cognitions one might utilize as a resource to cope with cancer (Thune-Boyle et al.). For this reason, the participants completed the Index of Core Spiritual Experiences (INSPIRIT). The INSPIRIT focuses on an individual's spiritual experiences and was felt to be a better measure of spirituality that had been incorporated into a person's regular cognitive processing and that effects one's behaviors as the questions focus on core spiritual experiences instead of religiosity (e.g. church attendance). (Kass, Friedman, Leserman, Zuttermeister, & Benson, 1991; McBride & Pilkington, 1998). The INSPIRIT is a 7-item self-report questionnaire with good reliability (Cronbach's alpha reliability coefficient of .90) and validity (Kass, Friedman, Leserman, Zuttermeister, & Benson, 1991).

Coping. To measure coping strategies the Brief COPE inventory was used (Carver, 1997). The inventory is a brief form of the COPE inventory (Carver, Scheier, & Weintraub, 1989) and consists of 28 items; 14 scales with 2 items per scale. Recognizing the need for brevity, especially when the sample population is from an applied setting, the Brief COPE inventory is specifically designed to minimize the length of time normally required for most coping questionnaires (Carver, 1997). Alpha reliabilities for each scale ranged from .50 to .90.

Locus of control. To measure internal and external locus of control, the Internal Versus External Control of Reinforcement (I-E Scale) developed by Rotter (1966) was used. The scale has 29 items, which includes 6 filler items designed to mask the purpose of the test (Rotter). The I-E Scale has reasonably high internal consistency, satisfactory test-retest reliability, and discriminate validity (Rotter).

Procedure

Participants who met the inclusion criteria were asked to voluntarily participate in this research project. A script was used to introduce the researcher and the general purpose of the study (see Appendix B). Questionnaires had been numbered from 1 to 100 prior to being given to the participants. Consent forms were not numbered to insure confidentiality of the participants as approved by the Institutional Review Board of the University of North Texas. Consent forms were reviewed with the participants and possible benefits, potential risks, and/or discomforts were explained. Specifically, participants were informed that nothing would be communicated to the participant’s treating physician or any of the facility’s staff (e.g. nurses), especially with regard to their prognostic information needs. After the consent forms were signed, each participant was given a questionnaire packet and advised that the researcher would return intermittently to answer any questions and to check on questionnaire completion progress. All completed questionnaires were collected and stored in separate manila envelopes. Both envelopes containing consent forms and questionnaire packets were removed from the facility upon the close of each day. When data collection was completed and upon the return of the researcher to the University of North Texas the consent forms were stored separate from the questionnaire packets in a locked file cabinet. They will be stored for five years as required by the American Psychological Association. After five years, all questionnaires and consent forms will be destroyed.

CHAPTER 3

DATA ANALYSIS

Preliminary Data Analyses

Initial preliminary data analysis began with checking frequencies on the three major questions about participants' desire for prognostic information. The first question was how many people with cancer wanted detailed information about their disease progress. Frequency analysis revealed 98% (*n* = 50), all but one participant, desired detailed information about their disease progress. The next question was how many people with cancer would want to know if their disease is no longer considered curable. Frequency analysis revealed 94% (*n* = 48) of the participants would want to be informed if their disease was no longer considered curable versus 6% (*n* = 3) who did not want this information. The final question was how many people with cancer who have been told their disease is no longer curable would want an estimation of life-expectancy. Frequency analysis was conducted and showed 78% (*n* = 40) would want an estimate of life-expectancy versus 22% (*n* = 11) endorsed they would not.

Formal Data Analyses

Three logistic regressions were performed using the stepwise forward entry method to test the first 6 hypotheses using SPSS 16.0 statistical software package. The stepwise forward entry method entered each independent variable one at a time based on likelihood ratio estimates to ascertain which independent variable contributed the most to the regression equation and continued in that manner until all independent variables were entered. The probability value to determine entry of each independent variable was set at 0.05.

The first logistic regression analysis performed used the dependent variable of whether people with cancer do or do not want detailed information about their disease progress based on the model of independent variables which included locus of control, level of active coping and planning strategies, level of spirituality, and age.

The next stepwise logistic regression performed used the dependent variable of whether people with cancer would or would not want to be given an estimation of life-expectancy if their disease was no longer considered curable. The independent variables included locus of control, level of active coping and planning strategies, level of spirituality, and age.

The final stepwise logistic regression analysis tested the dependent variable of whether or not people with cancer would want to be told if their disease was no longer curable based on the independent variables of locus of control, level of active coping and planning strategies used, level of spirituality, and age.

Finally, chi-square tests of independence were used to compare people who do or do not desire more information on their disease progress, who do or do not want to be given an estimation of life-expectancy if their disease is no longer considered curable, and who do or do not want to be told if their disease was no longer considered curable on a series of demographic variables (gender, marital status, and ethnicity).

CHAPTER 4

RESULTS

Detailed Information on Disease Progress

Results of the first logistic regression analysis using the stepwise forward entry method with the dependent variable of whether people with cancer do or do not want detailed information about their disease progress showed none of the independent variables (i.e., locus of control, level of active coping and planning strategies, level of spirituality, and age) to be statistically significant. This finding was expected due to 50 out of 51 participants answering affirmatively that they wanted detailed information about their disease progress.

Estimate of Life-Expectancy

Results of the second stepwise logistic regression analysis using the dependent variable of whether people with cancer would or would not want to be given an estimation of life-expectancy if their disease was no longer considered curable showed none of the model's independent variables (i.e., locus of control, level of active coping and planning strategies, level of spirituality, and age) to be statistically significant.

Inform Disease was No Longer Curable

Initially the results of the final logistic regression analysis using the stepwise forward entry method indicated that the independent variable of an active coping strategy was predictive of whether people with cancer would or would not want to be told if their disease was no longer considered curable. However on closer inspection there appeared to be a problem. The confidence interval for the odds ratio was found to have an excessive range with the lower boundary of 0.99 and an upper boundary of 20.46. This finding is a problem for two reasons. First the confidence interval should not include the value of 1 and second there should not be such an extreme range in the confidence interval. Both of these findings indicate invalid results. Certain statistical software programs have been found to give false statistically significant results and it is the responsibility of the researcher to recognize the error (Irala, Navajas, & Castillo, 1997). The error occurs because the algorithm estimating the logistic coefficients fails to converge while it moves through excessive repetitions towards positive infinity or negative infinity. Consequently it was determined that none of the variables were found to be significant predictors of whether people would or would not want to be told if their disease was no longer considered curable.

Gender, Marital Status, and Ethnicity

Results of the chi-square test for gender and the three variables of information needs (i.e., detailed information about disease progress, desire to be told if disease is no longer curable, and desire for estimation of life-expectancy if disease is no longer curable) were not significantly significant. Specifically, chi-square values obtained for detailed information about disease progress was $\chi^2(1, N = 51) = 0.28$, $p = 0.60$, for the desire to be told if the disease is no longer considered curable was $\chi^2(1, N = 51) = 0.26$, $p = 0.61$, and the desire for an estimation of life-expectancy if the disease is no longer curable was $\chi^2(1, N = 51) = 1.29$, $p = 0.26$. It should also be noted that there were multiple cells with expected counts of less than 5 which indicated the results were invalid.

Due to sample size limitations the demographic variables related to marital status were collapsed to differentiate between married and non-married participants. Results of the chi-square test for married and non-married participants and the three variables on information needs (i.e., detailed information about disease progress, desire to be told if disease is no longer curable, and desire for estimation of life-expectancy if disease is no longer curable) were also not statistically significant. Specifically, the chi-square values obtained for detailed information about disease progress was $\chi^2(1, N = 51) = 1.58$, $p = 0.21$, for the desire to be told if the disease was no longer considered curable it was $\chi^2(1, N = 51) = 1.01$, $p = 0.32$, and the desire for an estimation of life-expectancy if the disease was no longer considered curable was $\chi^2(1, N = 51) = 0.05$, $p = 0.83$. It should be noted the analyses were invalid due to expected cell counts being less than 5.

Chi-square analysis for the demographic variable of ethnicity was performed and was found to be invalid because 13 cells had an expected count of less than 5. The population sample was not ethnically diverse and resulted in a skewed sample bias.

CHAPTER 5

DISCUSSION

Although the study was unable to predict information needs of people with cancer based on specific coping strategies, locus of control, or spirituality the study nevertheless yielded some significant findings. For example, 98% of the people with cancer in this study wanted to be kept informed about their disease progress. This finding is consistent with the results of a previous study by Greisinger et al. (1997) which found 93% of people with cancer endorsed an item indicating that it was very to extremely important that they knew their prognosis. However, it is important to note that all of the people in this earlier study were terminally ill, with a life expectancy of 6 months or less. In contrast to 93% of people who were terminally ill that desired prognostic information in the aforementioned study, Reynolds et al. (1981) found only 88% of people who had recently been diagnosed with cancer wanted prognostic information. Perhaps, the desire for prognostic information changes at different time intervals, such as newly diagnosed versus 5 years after initial diagnosis. An alternative explanation could be that prognostic information needs change as the disease progresses. For example, each type of cancer is classified into stages based on disease progress as stage I through IV. Stage I cancer indicates smaller tumors that are metastasized locally and each higher stage number indicates a steady progression of disease severity (Venes, 2002). Possibly, as the cancer progresses to a more medically serious level with larger tumors and increased metastases the desire for more prognostic information increases.

Perhaps a more interesting finding of this study was that 94% of the people with cancer wanted to be informed if their disease was no longer considered curable. Only one other quantitative study was found that asked a similar question to members of cancer support groups (Marwit & Datson, 2002). The question posed was slightly different in that it asked the participants if their cancer advanced to a terminal stage if they would prefer the possibility of death be discussed with them (Marwit & Datson, 2002). The choices given were 1) “I would not want to be given any information about my condition being terminal. I would prefer that the possibility of death not be discussed with me”; 2) “I would not mind if the possibility of death at some time in the future was mentioned, but only if I was reassured, even falsely, that there was still a chance for recovery”; 3) “I would want to be told about the certainty of my prognosis, but not all at once. I would want my physician to tell me gradually perhaps over the course of several days or weeks, so I would be more prepared for the news when it finally came”; and 4) “I would want to be told about the certainty of my prognosis without delay” (Marwit et al.). The results found 86.6% of the people endorsed choice 3 or 4, indicating they wanted full disclosure (Marwit et al.). A potential problem with the study, due to the wording of the choices, is that there may have been some confusion over whether the choice involved talking about death or talking in a more general sense about a terminal prognosis. Regardless, the finding from the present study that 94.1% wanted to be told if their disease was no longer considered curable is higher than 86.6% found in the Marwit et al. study. One possible explanation for this discrepancy is that all but one of the participants in the present study were undergoing chemotherapy treatment for cancer at the time of the study. Medication side effects and the accompanying stress of being in active treatment could be a factor explaining why 94% wanted to know if the disease was no longer considered curable. Another factor to be considered is that approximately 55% of the people in this study had stage III or IV cancer. For these participants the cancer had progressed to a potentially life-threatening state and, as such, concerns over curability might have been highly salient.

Perhaps this information might also account for the finding that over two-thirds (78%) of the participants wanted an estimate of life-expectancy if their cancer was no longer considered curable. Previous studies have indicated a much lower percentage of people with cancer wanting life-expectancy predictions. Butow et al. (1996) found 57% wanted life-expectancy estimates; however, more recent studies have shown slightly less with 50% to 53% wanting life-expectancy information (Fried et al., 2003; Kaplowitz et al., 2002). The finding that more people wanted life-expectancy estimates than shown in previous research could be attributed to the specificity of the question in the present study. Specifically, the question asked participants if the cancer was no longer considered *curable* would they want an estimation of life-expectancy. None of the earlier studies qualified the desire for life-expectancy information based on the non-curable status.

Whether people with cancer wanted detailed information about their disease progress, wanted to know if their cancer was no longer considered curable, or wanted an estimation of life-expectancy if they were no longer consider curable was not contingent upon their gender. In other words, information needs were not dependent on whether the person was male or female. This is contrary to previous research which has shown that females with cancer want more detailed information in general about their illness than males (Butow et al., 1997; Jenkins, Fallowfield, & Saul, 2001).

Prognostic information needs were also not found to be contingent on whether someone was married or non-married (i.e., single, divorced, or widowed). Previous research indicated marital status might be a factor. For example, in a study conducted by Fried et al. (2003), 63% of unmarried people wanted to have a discussion about life expectancy with their physicians. However, it should be noted the participants were not necessarily cancer patients; instead all of the participants in the study had serious medical conditions with limited life expectancy, including, but not limited to cancer (Fried et al.).

A limitation of this study is that the Brief COPE inventory did not specifically state that participants were to think about the questions with regards to coping with their cancer. Instead the questionnaire instructions asked about coping with stress in their life in a general nonspecific sense. As such, it is questionable to use the participants' answers to predict information seeking behaviors based on coping strategies used to handle stress associated with their cancer experience. Any future studies should modify the instructions to the brief COPE questionnaire to address this issue.

A lack of ethnic diversity within the sample population (e.g. 86% Caucasian) resulted in insufficient data to conduct an analysis based on ethnic differences. It is noteworthy that, according to population estimates provided by the U.S. Census Bureau for July 2007, Washington State is approximately 84.6% white (U.S. Census Bureau).

An obvious limitation of the study was its small sample size (*n* = 51). Calculations performed prior to data collection determined that 50 participants would be adequate for the proposed analyses; however, a larger sample would have been preferable. Additionally, anecdotal information from the participants and nursing staff of the facility indicated a potential sample bias in that people might have specifically chosen that treatment center because it had a reputation for having physicians who encouraged and practiced a high level of open communication with patients. The sample was also found to have a potential bias in the educational level of the participants. Thirty-five percent of the participants had a 4 year or higher degree, which included 22% with a master's degree or higher. A previous study by Schattner, Bronstein, and Jellin (2006) found that higher levels of education were significantly associated with patients' desire to have physicians give them a full explanation about their illness and its possible treatment options. Although the patients sampled in that study had a variety of disorders and not specifically cancer, it could be that people with cancer having a higher level of education seek more information about their illness from their physicians.

Replication of this study should be considered with a larger sample size and different geographic locations, especially more urban locations, which should include more ethnically and educationally diverse populations. Future research should also explore whether the stage of cancer is a good predictor of a patient's prognostic information needs. Additionally, exploration of whether there is a time-line effect for information needs, differing for people newly diagnosed with cancer versus those diagnosed several years earlier. Clinical implications of this study might suggest that physicians have an ongoing, open dialogue with their patients about their prognostic information needs. The dialogue might be especially important for patients undergoing active treatment for cancer, since it could affect treatment decisions.

APPENDIX A

GENERAL INFORMATION QUESTIONNAIRE

General Information

Please complete the following information sheet. Thank you for agreeing to participate.

Age: _______Male______Female______

Circle your marital status: Married Single Divorced Widowed

Circle education level:
Grade school
High school
Some college
2 year college degree
4 year college degree
Graduate degree: Masters Doctoral Medical

Number of children: _________
Number of grandchildren: _________

Ethnicity:
African-American
Asian-American
Caucasian-American
Hispanic-American
Native American
Pacific Islander American
Other: ____

Have you ever been diagnosed with cancer: __________
If you have cancer; what type of cancer do you have:
____
If applicable, what stage of cancer do you have:
I II III IV

Continue to next page

Past research has found that some people want a prediction about the course of their disease and others do not. In other words, some people want information about such things as the chance of a cure or life expectancies about their disease and others do not. The following questions are asked to see what you would desire.

Would you want to be informed if the progress of your disease changes?

Yes No

Do you want detailed information about disease progress?

Yes No

Would you want to be given an estimated cure rate such as the percentage of other people with your type & stage of cancer that have been cured?

Yes No

Would you want to know if the disease is no longer considered curable?

Yes No

Would you want to know if the disease is no longer considered treatable?

Yes No

If disease is no longer considered curable, would you want to be given an estimation of life-expectancy (how long you had to live)?

Yes No

Would you rather not be told if the news was bad?

Yes No

If the news was bad would you rather have a family member or close friend told instead of having the news be given directly to you?

Yes No

If the news was bad would you want to have a family member or close friend with you when you receive the news?

Yes No

If you would like to add any comments please feel free to do so:
____

____

____

____.

APPENDIX B

SCRIPT TO INTRODUCE RESEARCHER

Script to Introduce Researcher

Hi, I’m Laurel. As you can see by my shirt, I am a cancer survivor and a graduate student. You might have seen posters in the clinic about my coming to conduct research. I am asking everyone here today if they would like to participate. The information I am collecting hopefully will help doctors everywhere communicate better with future patients. Your information will be kept totally confidential. I will not be sharing it with your doctor or any staff member. Please know you have every right to say either “yes” or “no” as to whether you want to participate. I will not be upset with you regardless of your decision. I appreciate you even considering to participate. Thank you.

IF THEY AGREE TO PARTICIPATE:

Thank you so much for agreeing to participate. Here is the consent form. Either you can read it or I can read it to you.

Do you have any questions about the consent form? Here are the questionnaires. If any questions bring up distressing emotions please let me know. I know this is a stressful time in your life and I do not want to add to your stress. If at any time you don’t want to finish, that is okay too. I totally understand. Let me know if you become upset over any of this and we can talk about it. If you would like I can give you my phone number and e-mail address so if you have questions or concerns that arise after you have left today you will be able to reach me. Or if you prefer I can give you Dr. Walsh’s phone number as she is here on a regular basis and would be happy to talk with you. Alright, I will leave you to work on the questionnaires. I will come back and check on you in a little while. Thanks again.

REFERENCES

Anderlik, M.R., Pentz, R.D., & Hess, K.R. (2000). Revisiting the truth-telling debate: A study of disclosure practices at a major cancer center. *Journal of Clinical Ethics, 11*(3), 251-259.

Auerback, S.M., Kendall, P.C., Cuttler, H.F., & Levitt, N.R. (1976). Anxiety, locus of control, type of preparatory information, and adjustment to dental surgery. *Journal of Consulting and Clinical Psychology, 44*(5), 809-818.

Bundek, N.I., Marks, G., & Richardson, J.L. (1993). Role of health locus of control beliefs in cancer screening of elderly Hispanic women. *Health Psychology, 12*(3), 193-199.

Butow, P.N., Kazemi, J.N., Beeney, L.J., Griffin, A.M., Dunn, S.M., & Tattersall, M.H.(1996). When the diagnosis is cancer: Patient communication experiences and preferences. *Cancer, 77*(12), 2630-2637.

Butow, P.N., Maclean, M., Dunn, S.M., Tattersall, M.H., & Boyer, M.J. (1997). The dynamics of change: Cancer patients' preferences for information, involvement, and support. *Annals of Oncology, 8*, 857-863.

Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*(1), 92-100.

Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267-283.

Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. *Annals of Internal Medicine, 92*, 832-836.

Cherlin, E, Fried, T., Prigerson, H.G., Schulman-Green, D., Johnson-Hurzeler, R. & Bradley, E.H. (2005). Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *Journal of Palliative Medicine, 8(6),* 1176-1185.

Christakis, N.A. (1999). *Death foretold: Prophecy and prognosis in medical care*. Chicago:University of Chicago Press.

Code of Ethics of the American Medical Association. 1847. Available at http:www.ama.assn.org/ama/upload/mm/369/1847code.pdf

Davey, H.M., Butow, P.N., & Armstrong, B.K. (2003). Cancer patients' preferences for written prognostic information provided outside the clinical context. *British Journal of Cancer, 89*, 1450-1456.

De Ridder, D. & Schreurs, K. (2001). Developing interventions for chronically ill patients: Is coping a helpful concept? *Clinical Psychology Review, 21*(2), 205-240.

Elger, B.S. & Harding, T.W. (2002). Should cancer patients be informed about their diagnosis and prognosis? Future doctors and lawyers differ. *Journal of Medical Ethics 28*(4), 258-265.

Ell, K.O., Mantell, J.E., Hamovitch, M.B., Nishimoto, R.H. (1989). Social support, sense of control, and coping among patients with breast, lung, or colorectal cancer. *Journal of Psychosocial Oncology, 7*, 63-88.

Endler, N.S., & Parker, J.D. (1994). Assessment of multidimensional coping: Task, emotion, and avoidance strategies. *Psychological Assessment, 6*(1),50-60.

Felton, B.J., & Revenson, T.A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology, 52*(3), 343-353.

Ferrell, B.R., Grant, M., Borneman, T., & Juarez, A. (1999). Family caregiving in cancer pain management. *Journal of Palliative Medicine, 2*(2), 185-195.

Fitts, W.T., Jr., & Ravdin, I.S. (1953). What Philadelphia physicians tell patients with cancer. *JAMA, 153,* 901-904.

Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., Delongis, A., & Gruen, R.J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology, 50*(5), 992-1003.

Fried, T.R., Bradley, E.H., & O'Leary, J. (2003). Prognosis communication in serious illness: Perceptions of older patients, caregivers, and clinicians. *Journal of American Geriatric Society, 51*, 1398-1403.

Friedrichsen, M.J., Strang, P.M., & Carlsson, M.E. (2000). Breaking bad news in the transition from curative to palliative cancer care - Patient's view of the doctor giving the information. *Supportive Care in Cancer, 8*, 472-478.

Friis, L.S., Elverdam, B., & Schmidt, K.G. (2003). The patient's perspective: A qualitative study of acute myeloid leukaemia patients; need for information and their information-seeking behavior. *Supportive Care in Cancer, 11*, 162-170.

Gordon, E.J., & Daugherty, C.K. (2003). 'Hitting you over the head': Oncologists' disclosure of prognosis to advanced cancer patients. *Bioethics, 17(2),* 142-168.

Greisinger, A.J., Lorimor, R.J., Aday, L.A., Winn, R.J., & Baile, W.F. (1997). Terminally ill cancer patients: Their most important concerns. *Cancer Practice, 5*(3), 147-154.

Hagerty, R.G., Butow, P.N., Ellis, P.M., Dimitry, S., & Tattersall, H.N. (2005). Communicating prognosis in cancer care: A systematic review of the literature. *Annals of Oncology 16*, 1005-1053.

Harris, R. J. (1985). *A primer of multivariate statistics* (2nd ed.). New York: Academic Press.

Heyland, D.K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D. et al. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal*. Retrieved online 7/2/07 http://www.cmaj.ca/cgi/content/full/174/5/627.

Howell, D.C. (2002). *Statistical methods for psychology* (5th ed.). Belmont, CA: Duxbury Press.

Irala, J.de, Navajas, R.F., & Castillo, A.S.del (1997). Abnormally wide confidence intervals in logistic regression: Interpretation of statistical program results. *Pan American Journal of Public Health 2*(4), 268-271.

Jenkins,V., Fallowfield, L. & Saul, J. (2001). Information needs of patients with cancer: Results from a large study in UK cancer centres. *British Journal of Cancer, 84*(1), 48-51.

Kaplowitz, S.A., Campo, S., & Chiu, W.T. (2002). Cancer patients' desires for communication of prognosis information. *Health Communication, 14*(2), 221-241.

Kass, J.D., Friedman, R., Leserman, J., Zuttermeister, P.C., & Benson, H. (1991). Health outcomes and a new index of spiritual experience. *Journal for the Scientific Study of Religion, 30*(2), 203-211.

Kelly, W.D. & Friesen, S.R. (1950). Do cancer patients want to be told? *Surgery 27*, 822-826.

Kirk, P., Kirk, I., & Kristjanson, L.J. (2004). What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. Retrieved online 4/29/2007 from *British Medical Journal,* doi:10.1136/bmj.38103.423575.55 (published 19 May 2004).

Kung, H., Hoyert, D.L., Xu, J., & Murphy, S. L. (2008). Deaths: Final data for

2005. *National Vital Statistics Reports, 56*(10), Retrieved October 18, 2008, from http://cdc.gov/nchs/FASTATS/lcod.htm.

Kutner, J.S., Steiner, J.F., Corbett, K.K., Jahnigen, D.W., & Barton, P.L. (1999). Information needs in terminal illness. *Social Science & Medicine, 48,* 1341-1352.

Lamont, E.B., & Christakis, N.A. (2001). Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine, 134*(12), 1096-1105.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Livneh, H. & Antonak, R.F. (1997). *Psychosocial adaptation to chronic illness and disability*. Gaithersburg, MD: Aspen.

Marwit, S.J., & Datson, S.L. (2002). Disclosure preferences about terminal illness: An examination of decision-related factors. *Death Studies, 26*, 1-20.

McBride, J.L., & Pilkington, L. (1998). Letters to the editor; Authors' reply. *Family Medicine, 30*(7), 470-471.

McNulty, K., Livneh, H., & Wilson, L.M. (2004). Perceived uncertainty, spiritual well-being, and psychosocial adaptation in individuals with multiple sclerosis. *Rehabilitation Psychology, 49*(2), 91-99.

McSkimming, S., Hodges, M., Super, A., Driever, M., Schoessler, M., Franey, S.G., et al. (1999). The experience of life-threatening illness: Patients' and their loved ones' perspectives. *Journal of Palliative Medicine, 2*(2), 173-184.

Miyaji, N.T. (1993). The power of compassion: Truth-telling among American doctors in the care of dying patients. *Social Science Medicine, 36*(3), 249-264.

Novak, D.H., Plumer, R., Smith, R.L., Ochitill, H., Morrow, G.R., & Bennett, J.M. (1979). Changes in physicians' attitudes toward telling the cancer patient. *JAMA, 241*(9), 897-900.

Oken, D. (1961). What to tell cancer patients. *JAMA, 175*(13), 86-94.

Rotter, J.B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs: General and Applied, 80*(1), 1-28.

Rowe, M.M., & Allen, R.G. (2004). Spirituality as a means of coping with chronic illness. *American Journal of Health Studies, 19*(1), 62-67.

Sapir, R., Catane, R., Kaufman, B., Isacson, R., Segal, A., Wein, S., et al. (2000). Cancer patient expectations of and communication with oncologists and oncology nurses: The experience of an integrated oncology and palliative care service. *Supportive Care of Cancer, 8*, 458-463.

Schattner, A., Bronstein, A., & Jellin, N. (2006). Information and shared decision-making are top patients' priorities. *Health Services Research, 6*(1), 21-27.

Schofield, P.E., Beeney, L.J., Thompson, J.F., Butow, P.N., Tattersall, M.H., & Dunn, S.M. (2001). Hearing the bad news of a cancer diagnosis: The

Australian melanoma patient’s perspective. *Annals of Oncology, 12*, 365-371.

Simon, C.E., Crowther, M., & Higgerson, H.K. (2007). The stage-specific role of Spirituality among African American Christian women throughout the breast cancer experience. *Cultural Diversity and Ethnic Minority Psychology, 13*(1), 26-34.

Sokol, D.K. (2006). How the doctor’s nose has shortened over time; A historical overview of the truth-telling debate in the doctor-patient relationship. *Journal of the Royal Society of Medicine, 99,* 632-636.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38,* 1161-1173.

Tolar, A. (1978). Some antecedents and personality correlates of health locus of control. *Psychological Reports, 43*, 1159-1165.

Thune-Boyle, I.C., Stygall, J.A., Keshtgar, M.R., & Newman, S.P. (2006). Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Social Science & Medicine, 63*, 151-164.

Tolar, A. (1978). Some antecedents and personality correlates of health locus of control. *Psychological Reports, 43*, 1159-1165.

U.S. Census Bureau. (2007). *Estimates of the population by race and Hispanic origin for the United States and states*. Retrieved September 20, 2008, from http://www.census.gov/popest/states/asrh/tables/SC-EST2007-04.xls

Venes, D. (Ed.). (2001). *Taber's cyclopedic medical dictionary* (19th ed.). Philadelphia: F.A. Davis Company.

Wallston, B.S., Wallston, K.A., Kaplan, G.D., & Maides, S.A. (1976). Development and validation of the health locus of control (HLC) scale. *Journal of Consulting and Clinical Psychology, 44*(4), 580-585.