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COGNITIVE-BEHAVIORAL INTERVENTION TO ENHANCE COMMUNICATION
SKILLS FOR CANCER PATIENTS

by

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A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

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2010

COGNITIVE-BEHAVIORAL INTERVENTION TO ENHANCE COMMUNICATION SKILLS FOR CANCER PATIENTS

HEATHER PRAYOR-PATTERSON

MEDICAL/CLINICAL PSYCHOLOGY

ABSTRACT

Introduction: With nearly 12 million Americans living with or having a history of cancer, the patient-doctor communication process is especially important for this population. Cancer patients are often dissatisfied with the quality of the information they receive regarding their treatment, side effects, symptom control, and the quality of the relationship with their healthcare provider. A patient's self-efficacy during patient-doctor interactions influences the level of trust in his/her doctor, satisfaction with care, and the type of information exchanged. Studies have focused on intervening in patient communication, but there are limitations in the literature, including a focus on improving self-efficacy, addressing communication issues of patients from lower socioeconomic status backgrounds and those with more lethal cancers, and utilizing empirically-supported theories for interventions. **Aim:** This dissertation study aimed to develop and implement a cognitive-behavioral communication intervention designed to enhance cancer patients' self-efficacy. **Design and Analyses:** Medically indigent cancer patients were recruited and randomized to either an intervention or wait-list control group. The two conditions were compared on self-efficacy across three timepoints (baseline, post-intervention, and 1-month post-intervention) using an analysis of variance procedure. Relationships between several psychosocial concepts were also explored. **Results:** Twenty-nine participants entered the study, and were predominantly women, African American, and middle-aged. No significant main effects were found in self-efficacy

between the groups, $F(1, 21) = .007, p = .94$, or across the three timepoints, $F(1, 21) = 3.57, p = .073$. Several significant correlations were found between psychosocial variables at baseline. Positive relationships were seen between self-efficacy and trust in doctor and satisfaction with doctor. Negative relationships were seen between self-efficacy and information needs and illness uncertainty. Negative relationships were also found between illness uncertainty and trust in doctor and between illness uncertainty and satisfaction with doctor. **Conclusions:** This is the first known study to utilize cognitive-behavioral theory in an intervention targeting cancer patient's self-efficacy in communicating with healthcare providers. Although no significant changes were found in participants' level of self-efficacy after completing the intervention, several significant relationships between the psychosocial variables were found that are consistent with the literature. Limitations of the study, including power, are discussed.

Keywords: patient-doctor communication, self-efficacy, cognitive-behavioral intervention, cancer

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CHAPTER 1

INTRODUCTION

Role and Importance of Effective Communication for Patients

Effective communication is key for both the patient and healthcare provider for establishing a quality relationship and ensuring quality patient care is delivered. Patient-doctor communication is a multidimensional process which serves as one important method for educating patients about several aspects of their care, including disease evaluation, diagnosis, and prognosis (Teutsch, 2003). To achieve effective and competent communication, both patient and provider must be motivated, have sufficient knowledge and self-awareness of what is required for effective communication, and have sufficient provision and linguistic skills to produce effective communication behaviors (Epstein & Street, 2007).

In looking at factors conducive to effective communication in the medical setting, patients should be motivated to discuss their concerns and preferences in an open and honest manner with their providers. In addition, patients are challenged to have adequate health literacy, which includes a general understanding of health, the process and flow of patient care in hospital or clinics, and relevant medical terminology. With an appropriate knowledge-base, patients are better equipped to discuss topics that arise during their office visit. Regarding level of skill, it is important that patients possess active communication behaviors, including asking questions, stating preferences, introducing

topics, and expressing emotion in order to attain effective communication with providers (Epstein & Street, 2007).

Associated Outcomes of Effective Communication for Cancer Patients

Acknowledgment of the importance of effective communication between healthcare professionals and patients has led to the implementation of communication skills training in medical school curriculum and as continuing medical education for physicians (Harrington, Noble, & Newman, 2004; Teutsch, 2003). But despite promising efforts in communication skills training for physicians, there is mounting evidence that patients are often unsatisfied with the communication process with healthcare providers. Studies have demonstrated the relationship between the quality of communication and patient satisfaction, patient adherence to the medical program, and clinical outcomes including illness survival and health-related quality of life (Epstein & Street, 2007). The communication process is especially important for the cancer population given the high prevalence of the disease in the US (American Cancer Society, 2010). Currently, approximately 12 million Americans are living with or have a history of cancer (National Cancer Institute, 2008). After a diagnosis of cancer, the incidence of clinically significant depression and anxiety is high for these patients (ACS, 2010). Challenges in the communication process with healthcare providers may increase their emotional distress (Braden, Mishel, & Longman, 1998). Cancer patients are often dissatisfied with the quality of the information they receive regarding their treatment, side effects, symptom control, and the quality of the relationship with their healthcare provider (McCann & Weinman, 1996).

When cancer patients are satisfied with patient-provider communication, there is increased satisfaction with overall medical care, greater levels of understanding about their disease and its treatment, they are more likely to adhere to their medical regimen (Epstein & Street, 2007), anxiety and depression are significantly reduced (Hack, Degner, & Parker, 2005), and well-being is enhanced (Clayton, Mishel, & Belyea, 2006). The relationship between patient-provider communication and patient outcomes highlights the importance of research that continues to address the inadequacies of communication between cancer patients and their healthcare providers.

Factors Associated With Communication: Self-efficacy

Self-efficacy is conceptualized as an individual's confidence in his/her ability to accomplish a task or behavior (Bandura, 1998). The level of self-efficacy a patient possesses is predictive of his/her engagement in specific behaviors. Higher levels of self-efficacy is predictive of behaviors important to patient communication including, asking questions during a doctor visit, initiating topics with healthcare providers, and reflecting information back to the doctor (Epstein & Street, 2007).

Patient Self-efficacy in Patient-Doctor Interactions

Patient self-efficacy in patient-doctor interactions is defined as the patient's confidence in his or her ability to interact or communicate effectively with doctors (Maly, Frank, Marshall, DiMatteo, & Reuben, 1998). A study assessing the impact of patient-doctor communication on symptom resolution in low-income breast cancer patients found self-efficacy to be predictive of patients' behaviors in resolving pain and nausea

symptoms (Maly, Lui, Leake, Thind, & Diamant, 2010). Studies have shown that self-efficacy can influence, as well as be influenced by, a patient's level of trust in their doctor, satisfaction with care, and the type of information exchanged (Liang, Burnett, & Rowland, 2002; Stewart, Meredith, Brown, & Galajda, 2000). Patients' understanding of instructions and treatments is positively associated with self-efficacy, and has been shown to affect patient outcomes and well-being (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). Studies specifically addressing cancer patients have shown similar results. Men with prostate cancer earning lower incomes reported low self-efficacy in patient-doctor interactions if they were less satisfied with the healthcare they received, felt that their doctor could have listened more carefully, explained information more completely, and had less confidence in their doctor (Maliski et al., 2004). In a sample of older breast cancer patients, women who reported more confidence in their interactions with physicians had more cancer knowledge, less time delay in starting treatment, and had higher rates of breast conserving surgeries (Maly, Leake, & Silliman, 2004). These studies highlight the importance of patients' perception of their ability to communicate effectively with their healthcare providers and the effect of their confidence on satisfaction and information they receive. Future directions discussed in these studies included developing interventions aimed at increasing patients' self-efficacy in communicating with physicians.

Several authors have undertaken the task of developing communication interventions aimed at increasing cancer patients' participation in interactions with healthcare providers (Brown, Butow, Boyer, & Tattersall, 1999; Brown, Butow, Dunn, & Tattersall, 2001; Glynn-Jones et al., 2006; McCann & Weinman, 1996; Street, Voigt,

Geyer, Manning, & Swanson, 1995; Wells, Falk, & Dieppe, 2004). The main outcome for these studies was number of questions asked by the patient, and in only one study was self-efficacy measured (McCann & Weinman, 1996).

Additional Factors Associated with Communication

Emotional distress is defined as a nonspecific unpleasant experience that includes symptoms of nervousness, depression, worry, and demoralization (Gross, Brammli-Greenberg, Tabenkin, & Benbasset, 2007). Patients' ability to discuss the distress they are experiencing is important during patient-doctor interactions given that doctors can be less observant to patients' verbal cues for emotional support (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). Patients who have opportunities to discuss their distress with their doctors have higher satisfaction with their care (Gross, Brammli-Greenberg, Tabenkin, & Benbasset, 2007). In a sample of low-income patients with prostate cancer, those having low self-efficacy in patient-doctor interactions were more likely to report emotional distress (Maliski et al., 2004).

Uncertainty about one's illness is the inability of a person to determine the meaning of illness-related events such as her disease process, treatment, or hospitalization. A patient has uncertainty about his/her illness as a result of not being able to understand or make sense of her illness event because the event is unexpected, unfamiliar, highly complex, or the patient lacks information (Sammarco & Konecny, 2010). Having uncertainty about your illness is linked to emotional distress and conversations about symptoms with providers for breast cancer patients (Clayton, Dudley & Musters, 2008). A study exploring the utilization of an internet-based support system

for breast and prostate cancer patients showed that the main themes of patients' communication with nurses were uncertainty about their physical symptoms, treatment, treatment side effects, and follow-up after treatment (Anderson & Ruland, 2009). These studies highlight the importance of communication with providers in managing patients' uncertainty about their cancer diagnoses, symptoms, and treatment.

Model of Factors Important to Patient Communication

Based on the previous review, a model of factors important to communication for cancer patients was conceptualized. A patient's satisfaction with his/her communication with a doctor, a patient's trust in his/her doctor, the level of need for cancer information, a patient's level of emotional distress, and a patient's level uncertainty about his/her illness are associated with level of patient self-efficacy in patient-doctor interactions (Figure 1).

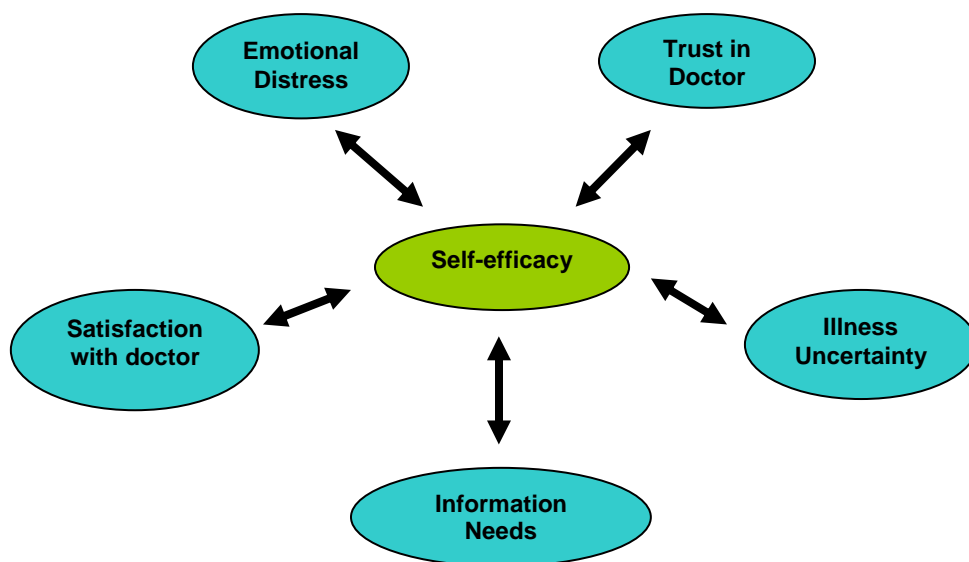


Figure 1. Model of factors important to patient communication.

Communication Interventions for Cancer Patients

Communication interventions focused on improving oncology healthcare providers' communication styles with patients have been implemented for many years. These interventions were designed to improve delivered patient care, for example, discussing bad news and improving patients' understanding of their illnesses (Epstein & Street, 2007; Schofield & Butow, 2004; Teutsch, 2003). Over the past 10 years, the number of patient-focused communication interventions concerning cancer care has increased (Cegala, 2003). Reports by the Institute of Medicine have sparked a growing interest in patients becoming more active in their healthcare (Epstein & Street, 2007). Several methods have been employed in studies oriented to improving communication skills for cancer patients. A primary aim has been to place patients in a participatory role with the intent that they will perceive a greater level of control and mastery over their cancer and treatment (Haywood, Marshall, & Fitzpatrick, 2006). The most frequently targeted behaviors include question-asking, introducing concerns, and requesting clarification on information when needed (Wells, Falk, & Dieppe, 2004). A common method has been to deliver the intervention immediately prior to the patient's appointment with a healthcare professional; although, delivering the intervention the day before the appointment has also been employed (Harrington, Noble, & Newman, 2004). Interventions have varied in length from 10-25 minutes to 2 hours, depending on the mode of presentation. Written interventions (i.e., question prompt sheets) have been the most widely utilized mode of presentation, followed by face-to-face coaching, videotape or DVD, and brochures (Brown, Butow, Boyer, & Tattersall, 1999; McCann & Weinman, 1996; Stewart et al., 2007; Street, Voigt, Geyer, Manning, & Swanson, 1995). Regarding

outcome variables, immediate outcomes such as patient satisfaction, information recall, and health locus of control have been measured. Intermediate outcomes have included adherence to clinician recommendations and self-efficacy, and long-term outcomes have included changes in health status or lifestyle (Epstein & Street, 2007).

Gaps in the Patient-Focused Communication Intervention Literature

Population Disparities

Despite the increase in research targeting improving communication skills for cancer patients, there is a significant lack in the literature of studies addressing communication issues of people with lower socioeconomic status (SES). Patients most commonly studied are middle-class. Individuals coming from low SES backgrounds face several hardships including access to health care, delayed diagnosis of cancer resulting in more advanced staging at the time of diagnosis, and more interruptions in treatment and higher frequency of incomplete treatment regimens (Epstein & Street, 2007). Cancer patients with less education tend to have less involvement in their consultation and ask fewer questions. Results of a study evaluating the effectiveness of an existing cancer education program in a lower income, medically indigent cancer population found that at entry into study participants' informational needs were not being met. The first sources consulted when seeking cancer information were books, brochures or magazines (Martin et al., in press). These findings suggest that helping individuals obtain the information needed related to their cancer is an important goal. One aspect of meeting the informational needs of cancer patients is effective communication with health care providers.

In addition, cancer communication research has focused on patients with specific cancers, especially breast cancer, and to a lesser extent, prostate cancer (Hack, Degner, & Parker, 2005). White women with breast cancer are commonly included in patient-provider communication research (Epstein & Street, 2007). Fewer studies have targeted more lethal cancers such as lung, pancreatic, and ovarian cancers. It is imperative that research on communication skills training include lower SES cancer patients and a variety of cancer diagnoses to uncover communication needs in these populations.

Communication Interventions across the Cancer Care Continuum

The cancer care continuum divides a patient's cancer experience into six phases: prevention, screening, diagnosis, treatment, survivorship, and end-of-life. A patient's position along the continuum determines concerns he or she may have during a clinical visit, most relevant health outcomes, and how communication with healthcare professionals affects these outcomes (Epstein & Street, 2007). However, regardless of place along the continuum, the need for attaining information is a common thread (Siminoff, Graham, & Gordon, 2006). Studies have engaged patients during the diagnosis phase of the cancer continuum (Brown, Butow, Dunn, & Tattersall, 2001; Butow, Dunn, Tattersall, & Jones, 1994; Street, Voigt, Geyer, Manning, & Swanson, 1995). Patients tend to be engaged just prior to their initial consultation appointment with their oncologists and provided a question prompt sheet, brochure or had the opportunity to view an interactive computer education program.

Studies have also targeted the communication and information needs of cancer patients in the survivorship phase of the continuum using similar tools, including

question prompt sheets, question lists reviewed by the doctor, and coaching, (Glynn-Jones et al., 2006; Sheppard et al., 2008; Wells, Falk, & Dieppe, 2004). Unfortunately, few of these studies have targeted or included patients who have had a recurrence of their cancers. According to reports from the National Cancer Society's Cancer Information Service, which is a health communication program delivered to cancer patients and their families through the telephone, patients who categorized themselves as having a recurrence were more likely to request specific treatment information than patients in all other phases of the cancer care continuum. Also, the third most requested informational need for recurrent cancer patients was a referral to medical services (Squiers, Finney Rutton, Treiman, Bright, & Hesse, 2005). These results indicate continuing information needs for recurrent patients and may allude to communication hindrances experienced with their current healthcare provider.

Addressing Gaps in the Literature with the Current Dissertation Research

Based on the previous review, there are several areas of future direction for research aimed at improving cancer patients' communication during patient-doctor interactions. There is a lack of theoretically-based interventions, and a limited number of well-designed studies addressing patient communication. Few studies have specifically targeted patient self-efficacy in patient-focused communication interventions. In addition, research targeting patients at different stages along the cancer continuum, a range of cancer diagnoses, and patients from low SES backgrounds is lacking in the literature. Therefore, building upon the literature, this dissertation study explored the

effect of a cognitive-behavioral-based intervention utilizing several communication-enhancing strategies on patient self-efficacy.

Cognitive-Behavioral Therapy

Cognitive therapy was developed by Aaron Beck in the 1960s as a structured, short-term, present-oriented therapy for depression, with the goal of modifying dysfunctional thinking and behavior (Beck, 1995). According to the cognitive model, distorted, negative thinking influences people's mood; and through realistic evaluation and modification of thinking, changes in mood can be made. Cognitive-behavioral therapy (CBT) is an extension of cognitive therapy. CBT examines cognitive beliefs and how they may impact emotions and behaviors. The focus is on individuals developing skills to address distorted beliefs and adopt healthier behaviors. CBT is empirically supported and has been prominently used in intervention research (Thorn, 2004). CBT has been found to be efficacious for a range of outcomes for cancer patients including addressing fatigue (Gielissen, Verhagen, & Bleijenberg, 2007) pain (Anderson et al., 2006; Tatrow & Montgomery, 2006), stress, and symptom severity (Given et al, 2004; Given et al, 2004; Sherwood et al, 2005). However, to our knowledge, no study has used CBT to enhance patient-provider communication for cancer patients.

Certain beliefs of cancer patients (e.g., beliefs on the relationships between illnesses, beliefs on illness symptoms, etiology, and appropriate treatment) have been shown to affect their outcomes (Taylor & Lurie, 2004) suggesting that cancer-related beliefs are appropriate targets for intervention. Automatic thoughts are thoughts that occur rapidly or automatically in response to a situation. The following are examples of

automatic thoughts a cancer patient may have during a visit with their provider: “I will never understand my diagnosis” or “My questions are not intelligent.” These thoughts can cause emotions or feelings such as anxiety and insecurity (see Figure 2). For this study, participants were educated on evaluating the validity and utility of their automatic thoughts, and learned to construct alternative thoughts and behaviors for the problematic thoughts and behaviors that were not conducive to effective communication during their doctor’s appointments. For example, an alternative thought to the automatic thought “I will never understand my diagnosis” is “I may not understand my diagnosis now, but I can ask questions to get clarification,” with the alternative behavior being to adjust posture and increase attention, and become an active listener.

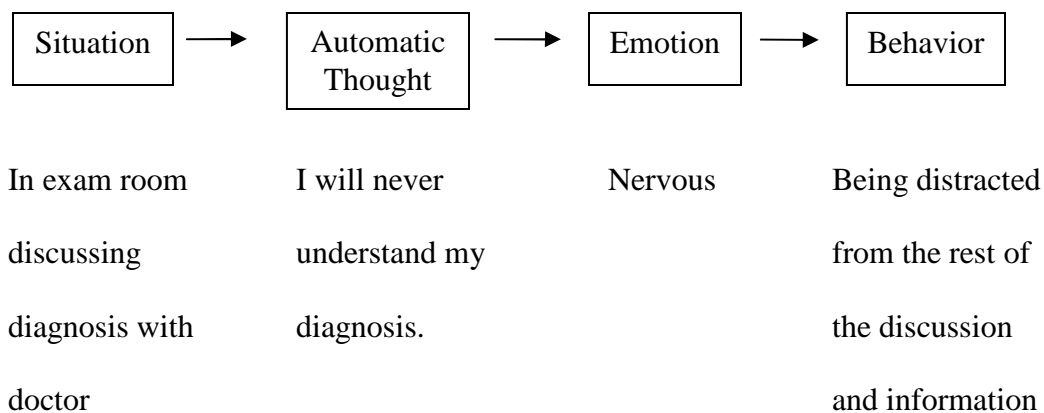


Figure 2. Schematic view of the cognitive-behavior model using a cancer-related belief.

Addressing Population Disparities in Cancer Communication Research

To address disparities in the type of patient recruited for patient-focused communication studies, low-income cancer patients in the treatment and survivorship stages were invited to participate in the dissertation project. In addition, African

American and white patients, first-time and recurrent patients, and varying cancer types were targeted for recruitment.

Aim and Hypothesis

The aim of this study was to:

1. Develop and pilot test a cognitive-behavioral, patient-focused communication intervention designed to enhance cancer patients' self-efficacy in patient-doctor interactions.

Primary Hypothesis

Self-efficacy in patient-doctor interactions will be higher post-intervention for patients randomized to the intervention than for patients randomized to the wait-list control.

Secondary Study Question

1. What are the relationships between concepts important to patient-doctor communication, including self-efficacy, trust in doctor, satisfaction with doctor, emotional distress, and information needs?

CHAPTER 2

RESEARCH DESIGN AND METHODS

Design Overview

The overall goal of the proposed study was to implement and evaluate a theoretically-based intervention to increase patient confidence in communicating effectively with clinicians. An independent-groups design was used to compare the effectiveness of a cognitive-behavioral intervention to a wait-listed control condition in a low-income cancer population including patients with new diagnoses and those with recurrent diagnoses. The primary outcome was self-efficacy in communicating during patient-doctor interactions. Self-efficacy was measured at baseline, immediately post-intervention, and at one month post-intervention. All questionnaires were completed by telephone. Research staff administering the surveys were blind to the randomization schedule. A total of 30 participants were targeted for recruitment for the study. Participants were randomized to one of two groups, the cognitive-behavioral intervention or the wait-listed control condition.

Study Population

Inclusion Criteria

The study invited adults aged 19 years and older to participate. ACS defines cancer recurrence as a “return of cancer after treatment and after a period of time during which the cancer cannot be detected.” The same type of cancer may return in the same

place where it originated or the cancer could occur in another area of the body (ACS, 2010). It is noted that that recurrent cancer patients were originally identified as the target population. However, due to low patient flow at the recruiting site, the study was opened to all cancer patients currently receiving treatment (i.e., chemotherapy, radiation, surgery, etc.). The new population included newly diagnosed patients, those already receiving treatment for a first time cancer, and patients diagnosed with a cancer recurrence. Participants were recruited from Cooper Green Mercy Hospital (CGMH).

CGMH is Birmingham's public safety net health care facility, providing care primarily to the medically indigent residents of Jefferson County, AL, which includes Birmingham and the surrounding metropolitan area. CGMH is the base for the HealthFirst system, which provides comprehensive health care, regardless of a patient's ability to pay, including primary care and specialty services, and both inpatient and outpatient. The HealthFirst package includes prescription medications for nominal co-pays. Out-of-pocket costs are based on the ability to pay. Outpatient services are provided through the Jefferson Outpatient Care clinics, which include a central clinic located within CGH. All outpatient and hospital utilization data are captured in a single database. All care is provided by full-time, Board-certified staff doctors working with doctors in training from UAB. There are approximately 165,000 yearly admissions, with 75% of the patient population being African-American and 65% female.

Patients with a wide range of cancer types were invited to enroll. However, it was anticipated that recruited patients would reflect the most common cancer types seen at CGMH, which include breast, lung, colon and prostate cancer. Because some patients have an existing high level of confidence in their ability to communicate their needs

while interacting with their doctors, a 5-item version of the self-efficacy measure used for this study (described later) was used to identify patients with low self-efficacy. Scores of the measure ranged from 5 to 25, with 25 being high self-efficacy. An inclusion criterion score of 15 or lower was used. However, early on in recruitment, no patients with low self-efficacy scores could be identified. Previous research suggests African Americans tend to overestimate their confidence and ability in accomplishing tasks in intervention research (Legardy, Macaluso, Artz, & Brill, 2005; Martin, Dutton, & Brantley, 2004). Therefore, the decision was made to discontinue this inclusion criterion.

Exclusion Criteria

Because patients receiving hospice care may have markedly different concerns and informational needs, these individuals were excluded from the study. In addition, non-English speaking patients were also excluded.

Recruitment Method

Recruitment occurred in partnership with CGMH and was of mutual benefit both to the hospital and for the pilot study. Recruitment took place at Clinic E (oncology). This clinic serves the needs of patients across a number of cancer diagnoses. It was anticipated that the clinic would serve nearly 200 patients per month. Nurse referral is important to the integration of the resource in a clinical setting. In a prior study, a recruitment method was established within Clinic E in which nurses referred patients to the study (Martin et al., in press). The recruitment method is described below.

The Principal Investigator was situated in CGMH Clinic E where she approached patients who were screened by the charge nurse as having a diagnosis of cancer and

currently receiving treatment or starting treatment. These patients were invited to participate in the study. Patients agreeing to learn more about the study were taken to a private office for the consent process. As a part of the consent process, patients were told that they would be randomized to either the intervention or to the wait-listed control condition. Patients agreeing to participate in the study signed the consent document. Support for recruitment for this study was received from Sandral Hullett, MD, MPH, the CEO and Medical Director of CGMH.

Intervention Development

Communication Program to Activate Cancer Survivors (COMPACT)

Overview of sessions. Lee et al. demonstrated the effectiveness of a 4-session CBT approach in improving self-esteem, optimism, and self-efficacy in responding to difficult situations among patients with cancer (Lee, Robin-Cohen, Edgar, Laizner, & Gagnon, 2006). Based on the efficacy of this brief CBT intervention, we elected to develop a 3-session intervention. Participants randomized to the Communication Program to Activate Cancer Survivors (COMPACT) condition received 3 weekly sessions. Originally, the COMPACT sessions were designed to be given individually. However, in the medical setting, offering group sessions can be an effective way to intervene with many patients in a shorter amount of time (Vos, Corry, Haby, Carter, & Andrews, 2005). Therefore, administration of session 1 was modified to a group format consisting of 3-5 participants.

All sessions were administered by the Principal Investigator. Session 1 of COMPACT was conducted at the study institution. Group sessions were scheduled after

at least 3 participants were randomized to the intervention condition. Participants were provided the intervention manual at the beginning of session 1. The duration of the group sessions was approximately 60 minutes. Given the effectiveness of using telephone calls as a means of contact for interventions for women with gynecological and breast cancers, (Braden, Mishel, & Longman, 1998; Mishel et al., 2005; Manne et al., 2007) this medium was utilized in the COMPACT condition. Sessions 2 and 3 were conducted through telephone calls. The duration of telephone calls was approximately 20-30 minutes. Telephone sessions were scheduled at the participant's convenience. A copy of the participant and facilitator manuals have been provided in Appendices A and B.

Intervention Curriculum. Table 1 provides an outline of the theoretically-based content that was used for COMPACT.

Table 1

Outline of the COMPACT intervention

| Session | Format | Objective | Theoretical approach | Content |
|---------|--------|--|----------------------|--|
| 1 | Group | To identify and evaluate automatic thoughts occurring during patient-doctor interactions and modify distorted thoughts | CBT, self-efficacy | <p>(1) Identify participant's needs regarding communication with healthcare providers</p> <p>(2) Introduction to the cognitive-behavior model as relates to perceptions of communication with healthcare providers</p> <p>(3) Identifying automatic thoughts that are barriers to communication with healthcare providers</p> <p>(4) Role-play to identify automatic thoughts and barriers during patient-provider communication</p> <p>(5) Evaluating automatic thoughts and constructing alternative responses</p> |

| Session | Format | Objective | Theoretical approach | Content |
|---------|-----------|--|--|--|
| 2 | Telephone | To provide an understanding of helpful communication skills; introduce the concept of using communication with doctor to overcome worry about illness; and provide strategies in discussing needs with providers | Communication skills training, self-efficacy, Managing uncertainty about illness | (1) Review of session 1 content, including addressing questions on material (2) Introduce assertiveness communication and good communication skills (3) Question generation to enhance communication with healthcare provider (4) Overcoming worry about illness |
| 3 | Telephone | To introduce concept of using positive statements to increase self-efficacy during patient-doctor interactions, and provide strategies to overcome barriers to communication | CBT, self-efficacy | (1) Review of session 1 and 2 content, including clarifying misunderstood material (2) Using positive self-talk to build confidence that information needs will be met during provider visits (3) Identifying barriers during visits and strategies to overcome barriers |

Session 1. As described by Beck (1995) the first session should begin with the patient identifying problems and issues they want to address, and then the therapist and patient develop behavioral goals to work towards. The first session of COMPACT was structured similarly. Participants identified their needs regarding communication with healthcare providers. The cognitive-behavior model was introduced. Applying the cognitive-behavior model to communication, participants were educated on how their thoughts occurring immediately prior and during their doctor visits affect their emotions, and subsequently could impact their behavior and communication during appointments. Participants practiced role-playing with each other during the session to identify automatic thoughts. They were paired and one played the role of the healthcare provider while the other played the role of the patient. Participants were instructed on how to evaluate their thoughts using the Automatic Thoughts Worksheet (see Appendix), and how to construct alternative thoughts to thoughts that were unhelpful to communicating with their doctor (Beck, 1995; Thorn, 2004). Participants practiced using their alternative thoughts through role-play as well. At the end of the session, participants were encouraged to continue identifying thoughts that occur during doctor visits and evaluate them using additional Automatic Thought Worksheets for homework.

Session 2. Session 2 began with a brief overview of session 1 material, and participants were given the opportunity to get clarification on the material and homework if needed. Assertive communication was introduced. Research has shown that individuals from disadvantaged backgrounds often have insufficient communication skills in the context of patient-doctor interactions to express themselves in an assertive

manner (Epstein & Street, 2007). Assertiveness involves asking for what you want in a simple, direct, and honest manner. Also, assertiveness involves nonverbal behaviors, i.e., looking directly at a person when speaking to him/her, remaining calm, and having an open posture (having the body turned toward the other person and having the arms resting at the sides or on the lap) (Thorn, 2004). Participants were educated on behaviors that are conducive to good communication, i.e., eye contact, speaking loudly enough to be heard, and listening intently.

Previous research has shown that helping patients construct questions that address their concerns prior to the appointment with their doctor has increased patient participation and communication with doctors (Harrington, Noble, & Newman, 2004). The advantages of making a question sheet were discussed during the session and participants were given the opportunity to write down their questions using example questions as a guide. In addition, participants received education on the downfalls of worrying about their illnesses (i.e., negative emotions and stress). Participants were encouraged to communicate worry about their illnesses with their doctors as a strategy of managing uncertainty they may have about their symptoms. For homework, participants were encouraged to practice asking their questions using the helpful communication skills they learned.

Session 3. Session 3 began with a review of session 2 material and participants were given the opportunity to get clarification on material and homework if needed. The focus of this session was to educate participants in using positive self-statements or self-talk in preparation for their next appointment with their healthcare provider. This

strategy was discussed in the context of building confidence to enhance communication and assertiveness skills, and increasing sense of control and mastery in getting their needs met during patient-provider interactions. In addition, barriers that may impede getting needed information were discussed and strategies were reviewed that may help overcome these barriers. Time was allotted to review the skills learned during the intervention and participants were encouraged to create a record of communication skills that they felt confident they would be able to practice and utilize during provider visits.

Session components specific to self-efficacy. Bandura postulated two main components of self-efficacy: establishment of goals and the ability to organize necessary skills to achieve the goals. In addition, successfully identifying barriers to reaching goals and strategies to overcome the barriers is important to self-efficacy (Bandura, 1998). During session 1, participants identified their needs or goals for communication with their providers, and CBT skills were taught and discussed to achieve their goals, including identifying negative, distorted automatic thoughts that may impede communication and generating alternative, more helpful thoughts. Participants role-played being a doctor or a patient to help identify automatic thoughts. Session 2 components that specifically addressed self-efficacy included learning assertive and good communication skills (e.g., appropriate body language and speaking clearly) to achieve goals. In addition, participants identified questions they may have for their next doctor visit as a means of accomplishing their goals. During session 3, participants learned to use positive self-talk as a way to encourage and motivate themselves during patient-doctor interactions and increase self-efficacy. Participants also identified barriers that

may lower their motivation and sense of empowerment in attaining goals and generated strategies to overcome these barriers, including overcoming not being prepared during appointments by having a list of symptoms or concerns.

Wait-listed Control Condition

Because this study employed a newly developed intervention, the first step in the research process was to compare the intervention to a no-treatment control condition. It is well documented that cancer patients are not getting all of their needs met during communication with healthcare providers. Therefore, a wait-listed control condition was used for this study instead of a no-treatment condition. Participants randomized to this condition were offered the intervention after completing all required follow-up assessments.

Measures

Table 2 details the time of assessment for the study. All measures were administered to participants in the control condition at the same assessment time points as those randomized to the COMPACT condition. A copy of the measures has been included in the Appendix C. Demographic and health information were collected at baseline and 1-month post-intervention. Variables collected included, but were not limited to, age, race, gender, marital status, employment status, insurance type, date of first cancer diagnosis, date of cancer recurrence diagnosis, and type of cancer (i.e., primary cancer site and recurrence site).

Table 2

Schedule of Assessment of the Study Variables

| Domain | Time of assessment | | |
|-------------------------|--------------------|-------------------|---------------------------|
| | Baseline | Post-intervention | 1-month post-intervention |
| Self-efficacy | X | X | X |
| Patient satisfaction | X | | X |
| Information needs | X | | X |
| Patient trust in doctor | X | | X |
| Emotional distress | X | | X |
| Illness uncertainty | X | | X |

Primary Outcome

Self-efficacy. The primary outcome was a measure of patients' confidence when interacting with their physicians as assessed by the Perceived Efficacy in Patient-Physician Interactions Questionnaire. The scale consists of 10 questions to measure patient's confidence in their ability to elicit and understand information from and communicate information to their physicians, as well as confidence in their ability to get their physicians to address and act on their main medical concerns. Each item begins with "How confident are you in your ability to...", and subjects respond to each question on a scale of 1 to 5, with 1 representing "not at all confident" and 5 representing "very confident." An example of an item is: "How confident are you in your ability to get a doctor to pay attention to what you have to say?" The range of possible scores for the scale was 0 to 40, with 40 representing highest patient-perceived self-efficacy. The full

scale takes approximately 3 minutes to be administered. The scale has good internal reliability (Cronbach's $\alpha = .91$) (Maly, Frank, Marshall, DiMatteo, & Reuben, 1998).

Secondary Outcomes

Satisfaction with doctor. The 30-item Princess Margaret Hospital Satisfaction with Doctor Questionnaire is a self-administered questionnaire that measures patients' satisfaction with their physicians. The scale is composed of four domains, (1) information exchange, (2) interpersonal skills, (3) empathy, and (4) quality of time. Subjects respond to items using four response categories ranging from "strongly agree" to "strongly disagree" and a "does not apply" category. The scale was validated using an oncology outpatient sample and has good internal reliability (Cronbach's $\alpha = 0.97$) (Loblaw, Bezjak, & Bunston, 1999). Possible scores ranged from 0 to 90, with higher scores representing higher satisfaction.

Information needs. The Supportive Care Needs Survey is a 34-item patient report measure that assesses patients' level of need in five areas, (1) psychological needs, (2) health system and information needs, (3) physical and daily living needs, (4) patient care and support needs, and (5) sexuality needs. Patients indicated their level of need on each of the items, over the past month, using the response choices: "No need, not applicable," "No need, satisfied," "Low need," "Moderate need," and "High need." The instrument has good internal reliability (Cronbach's α for scales range from .87-.97) and is written at a 4-5th grade reading level (Bonevski et al., 2000). The entire Supportive Care Needs Survey was administered to maintain the integrity of the scale; however, the 12-item

health system and information needs scale was used as a proxy to measure the extent that communication/information needs were being met by healthcare providers. Specifically, this scale assessed needs for information about disease, diagnosis, treatment, and follow-up. Possible scores ranged from 0 to 36. Higher scores indicated a higher need for information.

Trust in doctor. Patient's level of trust in their doctor was assessed by the 10-item Wake Forest Physician Trust Scale. Patients rated each item on a 5-point Likert scale ranging from "strongly disagree" to "strongly agree". The scale was validated using a national sample that included individuals from medically indigent populations. The scale has good internal reliability (Cronbach's $\alpha = .93$) (Hall et al., 2002). Possible scores ranged from 0 to 40. Higher scores indicated higher trust.

Illness Uncertainty. The Uncertainty in Illness Scale – Adult version is a 33-item that measures an individual's perceived uncertainty in his/her illness. Uncertainty is defined as an inability to determine the meaning of illness-related events. Patients were asked to respond to the items based on their perception of their present situation and rated the items on a 5-point Likert scale ranging from "strongly disagree" to "strongly agree". Higher scores represent higher uncertainty. This scale has been used extensively in cancer populations, including gynecological, lung, prostate, breast, bowel, blood, and lymph cancers, and demonstrates good internal reliability (Cronbach's $\alpha = .90$) (Mishel, 1997a). For the purposes of this study, five items were removed from the scale that were

not relevant to the sample population, resulting in a 28-item measure being administered. Possible scores ranged from 0 to 112.

Emotional Distress. Emotional distress was assessed by having patients rate their level of distress during the past week on a scale from 0 to 10, with 0 being no distress and 10 being extreme distress.

Data Management

Sample Size and Statistical Power

The study used a randomized controlled trial design in which participants were randomized to receive either the COMPACT or the no treatment condition. The primary outcome for this study was self-efficacy and we hypothesized positive changes in self-efficacy in interacting with healthcare providers for those receiving the COMPACT intervention. Self-efficacy was assessed at baseline, post-intervention, and at 1-month post-intervention. Power calculations revealed a large effect size equal to 1.06 was needed to achieve a power level of .80 for a total sample size of 30, 15 participants per group.

Analyses

Descriptive statistics were used to describe demographic, health, and psychosocial variables for the entire sample at baseline. Prior to the measures being scored, response scales were recoded for all measures, with item response choices starting with 0 for ease of interpretation. To determine whether the randomization method was successful in

equating the groups before the intervention, participants in the intervention and control groups were compared on demographic, health, and psychosocial variables at baseline. Demographic variables used to compare the two groups were gender, age, race, and education. Health variables included in the comparisons were cancer recurrence and time since diagnosis. Self-efficacy was also included in baseline comparisons. Statistical testing for differences between groups on categorical variables was done using the Pearson chi-square test. Comparisons of continuous variables were performed using the Wilcoxon rank-sum test, a nonparametric test that is useful in comparing groups of small samples and data that are skewed (Gravetter & Wallnau, 2002). Variables not being equal between the two groups were used as covariates in proceeding analysis.

The main outcome of this study was self-efficacy. To test the hypothesis, a 2 X 3 analysis of variance (ANOVA) design was used to make group by time comparisons of self-efficacy across the three time points (baseline, post-intervention, 1-month post-intervention) between the intervention and wait-listed control conditions. Prior to conducting analyses, certain assumptions to using ANOVA were tested, including, 1) errors in dependent variables are normally distributed, 2) homoscedasticity or homogeneity of variance, and 3) independence of observation across subjects. Homoscedasticity refers to the assumption that the dependent variable exhibits similar amounts of variance across the range of values for an independent variable. Violations of these assumptions can be corrected by conducting nonlinear transformations of the raw data (i.e., square root, log, inverse) (Gravetter & Wallnau, 2002). If a significant main effect was detected across time, the Tukey Honestly Significant Difference test was planned to compare the following time points for both the

COMPACT and control groups: baseline to post-intervention, baseline to 1-month post-intervention, and post-intervention to 1-month post-intervention. Significance was set at $\alpha = .05$.

To address the question of the relationships between self-efficacy, trust in doctor, illness uncertainty, satisfaction with doctor, information needs, and emotional distress, Pearson correlations were performed. Correlations between the variables were assessed at baseline using all data for both groups. Correlations of the variables were also assessed at 1-month post-intervention separately for the intervention group and the wait-list control condition to evaluate relationships between the variables that may be unique to participants receiving the intervention. All variable were used as continuous variables. Statistical significance was set at $\alpha = .05$. SPSS 17.0 statistical package was used for analyses.

CHAPTER 3

RESULTS

Table 3 describes characteristics of the study sample. A total of 29 participants entered the study. Participants were predominantly women, African American, middle-aged, single or divorced, and received a high school diploma or GED. Breast and lung cancer diagnoses were most prevalent. Average time since the participants' diagnosis at entry into the study was 44 months. Thirty-one percent of the sample reported having a cancer recurrence. The majority of participants had received chemotherapy or surgery for treatment. Fourteen participants were randomized to the wait-list control group and 15 were randomized to the intervention group. Over the course of the study, a total of 6 participants were lost. Five participants were lost from the intervention group after their baseline assessment due to an inability to contact them or drop-out. One participant was lost from the control group due to death.

Table 4 presents the characteristics of the participants by study condition. Groups were equivalent on all demographic characteristics and health and psychosocial variables, indicating that randomization was successful. Participants in both groups reported a moderate level of distress during the past week. Self-efficacy during patient-doctor interactions was high for both groups at baseline. Tables 5 and 6 describe means for all psychosocial variables assessed for the control and intervention groups.

Results of analysis comparing self-efficacy across all time points (see Table 6) did not support the hypothesis. No significant main effect for self-efficacy across the 3 time points (baseline, post-intervention, 1-month post-intervention) was found, $F(1, 21) = 3.57, p = .073$. No significant main effect for group (intervention vs. control group) was found, $F(1, 21) = .007, p = .94$. These results indicate that there was not a significant difference in level of confidence in doctor interactions before or after participants received the intervention compared to those that did not receive the intervention.

Table 7 presents Pearson correlations of the relationships between self-efficacy, trust in doctor, satisfaction with doctor, illness uncertainty, information needs, and emotional distress for the entire sample at baseline. Several statistically significant relationships emerged. Positive relationships were seen between self-efficacy and trust in doctor and satisfaction with doctor. As participants' trust in their doctor and satisfaction with their doctor increased, their confidence in getting information from their doctor and communicating information to their doctor increased. Negative relationships were seen between self-efficacy and information needs and illness uncertainty. As participants' uncertainty about their illness and their need for health information increased, their confidence in getting information or communicating with their doctors decreased. Negative relationships were seen between illness uncertainty and trust in doctor and between illness uncertainty and satisfaction with doctor. Higher levels of uncertainty about one's illness correlated with lower levels of satisfaction with and trust in one's doctor. Positive relationships were seen between illness uncertainty and information needs and between satisfaction with doctor and trust in doctor. More uncertainty about illness was correlated with more need for information about one's health. Having a

higher level of satisfaction with one's doctor was related to having more trust in one's doctor. No significant correlations were found between distress and the other variables.

The relationships between self-efficacy, trust in doctor, satisfaction with doctor, illness uncertainty, information needs and emotional distress were evaluated at the 1-month follow-up assessment time point. Pearson correlations were assessed separately for the intervention and control groups to evaluate relationships between the variables that may be unique for participants receiving the intervention (see Table 8). Four significant correlations were found between the variables for the control group. Trust in doctor was positively correlated with satisfaction with doctor. Illness uncertainty was positively correlated with emotional distress, indicating a relationship between participants' doubts in their medical illness and their level of distress. Information needs was also positively correlated with emotional distress, indicating that as the need for information about one's health increases so does the level of distress. Finally, information needs was positively correlated with illness uncertainty. No significant correlations were between self-efficacy and the other variables.

Six significant correlations were found between the variables for the intervention group (see Table 9). Unique correlations for the intervention group were found between self-efficacy and other variables. Self-efficacy was positively correlated with trust in doctor and satisfaction with doctor, indicating that as confidence in getting information during patient-doctor interaction increased, so did trust and satisfaction with the doctor. Negative correlations were found between self-efficacy and illness uncertainty. Negative correlations were also found between illness uncertainty and satisfaction with doctor and trust in doctor. Satisfaction with doctor was positively correlated with trust in doctor.

No significant correlations were found between emotional distress or information needs and the remaining variables.

Post-hoc Analyses

Because five participants were lost from the intervention group prior to completing COMPACT, further analyses were done to determine if there were differences between completers and non-completers. The two groups were compared on categorical variables using the Pearson chi-square test. The Wilcoxon rank-sum test was used to comparisons between the two groups on continuous variables. No differences were found between completers and noncompleters on age, race, gender, education, cancer recurrence status, or self-efficacy (see Table 10). Although the average amount of time since the first cancer diagnosed was 90 months for the completers group and 16 months for the noncompleters group, this difference was not significant.

Table 3

Baseline Sample Characteristics

| <i>N</i> =29 | Mean or % | SD |
|---------------------------------|-----------|------|
| Age | 48.7 | 10.5 |
| Gender | | |
| Male | 37.9 | |
| Female | 62.1 | |
| Race | | |
| African American | 69.0 | |
| Caucasian | 31.0 | |
| Marital Status | | |
| Married | 6.9 | |
| Single | 41.4 | |
| Divorced | 41.4 | |
| Widowed | 10.3 | |
| Education status | | |
| Less than 8 th grade | 20.7 | |
| High school graduate/GED | 37.9 | |
| Vocational school/some college | 27.6 | |
| College graduate | 13.8 | |

| <i>N</i> =29 | % |
|---------------------------------|------|
| Employment status | |
| Full-time/Part-time | 10.3 |
| Unemployed/looking for work | 6.9 |
| Unemployed/not looking for work | 55.2 |
| Retired | 3.4 |
| Disability | 24.1 |
| Cancer Type | |
| Breast | 37.9 |
| Lung | 13.8 |
| Lymphoma | 10.3 |
| Colon | 10.3 |
| Ovarian/uterine | 6.9 |
| Prostate/testicular | 6.8 |
| Kidney | 3.4 |
| Neck/throat | 3.4 |
| Lung and other areas | 3.4 |
| Recurrent Cancers | 31.0 |

| <i>N</i> =29 | % |
|---------------------|------|
| Treatments received | |
| Chemotherapy | 62.1 |
| Surgery | 62.1 |
| Radiation | 20.7 |
| Hormone therapy | 10.3 |
| Health Insurance | |
| Yes | 24.1 |
| No | 75.9 |

Table 4

Sample Characteristics of Study Variables by Randomization Group

| Characteristic | CON | INT | <i>p</i> |
|---|------|------|----------|
| Gender | | | |
| Male | 6 | 5 | .60 |
| Female | 8 | 10 | |
| Race | | | |
| White | 4 | 5 | .78 |
| Black | 10 | 10 | |
| Recurrent cancer | | | |
| No | 12 | 8 | .06 |
| Yes | 2 | 7 | |
| Age (<i>M</i>) | 46 | 51 | .16 |
| Number of education years (<i>M</i>) | 12.6 | 13 | .46 |
| Months since first diagnosis (<i>M</i>) | 20.9 | 65.8 | .09 |
| Self-efficacy (<i>M</i>) | 33.8 | 32.2 | .43 |

Note. CON = control group, n = 14; INT = intervention group, n = 15.

Table 5

Baseline Means and Standard Deviations of Psychosocial Variables

| Variable | CON | | INT | |
|--------------------------|------|------|------|------|
| | Mean | SD | Mean | SD |
| Emotional distress | 5.6 | 3.7 | 5.2 | 2.5 |
| Illness uncertainty | 47.9 | 15.5 | 38.2 | 22.3 |
| Information needs | 11.4 | 10.0 | 9.27 | 9.8 |
| Satisfaction with doctor | 59.6 | 17.2 | 68.6 | 14.6 |
| Self-efficacy | 33.8 | 7.4 | 32.2 | 7.3 |
| Trust in doctor | 31.1 | 4.7 | 31.7 | 5.6 |

Note. CON = control group, n = 14; INT = intervention group, n = 15. There were no significant differences in self-efficacy between the groups.

Table 6

Post-Intervention and 1-Month Post-Intervention Means and Standard Deviations of Psychosocial Variables

| Variable | CON | | INT | |
|---------------------------|------|------|------|------|
| | Mean | SD | Mean | SD |
| Post-Intervention | | | | |
| Self-efficacy | 33.8 | 6.5 | 35.4 | 3.6 |
| 1-Month Post-Intervention | | | | |
| Emotional distress | 3.77 | 3.9 | 4.3 | 3.3 |
| Illness uncertainty | 42.9 | 14.8 | 28.6 | 19.6 |
| Information needs | 13.7 | 8.2 | 12.9 | 9.8 |
| Satisfaction with doctor | 62.1 | 10.5 | 70.4 | 15.5 |
| Self-efficacy | 34.1 | 7.8 | 34.5 | 5.7 |
| Trust in doctor | 29.6 | 6.3 | 33.1 | 5.8 |

Note. CON = control group; INT = intervention group. Post-intervention CON group n=14, INT group n=10. 1-month post-intervention CON group n=13, INT group n=10. There were no significant differences in self-efficacy between the groups.

Table 7

Analysis of Variance for the Effect of the COMPACT intervention

| Source | df | Mean Square | F | p |
|------------------|----|-------------|------|------|
| Between subjects | | | | |
| Group | 1 | .77 | .007 | .94 |
| error | 21 | 115.56 | | |
| Within subjects | | | | |
| Time | 1 | 39.34 | 3.57 | .073 |
| Time X Group | 1 | 30.21 | 2.74 | .11 |
| error | 21 | 11.02 | | |

Table 8

Correlations Between Psychosocial Variables for All Baseline Participants

| Variable | 1 | 2 | 3 | 4 | 5 | 6 |
|-----------------------------|---|------|------|-------|--------|--------|
| Baseline (N=29) | | | | | | |
| 1. Self-efficacy | - | .41* | -.07 | -.45* | -.50** | .41* |
| 2. Trust in doctor | | - | .18 | -.31 | -.72** | .72** |
| 3. Distress | | | - | -.002 | .064 | .14 |
| 4. Information needs | | | | - | .41** | -.32 |
| 5. Illness uncertainty | | | | | - | -.70** |
| 6. Satisfaction with doctor | | | | | | - |

Note. *Correlation is significant at the .05 level. **Correlation is significant at the .01 level.

Table 9

Correlations between Psychosocial Variables for Control and Intervention Groups at 1-Month Post-Intervention

| Variable | 1 | 2 | 3 | 4 | 5 | 6 |
|-----------------------------|---|-------|------|------|--------|--------|
| Control group (n=13) | | | | | | |
| 1. Self-efficacy | - | .31 | -.22 | -.28 | -.45 | .45 |
| 2. Trust in doctor | | - | .006 | -.34 | -.29 | .75** |
| 3. Distress | | | - | .64* | .61* | -.02 |
| 4. Information needs | | | | - | .58* | -.36 |
| 5. Illness uncertainty | | | | | - | -.43 |
| 6. Satisfaction with doctor | | | | | | - |
| Intervention group (n=10) | | | | | | |
| 1. Self-efficacy | - | .83** | -.48 | -.54 | -.79** | .79** |
| 2. Trust in doctor | | - | -.30 | -.51 | -.91** | .97** |
| 3. Distress | | | - | -.09 | .11 | -.20 |
| 4. Information needs | | | | - | .57 | -.59 |
| 5. Illness uncertainty | | | | | - | -.93** |
| 6. Satisfaction with doctor | | | | | | - |

Note. *Correlation is significant at the .05 level. **Correlation is significant at the .01 level.

Table 10

Characteristics of Intervention Completers and Noncompleters

| Characteristic | Completers | Noncompleters | <i>p</i> |
|---|------------|---------------|----------|
| Gender | | | |
| Male | 3 | 2 | .70 |
| Female | 7 | 3 | |
| Race | | | |
| White | 3 | 2 | .70 |
| Black | 7 | 3 | |
| Recurrent cancer | | | |
| No | 5 | 3 | .71 |
| Yes | 5 | 2 | |
| Age (<i>M</i>) | 50 | 51 | .77 |
| Number of education years (<i>M</i>) | 13.4 | 12.2 | .21 |
| Months since first diagnosis (<i>M</i>) | 90.3 | 16.8 | .21 |
| Self-efficacy (<i>M</i>) | 31.0 | 34.6 | .31 |

Note. Completers, n = 10; noncompleters, n = 5.

CHAPTER 4

DISCUSSION

This study sought to evaluate a cognitive-behavioral intervention designed to improve cancer patients' confidence in communicating and obtaining needed information during patient-doctor interactions. Unfortunately, the intervention did not demonstrate a significant improvement in self-efficacy compared to the wait-list control. However, the mean for self-efficacy changed in the expected direction from baseline to post-intervention for participants completing the intervention, and the post-intervention mean was higher compared to the control condition. It is difficult to compare our results to the literature given that this is the first study to our knowledge utilizing a CBT-based, patient-focused communication intervention. Our results are consistent with findings by Brown et al. (1999) in that neither a question prompt sheet intervention or brief coaching intervention (included question prompt sheet, discussion about the importance of asking questions, review of benefits and barriers to asking questions, and rehearsal) did not have a significant effect on desired outcomes compared to the control condition. They did not find an increase in the number of questions patients asked during a cancer consultation. In addition, they did not find an increase in the patient's sense of control over the consultation. Several explanations are discussed that may provide insight on why the intervention was not successful.

Brown et al. (1999) discussed the possibility that a ceiling effect in the question-asking behavior had been achieved after participants were given a prompt sheet, and therefore, further coaching did not increase number of questions asked. A similar phenomenon may explain findings of the present study. First, patients entering the study endorsed a high level of self-efficacy, creating a possible ceiling effect, and consequently, there was not much room for improvement in scores post-intervention. Other studies have reported similar skewed distributions using the same self-efficacy measure (Anger et al., 2007; Gore, Krupski, Kwan, Maliski, & Litwin, 2005; Maly, Leake & Silliman, 2004; Zandbelt et al., 2004). This is a limitation of the present study and of the self-efficacy measure.

Bandura postulated that self-efficacy is not a context-free measure. In other words, self-efficacy is highly dependent on the type of activity, the different levels demanded for the task, and different situational circumstances. Self-efficacy measures should be behavior-specific and situation-specific in assessment (Bandura, 1998). One strategy of increasing the specificity of patient communication self-efficacy measures is to focus on behaviors deemed problematic for patients or behaviors that are barriers during patient-doctor interactions. A future direction would be to employ or develop a self-efficacy measure that is able to assess different levels of communication behavior and address problematic behaviors and barriers. Cancer patients often report difficulties asking questions due to their doctors being rushed during consultations (Hack, Degner, & Parker, 2005). Examples of more behavior- and situation-specific questions are: How confident are you in requesting a set time to ask all your questions during your doctor visit? How confident are you in asking all your questions even if the doctor appears to be

in a hurry? Questions such as these would likely result in a self-efficacy measure with more sensitivity to detect changes in confidence and a measure less affected by demand characteristics (e.g., responding in a perceived socially desirable manner) that may potentially influence participants' responses.

A review of the literature on patient preference in level of involvement in consultation appointments and discussions about treatment with doctors is beyond the scope of this paper, but this concept may provide another possible explanation of the findings of the present study. Research has found that younger and more educated patients generally prefer more assertive relationships with providers, ask more questions, offer more opinions, and have stronger beliefs in participating in decision-making about their treatment than do older and less educated patients (McCann & Weinman, 1996; Street, Voigt, Geyer, Manning, & Swanson, 1995). Given that our sample was middle-aged and more than half of the sample reported receiving a high school diploma or GED or having less than an 8th grade education, some participants' preferences for involvement may have been more passive. Consequently, attempting to increase some patient's confidence in being more active and involved in obtaining needed information may have been in conflict with their comfort level and personal styles during patient-doctor interactions. Some participants may have been as activated and as confident as they wanted to be entering the study.

The present study aimed to increase patients' confidence in getting needed information, specifically with a focus on information about the disease process and treatment concerns. A growing body of literature provides evidence that cancer patients communication and information needs includes discussions related to psychosocial and

emotional functioning issues (Hack, Degner, & Parker, 2005; Sanson-Fisher et al., 2000). This may provide another explanation of why the intervention was not successful. Although participants were encouraged to ask any questions they had, the intervention did not specifically address psychological well-being, social support, health-related quality of life concerns, or concerns with performance of daily activities. Both doctors and cancer patients are hesitant to initiate discussions about psychosocial issues, and consequently, these issues are not commonly addressed in consultations (Fagerlind et al., 2008). By including coaching and discussions in the intervention on patients broaching concerns related psychosocial and emotional concerns during patient-doctor interactions, perhaps their confidence in communicating their needs met in more areas could have been boosted, possibly increasing over self-efficacy.

An integral component of CBT is the continued use of homework and skills practice (Beck, 1995). Homework compliance in CBT is a significant predictor in improvement of treatment outcomes (Kazantzis, Deane, & Ronan, 2000). Another possible explanation for the ineffectiveness of the intervention is that it is uncertain the amount of skill practice the participants engaged in between intervention sessions and also after the completion of the intervention. Although participants were given the opportunity to review any questions they may have had regarding homework assignments, the level of homework compliance, including practicing communication and assertiveness skills, among the sample completing the intervention is not known. Repeated successful engagement in a new task or skill increases self-efficacy in adopting and performing a new behavior (Bandura, 1998). Therefore, if participants in this study

were not compliant with practicing strategies learned during the intervention sessions, this would have likely impacted their level of self-efficacy.

Other Possible Theoretical Frameworks for a Communication Intervention

Other theories have been used to improve outcomes for cancer patients. Consideration of other theoretical models that may have lead to a different result with the intervention is important. The Health Belief Model (HBM) is a well-established, empirical model that has been used to evaluate and predict people's adoption of health-related behaviors. Components of the model that may be useful for increasing patient self-efficacy in communicating effectively and getting needed information during interactions with providers are: perceived benefits (beliefs regarding the effectiveness of the intervention in reducing the threat of the illness), perceived barriers (individual assessment of the cost-benefit of adopting a behavior), perceived efficacy (self-assessment of ability to successfully adopt the desired behavior) and cues to action (external influences promoting the desired behavior, i.e., information provided or sought, reminders by powerful others, persuasive communications, and personal experiences) (Roden, 2004).

Results of a recent study piloting a church-based intervention incorporating components of the HBM demonstrate an increase in self-efficacy to participate in decision-making for African American patients with prostate cancer (Drake, Shelton, Gilligan, & Allen, 2010). The HBM has been applied to interventions aimed at increasing screening behaviors, breast self-examinations, and medication adherence for cancer patients. Research also demonstrates the success interventions based on the HBM in improving health prevention behaviors in low-income populations. Specifically,

studies have focused on addressing barriers to patients adopting new behaviors, including health literacy, cultural or personal beliefs, inconvenience barriers, or embarrassment associated with the new behavior (Davis et al., 2001; Jibaja-Weiss, Volk, Kingery, Smith, & Holcomb, 2003; Ogedegbe et al., 2005; Yabroff & Mandelblatt, 1999). A communication intervention focusing on identifying and modifying or compensating for perceived barriers to communicating or getting needed information, as well as, as focusing on the benefits vs. costs of using new behaviors during patient-doctor interactions may be a better fit for our study population. In addition, helping patients develop cues to action (e.g., reminder calls from family and friends and developing stories to prompt new behaviors) for new communication behaviors may be helpful.

Bandura's Social Cognitive Theory (SCT) explains how people acquire and maintain certain behavioral patterns and has been the basis for behavior change interventions in a variety of fields. SCT is based on a dynamic and reciprocal model of interactions among behavior, personal factors, and environmental influences. Personal and environmental factors form the constructs of SCT and include psychological determinants, which are cognitive factors that influence behavior. Cognitive factors include outcome expectations and self-efficacy. Outcome expectations is defined as the expected results that will occur with the performance of the behavior. The impact of the value of the expected outcome on the person's behavior is also considered in the outcome expectation construct. Self-efficacy is defined as a person's confidence in his/her ability to perform a certain behavior. Environmental determinants are external and physical factors that influence behavior, and include reinforcements (responses to the behavior that increase or decrease the likelihood of the behavior recurring) and facilitation

(introducing tools, resources, and environmental changes to make new behaviors easier to perform). Other constructs of SCT include observational learning (watching the actions and outcomes of others' behaviors) and self-control (personal regulation of goal-directed behavior including goal setting and problem-solving) (Bandura, 1998).

SCT has been used to evaluate physical activity adoption behaviors for cancer patients (Rogers et al., 2005), self-efficacy to manage cancer-related pain (Kravitz et al., 2009), dietary changes (Madlensky et al., 2008; Mosher et al., 2008), and improving quality of life behaviors (Graves, Carter, Anderson, & Winett, 2003). Using components of SCT such as exploring expected outcomes and the value of using new communication behaviors, including rewards or punishments to modifying behavior, goal setting, and opportunities to observe other engaging in the desired behavior could improve adoption of communication and assertiveness skills.

Contributions to the Patient-Focused Communication Literature

Another goal of this research was to answer the question: What relationships exist between constructs important to patient-doctor communication: patient self-efficacy, trust in doctor, satisfaction with doctor, uncertainty about illness, and emotional distress? To our knowledge, the relationships between these factors have not been explored before and after implementing a patient-focused communication skills and self-efficacy enhancing intervention for cancer patients. At baseline, self-efficacy was significantly correlated with all variables except emotional distress. Baseline results and directions of the relationships are consistent with the literature (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Liang, Burnett, & Rowland, 2002; Stewart, Meredith, Brown, & Galajda,

2000) and provide further evidence of the significance of the relationships between self-efficacy, trust in doctor, satisfaction with doctor, illness uncertainty and information needs.

Significant correlations were found between trust in doctor and both satisfaction with doctor and illness uncertainty, between information needs and illness uncertainty, and between illness uncertainty and satisfaction with doctor at baseline. These results are consistent with previous findings. Frostholtm et al. (2005) found that uncertainty or worry about illness symptoms was predictive of patient dissatisfaction with the consultation. Mishel (1997b) found that as uncertainty decreased, patients trust in their medical increased. Our findings highlight the relationships between the level of uncertainty a cancer patient has about his/her illness and other factors known to impact communication with healthcare providers.

At the 1-month follow-up time point, correlations between the study variables varied from baseline for both the control and intervention groups. For those participants not receiving the intervention, no significant correlations were found between self-efficacy and the other variables for the control group. However, emotional distress was positively correlated with information needs and illness uncertainty, and information needs was positively correlated with illness uncertainty. In a study engaging newly diagnosed prostate cancer patients in a computer-based, interactive health education program, participants knowledge about prostate cancer and most important information needs were met after using the program and emotional distress was significantly reduced (Flynn et al., 2004). Although no causal relationship can be implied from these correlations, this finding does suggest that over time emotional distress, level of

uncertainty about illness and level of information needed are important factors for this population of cancer patients. Considering that up to 25% of new cancer patients will have clinically significant distress (Sellick & Edwardson, 2007), our finding also suggest that addressing these concepts over the course of care for cancer patients may be important.

For participants receiving the intervention, findings indicated that at 1-month follow-up, significant positive correlations were seen between self-efficacy and trust in doctor, and self-efficacy and satisfaction with doctor. Self-efficacy was negatively correlated with illness uncertainty. Consistent with previous research, a study assessing quality of life for recurrent breast cancer patients also found a negative correlation between uncertainty and self-efficacy (Northouse, 2002). Again, no causal relationships can be inferred between the study variables; however, the intervention appears to have impacted cancer patients' self-efficacy and satisfaction with their doctor, which includes satisfaction with the information exchanged, the doctor's interpersonal skills, the doctor's level of empathy, and satisfaction with the quality of the visit. In addition, the intervention appears to have had an effect on the level of trust the patients have in their doctors and the level of uncertainty about the meaning of illness-related events.

Given the significant relationships found between study variables important to communication, these findings suggest that patient-centered interventions would benefit from focusing on outcomes such as satisfaction with doctor, illness uncertainty, and trust in doctor. Earlier discussion of these concepts has shown their importance in cancer communication literature. Our study demonstrates the value and necessity of evaluating

these variables as primary outcomes since significant relationships were found even after one month following the intervention.

Additional Limitations

Limitations to this study have been discussed previously, but additional limitations need to be addressed. Although this study was designed to pilot the communication intervention, the small sample size may have contributed to the amount of power available to detect a significant effect. Factors affecting the sample size included the retention of participants once recruited and retention of participants through the completion of all assessment time points. Five of the 15 participants randomized to the intervention condition were either dropped from the study due to inability to be contacted or declined continuing in the study. This attrition prior to completing the intervention and final assessment time point likely impacted the power to detect an effect in self-efficacy. Modifying the delivery of the intervention to the clinic setting may alleviate transportation or inconvenience burden experienced by patients.

Participant drop-out from the intervention condition could have resulted in differential effects between the two groups. Differential effects due to attrition is defined as potential bias introduced into data due to drop out of participants from the study comparison groups. The problem with differential attrition is that comparison groups can become different because of the loss of participants rather than due to the treatment, and the subsequent groups no longer resemble the original groups (Graham & Donaldson, 1993). Post-hoc analyses demonstrated no differences in age, gender, race, education or self-efficacy between participants that completed the intervention versus those that did

not. These results provide evidence that despite attrition predominantly coming from the intervention group, the characteristics of the intervention group were not significantly altered. Therefore, bias due to differential effects is likely not an issue.

Future Directions

Some future directions for this research have been discussed previously, including incorporating alternate theoretical components into the intervention, addressing emotional functioning in the intervention, assessing homework compliance and implementing more opportunities for skills practice, and using or developing behavior- and situation-specific self-efficacy measure assessing different levels of communication behavior. To enhance the ability to test the effect of the intervention, a future direction would be to optimize detecting changes in self-efficacy by modifying recruitment. Newly diagnosed and recurrent cancer patients currently receiving treatment were recruited for the present study. As newly diagnosed cancer patients are likely to have a high level of communication/information needs, focusing on this group for recruitment would likely improve the ability to test the efficacy of the intervention. In addition, by administering the self-efficacy measure immediately after patient-doctor encounters, patients reporting of level of confidence in performing specific communication behaviors potentially may be more accurate as it is anchored in a recent and salient experience. Another future direction would be to directly evaluate the efficacy of the intervention on patients' behavior during patient-doctor interactions by audiotaping or video recording appointments and assessing changes in number of questions asked, communication behaviors, and length of the appointment. Self-efficacy has been conceptualized as an

intermediate outcome linking patient needs to health outcomes (Epstein and Street, 2007). Another future direction could be to assess the impact of the intervention on patients' health outcomes including completion of treatment and health-related quality of life constructs such as emotional and physical well-being, perceived health status, and cognitive and social functioning.

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APPENDIX A

Participant COMPACT Manual

COMPACT

Communication
Program to Activate
Cancer Survivors

Welcome to COMPACT!

It's wonderful to have you.

What will you learn in COMPACT?

- ◆ How using certain skills can improve your communication with your doctor
- ◆ How your thoughts affect your feelings and behavior during doctor visits
- ◆ How your thoughts, feelings, and behavior affect your communication with your doctor

Session 1

✿ Session 1 Goals

1. Introduction to connection between our thoughts and our behavior.



2. Learn to manage thoughts that “spring up” before or during doctor visits.

.....

What is your role as a group member?

- Be active.
- Privacy is important! Let’s leave what is shared by group members at the door.
- Practice at home.

Now, let's get to know each other. Tell everyone a little about yourself, such as...

1. What is your first name?
2. Where were you raised?
3. What do you do for fun?

.....

Okay, let's get started!

It is important for you to know all your medical history in order to correctly inform your doctors.

What is your medical history?



Medical history includes

- | | |
|-----------------------|------------------------------------|
| ✿ Dates of diagnoses | ✿ Any side effects experienced |
| ✿ Illness names | ✿ Important family medical history |
| ✿ Treatments received | |

What is communication?



- ◆ A process used to exchange information with others.

Communication is a learned skill. What you say, your body movements, and your facial expressions are all a part of communication.



Talking with your doctor during visits is the time to exchange information about your needs, issues, or concerns related to your illness.

Take a moment to think about the needs you have when discussing your illness with your doctor.

For example, you may have a strong need for...

- ◆ Information on pain caused by your illness
- ◆ Information on how to relieve nausea

How are your thoughts related to your behavior?



- ◆ Our thoughts are connected to our feelings.

Consider a situation where you had a strong emotion such as anger or happiness.

What were you thinking at that time?

It is likely that the thoughts you were having caused you to have that emotion.



If you have ever driven or rode in traffic, you may have thought, "This traffic is awful!"

And then experienced worry or frustration immediately after that thought.

- ◆ This example demonstrates how our thoughts are related to the emotions we feel.
- ◆ Our feelings are also connected to how we act or behave.

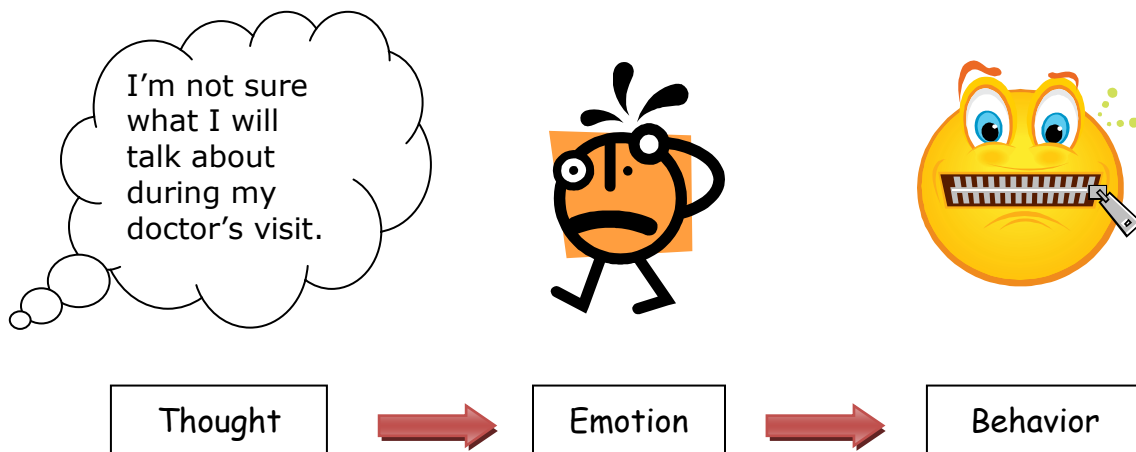
In the previous traffic example, after feeling worry or frustration, you may have yelled or hit the dashboard.

- ◆ In this way, our feelings cause actions or behaviors.

We will refer to this connection as the –

Thought-Behavior Process

The following diagram shows how our thoughts, feelings, and behavior are related:



This cartoon gives an example of the thought process a patient could have before seeing their doctor.

- ◆ Their uncertainty about what will be discussed during the visit leads to worry, which leads to that person being quiet and reserved when while the doctor is in the room.

The example shown in the cartoon also summarizes another relevant process –

The **E**vent, **T**hought, and **A**ction model or “ETA.”

- ◆ The ETA model shows us how thoughts occurring in a certain situation, often stressful in nature, and our current beliefs lead to an emotional consequence.

For the cartoon on the previous page, let's fill in the Event, Thought, and Action.

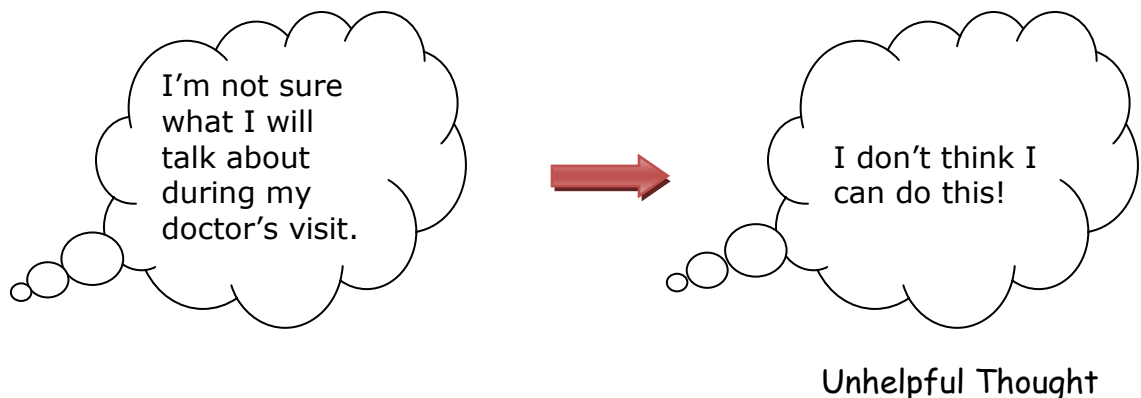
| | |
|----------------|--|
| Event | |
| Thought | |
| Action | |

Exercise 1: Practice increases our chances of retaining what we learn. Let's pair up and briefly explain the Thought-Behavior process and the ABC model to your partner.

Automatic Thoughts

The thoughts we learned about earlier we will refer to them as automatic thoughts.

- ◆ Automatic thoughts occur when we make judgments about situations, emotions, and behaviors.
- ◆ They are “automatic” because they spring up out of nowhere and are usually the first thoughts we have in a situation.
- ◆ Sometimes automatic thoughts are unhelpful – these are the thoughts we will focus on.
- ◆ In some situations, we sense what is happening as a loss or a threat to us. When we judge our situations this way, the automatic thoughts we have are usually unhelpful.





What are the dangers of having unhelpful thoughts...

- Unhelpful thoughts can twist your view of a situation.
- Unhelpful thoughts can cause you to think you are helpless to change a situation.
- Unhelpful thoughts can cause you to believe you have no control over a situation.

Unhelpful thoughts can be distracting during your doctor visits.

And create barriers to communication with your doctor.

Exercise 2: Role-playing to identify automatic thoughts during doctor visits

For this exercise, you will team up with a group member and one person will play him/herself and the other member will play the role of a medical doctor.

- ◆ This exercise will help you recall your automatic thoughts during your doctor visits.
- ◆ Try to picture one of your most recent doctor appointments. What thoughts did you have the morning of the appointment, traveling to the clinic, in the waiting room, and face-to-face with your doctor.

Exercise 3: Automatic Thoughts Worksheet

Looking at the ATW handout, you may see some statements that you have said before.

Naming your unhelpful thoughts is the first step to changing them!

- 1) Think about one of your recent doctor visits.
- 2) Write about any changes you noticed in your feelings or emotions.
- 3) Write about any changes you noticed in your actions or behavior.
- 4) Write down the automatic thoughts or pictures that were in your mind during your doctor visit.
- 5) Rate how much you believe each automatic thought or picture on a scale from 1 to 5, with 5 meaning you completely believe the thought.

Automatic Thoughts Worksheet

| Times before, during or after your doctor visit | Automatic thoughts or pictures in your mind How much do you believe it? Rate from 0-5 with 0= "I do not believe thought" and 5= "I completely believe thought" | Changes in feelings or behavior. | <u>Judging Automatic Thoughts</u> Write some facts that are <u>true</u> about your automatic thought. | <u>Making Alternative Thoughts</u> * Write some facts that are <u>not true</u> about your automatic thought. | Is the thought unhelpful? How much do believe your Unhelpful Thoughts Now? Rate from 0-5 with 0= "I do not believe thought" and 5= "I completely believe thought" |
|--|--|---------------------------------------|--|---|---|
| Sitting in the exam room before the doctor comes in. | "I have no idea what we will talk about." – 5 "I don't think I can do this." – 4 | Nervous, worried All tensed up | I don't remember being told what my next appointment would cover. I get really nervous right before the doctor comes in the room. | In my last appointment, I did a procedure and we could be discussing the results today. I could call the clinic and find out some details about the appointment. I've been able to get through my last 2 doctor visits. | "I have no idea what we will talk about." (unhelpful) – 2 "I don't think I can do this." (unhelpful) – 1 |
| | | | | | |

*What is true about my Automatic Thought? What is twisted or not true about my Automatic Thought? Most of the time Automatic Thoughts are partly true and partly not true. Often Automatic Thoughts are unhelpful.

Constructing Alternative Thoughts

Alternative thoughts are more real, useful, and positive.

Having useful, positive thoughts can help you look at a situation more accurately.



To judge your automatic thoughts to determine if they are unhelpful, write some facts that are true and not true about your automatic thoughts.

Changing any automatic thoughts judged to be unhelpful to useful, real, more positive thoughts can help boost talks you have with your doctor!

Exercise 4: Automatic Thoughts Worksheet continued.

Creating alternative thoughts is not as hard as it may seem. When you judge a thought, you write down facts that are true about the thought.

- ◆ To make an alternative thought, write down facts that are not true about the thought.
 - ◆ You can think of an alternative thought as another way to look at the situation.
- ◆ Once you have an alternative thought, then rate how much you now believe that thought.

Now complete the ATW by making alternative statements for the automatic thought you wrote down.

Summary



- ✿ Communication is a process used to exchange information with others.
- ✿ Communication is a learned skill.
- ✿ Our thoughts, feelings and behavior are connected
- ✿ Automatic thoughts “spring up” out nowhere and occur when we make judgments about situations, emotions, and behaviors.
- ✿ Unhelpful thoughts happen when we judge our situations, emotions, and behaviors as a threat or a loss.
- ✿ Unhelpful thoughts can be distracting and create barriers to communication with your doctor.

Practice Work:

Remember practice makes perfect!

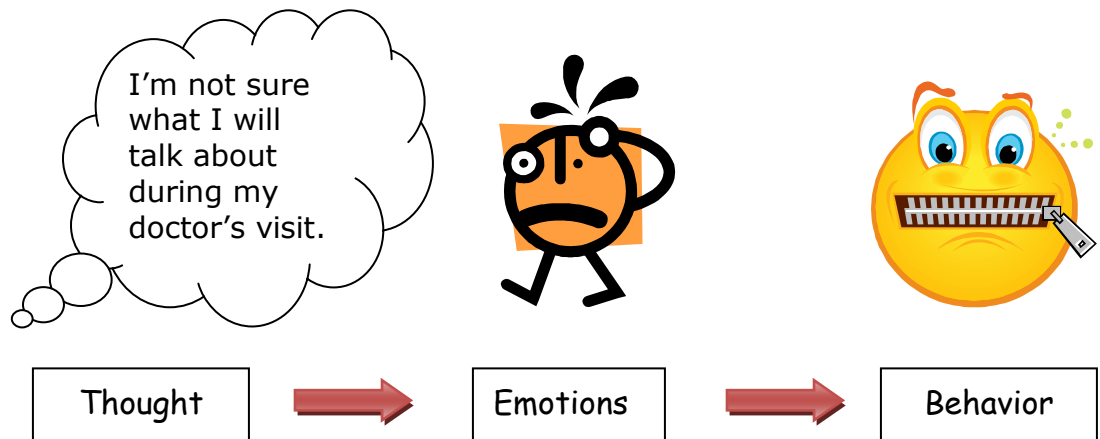
- ◆ Using the thoughts from role-playing and the ATW handout, write down your thoughts that occur during doctor visits.
- ◆ Next, judge them using positive, neutral, and unhelpful criteria. Then, create alternative thoughts.

Session 2

Review of last session

- Communication is a process used to exchange information with others.
- Our thoughts are connected to our feelings.
- Our feelings are connected to how we act or behave.

Thought-Behavior Process



- ◆ Automatic thoughts occur when we make judgments about situations, emotions, and behaviors.
- ◆ They are “automatic” because they spring up out of nowhere and are usually the first thoughts we have in a situation.

- ◆ Sometimes automatic thoughts are unhelpful.
 - ◆ Unhelpful thoughts can twist your view of a situation.
 - ◆ Unhelpful thoughts can be distracting during your doctor visits.
 - ◆ And create barriers to communication with your doctor.
-

◆ **Session 2 Goals**

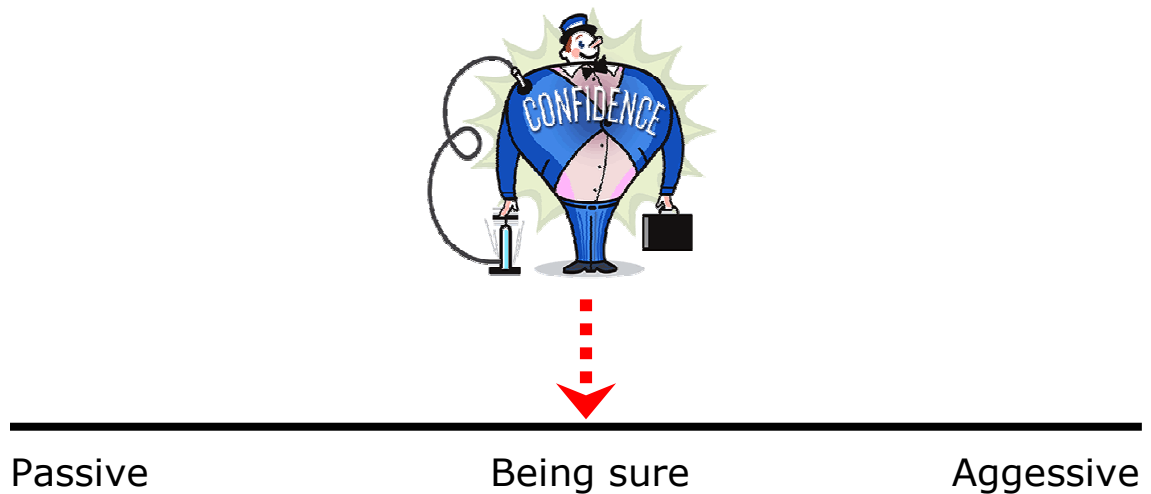
1. Learn about “Being Sure-of-Yourself” when talking with your doctor.
2. Learn helpful communication skills

Being Sure-of-Yourself

Speaking up for needs can be difficult. Knowing certain skills helps with being sure of yourself when talking with others.

Communication falls along a range. The figure below shows a range of communication from being too passive to being too aggressive when talking to others.

You want to be in the middle – this is having confidence or “being sure-of-yourself” when communicating.



Passive Communication

Being passive, you may not be discussing your feelings and thoughts in an open and honest way. If you are passive when talking with others, you could be giving them the impression that your feelings and needs are less important.

Aggressive Communication

If you are aggressive when talking with others, you may be taking away from their time to express their feelings and needs. Aggressiveness could give others the message that their views and feelings are less important to you.

Being Sure-of-Yourself

In this type of communication, you are expressing yourself clearly and honestly, and respect is being given to everyone involved in the discussion.

Helpful communication skills

Below are some skills that may be helpful to you when you are talking with your doctor:

- Make direct eye contact
- Be aware of what your body language is expressing
- Practice good listening skills
- Speak loud enough to be heard
- Speak clearly
 - Slowing down your words may help if you are nervous

Worrying About Your Illness

There may be times when you have worrying thoughts about the future of your cancer or feel upset, sad, or angry.



This worry usually comes and goes, but can be linked to other stressful events in your life. Out-of-the-blue stress can trigger you to feel jittery and tense.

A trigger is anything that brings up thoughts, feelings, memories, or concerns about your cancer.

Overcoming Worry

The best way to deal with worrying about your symptoms or illness is to talk with your doctor about what you are experiencing.

By using helpful communication skills and being sure of yourself when talking with your doctor, you can get the information you need.

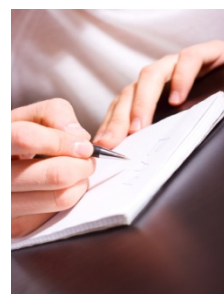
And put the worry behind you.

Tips when discussing your needs with your doctor:

1. Write down your questions or make a list of what you want to talk about.
2. Ask your most important questions first.
3. Ask a family member or friend to come with you to the visit to take notes.
4. If something comes up in the conversation you don't understand, ask your doctor to repeat it in a clearer way.

Making your question sheet

Having questions in advance before seeing your doctor is a great way to improve your chances of talking about your needs with your doctor.



Below are some questions survivors often ask during their doctor visits. Use these to help guide your questions.

1. What symptoms will the cancer cause?
2. Does the treatment have any side-effects?
3. How long will it be before I know the treatment is working?

Summary



- Communication falls along a range – passive, being sure, and aggressive.
- You want to be in the middle – this is having confidence or “being sure-of yourself” when communicating.
- Knowing helpful communication skills and being sure-of-yourself can improve talks with your doctor and help you overcome worry about your illness.

Practice Work:

1. Practice asking your questions with someone or in front of your mirror.
2. Use index cards or small pieces of paper to make “communication cards.” Write down one communication skill on each card; with the name of the skill on one side and the explanation of the skill on the other side of the card.

Session 3

Review of last session

- Communication falls along a range – passive, being sure, and aggressive.
- You want to be in the middle – this is having confidence or “being sure-of yourself” when communicating.



Passive

Being sure

Aggressive

- Helpful communication skills include:
 - Making direct eye contact
 - Good listening skills
 - Speaking clearly
- Knowing helpful communication skills and being sure-of-yourself can improve talks with your doctor and help you overcome worry about your illness.

● **Session 3 Goals:**

1. Learn to talk positively to yourself to build confidence in communicating with your doctor
 2. Empower yourself
 3. Strive to talk openly with your doctor to reduce worry about unknowns about your illness
-

Positive Self-Talk

What is positive self-talk?

- ◆ It's a powerful tool that can build your confidence to accomplish any task you set out to do.

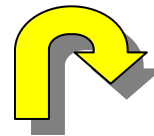
Positive self-talk is more than simply talking to yourself, it's being your own cheerleader!



When you use positive self-talk, you...

- ◆ Use motivating statements
- ◆ Gain control over your thoughts and feelings
- ◆ Get rid of unhelpful thoughts

By using positive self-talk, you can turn unhelpful thoughts into positive ones.



And build your confidence to get the information you need and express your concerns when talking with your doctor.



Take a few minutes to write down your positive self-statements that you can use before and during your doctor visit.

For example, "I can tell my doctor what's important to me."

Empowering Yourself

Feeling empowered means having a strong will or belief in yourself that you can actively go after a goal.

- ◆ When you use positive self-talk, you are empowering yourself to reach your goals.



- ◆ Remember, being empowered is being in control.

Empower yourself to make the most of your time at your doctor visit.



Barriers during your doctor visit: What to do?

Even when you feel empowered and motivated to get the information you need or tell your doctor your concerns, sometimes barriers or obstacles come up.

These barriers can be intimidating and make you feel less motivated to meet your goals when talking with your doctor.

So, what can you do about these barriers?

- ◆ First take a few minutes to write down any obstacles you've had in talking about your needs and concerns with your doctor.



- ◆ Now that you've identified barriers that you have experienced during talks with your doctor, the list below provides some strategies that you can use to overcome these barriers.
- ◆ Ready, set...go! Sometimes going to the doctor can seem like you're in a race to the finish line.

Here are some strategies to use that can help you stay in the lead!



- 1)** Have your question sheet ready before you see the doctor.
- 2)** Prioritize your questions and concerns.
- 3)** Order your list so that you ask what's important first.
- 4)** Make a list of symptoms you want to discuss.
- 5)** Try repeating the question or issue you want to discuss.

Summary



- Positive self-talk is a powerful tool that can build your confidence to accomplish any task you set out to do.
- It can turn unhelpful thoughts into positive ones and build your confidence to get the information you need and express concerns when talking with your doctor.
- Feeling empowered means having a strong will or belief in yourself that you can actively go after a goal.
- Being prepared with strategies can help overcome any barriers you may have when talking with your doctor.

Thank you

**For participating in
COMPACT!**

APPENDIX B

Facilitator COMPACT Manual

COMPACT

Communication
Program to Activate
Cancer Survivors

Facilitator Intervention Manual

Welcome to COMPACT!

It's wonderful to have you.

Thank you everyone for attending today's session. COMPACT stands for 'Communication Program to Activate Cancer Survivors.' This program was designed with cancer survivors like you in mind, to offer skills and activities that may be useful for you in the medical setting.

Before we continue, let's make sure all cell phones are placed on silent or vibrate.

What will you learn in COMPACT? You will learn...

What will you learn in COMPACT?

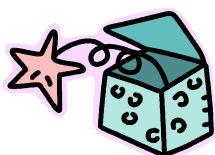
- ◆ How using certain skills can improve your communication with your doctor
- ◆ How your thoughts affect your feelings and behavior during doctor visits
- ◆ How your thoughts, feelings, and behavior affect your communication with your doctor

Session 1

Session 1 goals will include...

☀ Session 1 Goals

3. Introduction to connection between our thoughts and our behavior.



4. Learn to manage thoughts that “spring up” before or during doctor visits.

.....

Before we begin session 1, let’s discuss roles of participants in the group.

What is your role as a group member?

- **Be active.** Being active means asking any questions that come to mind or sharing your experiences that are relevant to the topic.
- **Privacy is important!** Let’s leave what is shared by group members at the door.
Remembering to keep what is shared in the group private is important. We want everyone to feel that they can be open about their experiences.
- **Practice at home.** Practicing at home is very important. Practice increases your chances of remembering new skills that you have learned. The more you practice, the more what you learn will become a habit.

Now, let's get to know each other. Tell everyone a little about yourself, such as...

4. What is your first name?
5. Where were you raised?
6. What do you do for fun?

.....

Okay, let's get started!

And remember, if you have any questions on the material we will be covering, don't hesitate to ask.

It is important for you to know all your medical history in order to correctly inform your doctors.

What is your medical history?



Medical history includes

- | | |
|-----------------------|------------------------------------|
| ✿ Dates of diagnoses | ✿ Any side effects experienced |
| ✿ Illness names | ✿ Important family medical history |
| ✿ Treatments received | |



Please take a few minutes to jot down your medical history.

It may be helpful to take this approach in writing down your medical history:

- 1) List in order by age. It may be difficult to remember the exact date a medical problem began, so you may have a better idea of the age you were. So, start with the first major medical problem you've had as an adult and fill in the date or year if you can, or a ballpark idea of your age when it occurred. Also, write in any treatment you had for each medical condition and any negative side effects you may have experienced such as pain, nausea, and swelling. Treatments include any medicine or procedure you had for the illness (i.e., surgery, medications taken by mouth, medications taken by an I.V). If you've had any major medical problems during your childhood years and can remember the treatment you had, feel free to write that down as well – this is optional though.
- 2) Also, remember to include anything you have an allergic reaction to.

What is communication?

- ◆ A process used to exchange information with others.



Communication is a learned skill. What you say, your body movements, and your facial expressions are all a part of communication.

So, our communication not only involves what we say, but also our body movements also called “body language” and what we express on our faces. All these pieces convey what we are trying to communicate to the person we are speaking. We learn how to match faces and body language to what a person says.

For example, if you tell a person “I am feeling good today,” but your face is pinched and you are sort of hunched over, that person recognizes that all the parts of communication don’t match, and may ask you, “Are you sure you’re alright?”



Talking with your doctor during visits is the time to exchange information about your needs, issues, or concerns related to your illness.

When you talk with your doctor, you should keep in mind all 3 parts of communication when sharing your needs and concerns about your illness.

Take a moment to think about the needs you have when discussing your illness with your doctor.

For example, you may have a strong need for...

- ◆ Information on pain caused by your illness

- ◆ Information on how to relieve nausea

Take a few minutes to write down your needs and any concerns you have had when talking with your doctor about your illness.



Write down your needs and any concerns you have when talking with your doctor.

Note: If participants have difficulty thinking of needs and concerns to write down, prompt them by saying ... “If you went to see your doctor tomorrow, what would you really need to talk to him/her about? Any symptoms concerning you? Medications?”

Okay, so we have learned the important parts of communication and that these parts are important to think about when talking about your needs and concerns with your doctor.

We will now move on to another concept that impacts your talks with your doctor...this concept involves how your way of thinking is related to your behavior?

How are your thoughts related to your behavior?



- ◆ Our thoughts are connected to our feelings.

First, what we think is related to the feelings or emotions we have.

Consider a situation where you had a strong emotion such as anger or happiness.

What were you thinking at that time?

It is likely that the thoughts you were having caused you to have that emotion.

Let's look an example that can further explain.



If you have ever driven or rode in traffic, you may have thought, "This traffic is awful!"

And you may have thought, "I'm going to be late!" Soon after these thoughts, you probably felt worried or frustrated.

And then experienced worry or frustration immediately after that thought.

So, this is how what we think is connected to what we feel. We have a thought and then immediately afterwards, the thought triggers some kind of or feeling; like in the example.

- ◆ This example demonstrates how our thoughts are related to the emotions we feel.

The second part of this concept is that our feelings are connected to our behavior or what we do.

- ◆ Our feelings are also connected to how we act or behave.

In the previous traffic example, after feeling worry or frustration, you may have yelled or hit the dashboard.

- ◆ In this way, our feelings cause actions or behaviors.

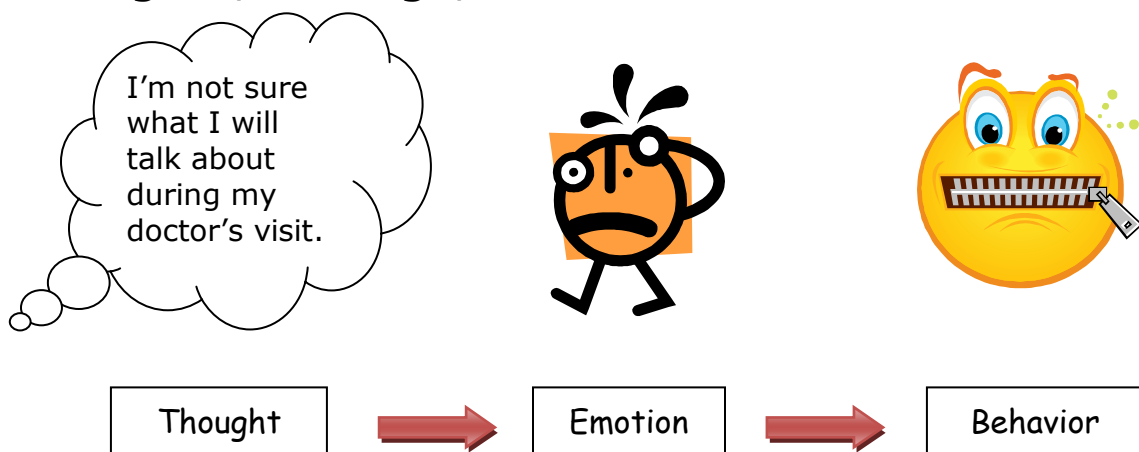
Now we have connected the whole concept... The thoughts we have are related to the feelings we have, and these feelings are related to what we do in a situation.

We will refer to this connection as the –

Thought-Behavior Process

The situations we will focus on are your doctor visits. This includes the period of time right before your appointment, waiting at the clinic, when you are in the room with your doctor, and right after the appointment.

The following diagram shows how our thoughts, feelings, and behavior are related:



This cartoon gives an example of the thought process a patient could have before seeing their doctor.

- ◆ Their uncertainty about what will be discussed during the visit leads to worry, which leads to that person being quiet and reserved when while the doctor is in the room.

The example shown in the cartoon also summarizes another relevant process –

The **E**vent, **T**hought, and **A**ction model or “ETA.”

The ETA process is similar to the Thought-Behavior process shown in the cartoon example. When we are in stressful situations, thoughts or beliefs that we have can lead to actions or behaviors that typically are not positive or helpful.

- ◆ The ETA model shows us how thoughts occurring in a certain situation, often stressful in nature, and our current beliefs lead to a behavior or action.

For the cartoon on the previous page, let's fill in the Event, Thought, and Action.

1. What was the event or situation in the example?
2. What was the thought in the example?
3. What was the person's action of behavior in the example?

| | |
|----------------|--|
| Event | |
| Thought | |
| Action | |

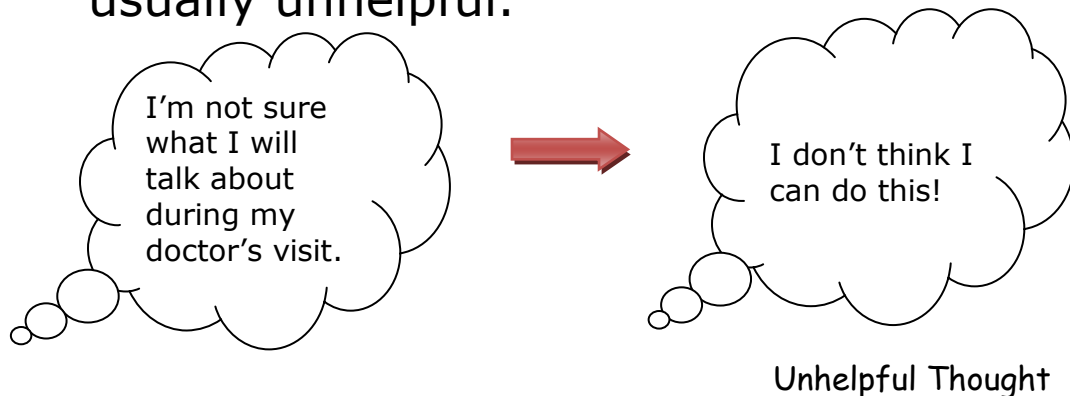
Exercise 1: Practice increases our chances of remembering what we learn. Let's pair up and briefly explain the Thought-Behavior process and the ETA model to your partner.

So let's move on. In this next section, we will discuss those thoughts we have been talking about...

Automatic Thoughts

The thoughts we learned about earlier we will refer to them as automatic thoughts.

- ◆ Automatic thoughts occur when we make judgments about situations, emotions, and behaviors.
- ◆ They are “automatic” because they spring up out of nowhere and are usually the first thoughts we have in a situation.
- ◆ Sometimes automatic thoughts are unhelpful – these are the thoughts we will focus on.
 - ◆ In some situations, we sense what is happening as a loss or a threat to us. When we judge our situations this way, the automatic thoughts we have are usually unhelpful.



Using the previous example, “I don’t think I can do this!” is an unhelpful thought that sprang up automatically. This person likely feels a sense of loss because they are unclear about the purpose of the appointment.



What are the dangers of having unhelpful thoughts...

- ◆ Unhelpful thoughts can twist your view of a situation.
- ◆ Unhelpful thoughts can cause you to think you are helpless to change a situation.
- ◆ Unhelpful thoughts can cause you to believe you have no control over a situation.

Unhelpful thoughts can be distracting during your doctor visits.

And create barriers to communication with your doctor.

The unhelpful thought, “I don’t think I can do this!” creates these dangers. The person in the example likely feels like they are helpless and have no control over the doctor visit.

Next, you will do another exercise in which you will use role-playing to identify automatic thoughts you may have had during visits to see your doctor.

Role-playing is a technique where two or more people “play” roles to teach and learn skills. It involves using your imagination and knowledge about an experience. Role-playing will help you relieve the experience of going to a doctor visit.

Exercise 2: Role-playing to identify automatic thoughts during doctor visits

For this exercise, you will team up with a group member and one person will play him/herself and the other member will play the role of a medical doctor.

- ◆ This exercise will help you recall your automatic thoughts during your doctor visits.
- ◆ Try to picture one of your most recent doctor appointments. What thoughts did you have the morning of the appointment, traveling to the clinic, in the waiting room, and face-to-face with your doctor?

[After about 5 minutes, have partners switch roles].

On the next page, you have been provided space to write down your thoughts.



Take a moment to write down your automatic thoughts.

Now that you have identified some automatic thoughts, the next exercise will help you determine if they are unhelpful and you will learn how to change those unhelpful thoughts into more positive ones.

Exercise 3: Automatic Thoughts Worksheet

Looking at the ATW handout, you may see some statements that you have said before.

You completed the first 2 steps in the role-playing exercise, but they have been provided in your manual to refer to in the future. Let's go through the remaining steps on the ATW worksheet filling in the automatic thoughts you identified.

Naming your unhelpful thoughts is the first step to changing them!

- 1) Think about one of your recent doctor visits.
- 2) Write down the automatic thoughts or pictures that were in your mind during your doctor visit.

Sometimes automatic pictures of a situation pop up in our minds instead of thoughts or along with thoughts. Also write down your description of the picture in your mind.

- 3) Rate how much you believe each automatic thought or picture on a scale from 1 to 5, with 5 meaning you completely believe the thought.
- 4) Write about any changes you noticed in your feelings or emotions.

So think about how you felt immediately after the thought you had. Did you feel sadness, worry, nervousness, or confusion? Or did you feel calm and relaxed?

- 5) Write about any changes you noticed in your actions or behavior.

Changes in your actions or behavior could include being quieter than usual, shaking or being more talkative than usual.

Okay, we will stop here for now with completing the ATW worksheet. Next, we will talk about making alternative thoughts for the automatic thoughts you have written down.

Automatic Thoughts Worksheet

| Times before, during or after your doctor visit | Automatic thoughts or pictures in your mind How much do you believe it? Rate from 0-5 with 0= "I do not believe thought" and 5= "I completely believe thought" | Changes in feelings or behavior. | <u>Judging Automatic Thoughts</u> Write some facts that are <u>true</u> about your automatic thought. | <u>Making Alternative Thoughts*</u> Write some facts that are <u>not true</u> about your automatic thought. | Is the thought unhelpful? How much do believe your Unhelpful Thoughts <u>Now</u> ? Rate from 0-5 with 0= "I do not believe thought" and 5= "I completely believe thought" |
|--|--|---------------------------------------|--|---|---|
| Sitting in the exam room before the doctor comes in. | "I have no idea what we will talk about." – 5 "I don't think I can do this." – 4 | Nervous, worried All tensed up | I don't remember being told what my next appointment would cover. I get really nervous right before the doctor comes in the room. | In my last appointment, I did a procedure and we could be discussing the results today. I could call the clinic and find out some details about the appointment. I've been able to get through my last 2 doctor visits. | "I have no idea what we will talk about." (unhelpful) – 2 "I don't think I can do this." (unhelpful) – 1 |
| | | | | | |

*What is true about my Automatic Thought? What is twisted or not true about my Automatic Thought? Most of the time Automatic Thoughts are partly true and partly not true. Often Automatic Thoughts are unhelpful.

Constructing Alternative Thoughts

Alternative thoughts are more real, useful, and positive.

Having useful, positive thoughts can help you look at a situation more accurately.



To judge your automatic thoughts to determine if they are unhelpful, write some facts that are true and not true about your automatic thoughts.

If you write down more facts that are not true about the automatic thought, judge it as unhelpful.

Changing any automatic thoughts judged to be unhelpful to useful, real, more positive thoughts can help boost talks you have with your doctor!

Now lets complete the ATW by coming up with alternative thoughts.

Exercise 4: Automatic Thoughts Worksheet continued.

Creating alternative thoughts is not as hard as it may seem. When you judge a thought, you write down facts that are true about the thought.

- ◆ To make an alternative thought, write down facts that are not true about the thought.
 - ◆ You can think of an alternative thought as another way to look at the situation.
- ◆ Once you have an alternative thought, then re-rate how much you now believe that thought.

Now complete the ATW by making alternative statements for the automatic thought you wrote down.

We are at the end of the session! Let's go over some points to summarize what we learned.

Summary



- ✿ Communication is a process used to exchange information with others.
- ✿ Communication is a learned skill.
- ✿ Our thoughts, feelings and behavior are connected
- ✿ Automatic thoughts “spring up” out nowhere and occur when we make judgments about situations, emotions, and behaviors.
- ✿ Unhelpful thoughts happen when we judge our situations, emotions, and behaviors as a threat or a loss.
- ✿ Unhelpful thoughts can be distracting and create barriers to communication with your doctor.

Practice Work:

Complete your practice work at home. Write down more automatic thoughts and judge them as unhelpful if appropriate.

Remember practice makes perfect!

- ◆ Using the thoughts from role-playing and the ATW handout, write down your thoughts that occur during doctor visits.
- ◆ Next, judge them using positive, neutral, and unhelpful criteria. Then, create alternative thoughts.

Session 2

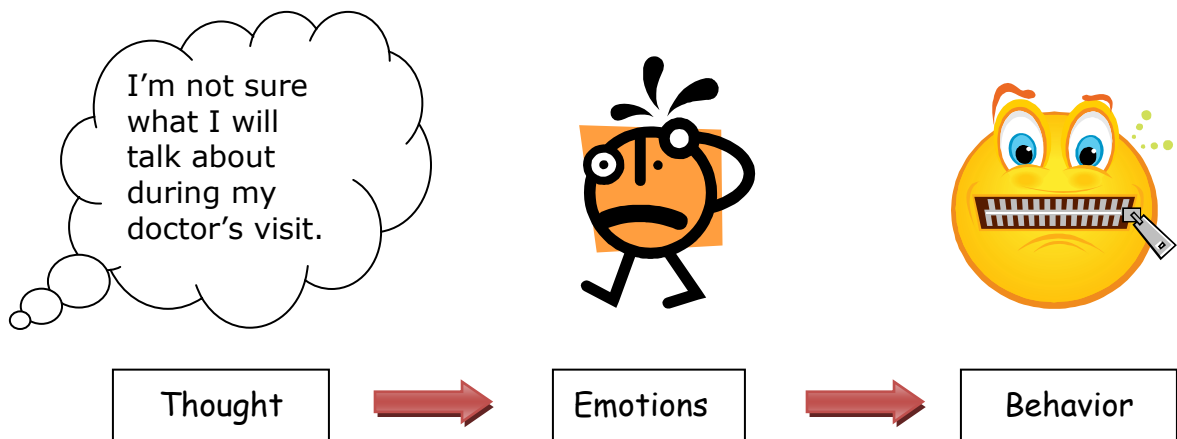
**Note: [Sessions 2 and 3 are conducted by telephone individually to participants. Before starting, make sure the participant is in a quiet place, without distractions and has the manual to refer to].*

Hello, we are going to continue the COMPACT program today with session 2. Before we get started with new material, let's review what we discussed in session 1...

Review of last session

- Communication is a process used to exchange information with others.
- Our thoughts are connected to our feelings.
- Our feelings are connected to how we act or behave.

Thought-Behavior Process



- Automatic thoughts occur when we make judgments about situations, emotions, and behaviors.
- They are "automatic" because they spring up out of nowhere and are usually the first thoughts we have in a situation.

- ◆ Sometimes automatic thoughts are unhelpful.
- ◆ Unhelpful thoughts can twist your view of a situation.
- ◆ Unhelpful thoughts can be distracting during your doctor visits.
- ◆ And create barriers to communication with your doctor.

For practice work from 1st session, you were to continue writing down your automatic thoughts from your doctor visit and complete the worksheet. Let's quickly review what you have done and address any questions you may have.

[If participant has questions or had difficulty with ATW, review automatic thoughts during doctor visits, creating alternative thoughts, and judging thoughts as unhelpful.]

.....

Okay, let's go on to session 2! Goals for session 2 are to...

◆ **Session 2 Goals**

3. Learn about "Being Sure-of-Yourself" when talking with your doctor.
4. Learn helpful communication skills

Being Sure-of-Yourself

Speaking up for needs can be difficult. Knowing certain skills helps with being sure of yourself when talking with others.

Think of “being sure of yourself” as feeling as if you have the power and the knowledge to talk about whatever you need to with people.

Research shows us that communication falls along a range...

Communication falls along a range. The figure below shows a range of communication from being too passive to being too aggressive when talking to others.

On one end people talk with others very passively, and on the other end are people who tend to talk aggressively with other. We will go over these terms in just a minute.

You want to be in the middle – this is having confidence or “being sure-of-yourself” when communicating.

The cartoon shows someone pumping themselves up with confidence, or the feeling that they can do whatever they set their minds to. Think of being “pumped up with confidence” when you are talking with your doctor.



Passive

Being sure

Aggressive

Let's go over those terms we just talked about.

Passive Communication

Being passive, you may not be discussing your feelings and thoughts in an open and honest way. If you are passive when talking with others, you could be giving them the impression that your feelings and needs are less important.

Aggressive Communication

If you are aggressive when talking with others, you may be taking away from their time to express their feelings and needs. Aggressiveness could give others the message that their views and feelings are less important to you.

Being Sure-of-Yourself

In this type of communication, you are expressing yourself clearly and honestly, and respect is being given to everyone involved in the discussion.

On the next page are some helpful skills that you can use when talking with your doctor. Think of these skills as adding tools to your communication toolbox!

Helpful communication skills

Below are some skills that may be helpful to you when you are talking with your doctor:

- **Make direct eye contact**

Just looking into the eyes of the person you are having a conversation with can make the experience successful. Eye contact shows that you are interested and encourages the other person to be interested in you.

- **Be aware of what your body language is expressing**

Sometimes our body language can “say” much more than our words. For example, someone whose arms are by their sides and shoulders are back tells others that he or she is approachable and open to hearing what is said. On the other hand, having crossed arms at your chest and hunched over shoulders may make you seem disinterested or not open to talking. So having good posture (sitting up with arms to your sides) can make a difficult conversation go more smoothly.

- **Practice good listening skills**

Being a good listener is half of the communication process. Try to avoid listening only at the end of the sentence, or being attentive to the beginning of the conversation and thinking you know what’s going to come next.

- **Speak loud enough to be heard**

Be sure of yourself when you speak so that you can be heard. Having the right volume level shows that you mean what you say, have thought about it, and what you are saying is important! Also, the listener hears exactly what you are saying and there is no room for misunderstandings.

- **Speak clearly**

- **Slowing down your words may help if you are nervous**

Taking your time to think about what you want to say will help in speaking clearly so the other person fully understands what you want to talk about.

Now that we have learned some helpful communication tools, let's talk about a very important concern that is relevant to your discussions with your doctor...worry about your illness.

Worrying About Your Illness

There may be times when you have worrying thoughts about the future of your cancer or feel upset, sad, or angry.



This worry usually comes and goes, but can be linked to other stressful events in your life. Out-of-the-blue stress can trigger you to feel jittery and tense.

A trigger is anything that brings up thoughts, feelings, memories, or concerns about your cancer.

Overcoming Worry

The best way to deal with worrying about your symptoms or illness is to talk with your doctor about what you are experiencing.

By using helpful communication skills and being sure of yourself when talking with your doctor, you can get the information you need.

And put the worry behind you.

We have provided you some tips to discussing your needs when you see your doctor.

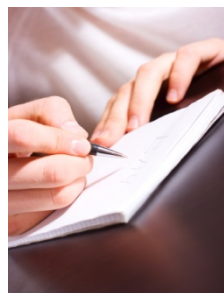
Tips when discussing your needs with your doctor:

1. Write down your questions or make a list of what you want to talk about.
2. Ask your most important questions first.
3. Ask a family member or friend to come with you to the visit to take notes.
4. If something comes up in the conversation you don't understand, ask your doctor to repeat it in a clearer way.

Asking questions is really important in getting your needs discussed when you see your doctor, so we will look at this in a little more detail.

Making your question sheet

Having questions in advance before seeing your doctor is a great way to improve your chances of talking about your needs with your doctor.



Let's come up with some questions to help you make the most of your time with your doctor. You can keep this sheet as a checklist when you see the doctor. Below are some questions survivors often ask during their doctor visits. Use these to help guide your questions.

1. What symptoms will the cancer cause?
2. Does the treatment have any side-effects?
3. How long will it be before I know the treatment is working?

Take a minute or two to think about other question you have to ask your doctor. You can use the space in the booklet to jot them down later.



Use the space below to make your question list.

Okay, so we are at the end of today's session. But before we finish, let's review what we learned today.

Summary



- Communication falls along a range – passive, being sure, and aggressive.
- You want to be in the middle – this is having confidence or “being sure-of yourself” when communicating.
- Knowing helpful communication skills and being sure-of-yourself can improve talks with your doctor and help you overcome worry about your illness.

For your practice work, continue writing down your questions in the space provided in the booklet. You've been given some additional techniques to use that can help with practicing the skills you have learned today.

Practice Work:

1. Practice asking your questions with someone or in front of your mirror.
2. Use index cards or small pieces of paper to make “communication cards.” Write down one communication skill on each card; with the name of the skill on one side and the explanation of the skill on the other side of the card.

Before starting, make sure the participant is in a quiet place, without distractions and has the manual to refer to]

Today is the final session of the COMPACT program, session 3. As we did the last time, let's review what we discussed in session 2...

Session 3

Review of last session

- Communication falls along a range – passive, being sure, and aggressive.
- You want to be in the middle – this is having confidence or “being sure-of yourself” when communicating.



Passive
Aggressive

Being sure

- Helpful communication skills include:
 - Making direct eye contact
 - Good listening skills
 - Speaking clearly
- Knowing helpful communication skills and being sure-of-yourself can improve talks with your doctor and help you overcome worry about your illness.

Did you have any questions after completing the question sheet for practice work? Did you find the other practice work techniques helpful, practicing questions with someone or in front of the mirror or making communication cards?

Okay, let's go on to session 3! Goals for session 3 are to...

● **Session 3 Goals:**

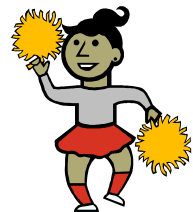
4. Learn to talk positively to yourself to build confidence in communicating with your doctor
 5. Empower yourself
 6. Strive to talk openly with your doctor to reduce worry about unknowns about your illness
-

Positive Self-Talk

What is positive self-talk?

- ◆ It's a powerful tool that can build your confidence to accomplish any task you set out to do.

Positive self-talk is more than simply talking to yourself, it's being your own cheerleader!



When you use positive self-talk, you...

◆ Use motivating statements

Such as “I can do anything I set my mind to!”

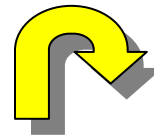
◆ Gain control over your thoughts and feelings

◆ Get rid of unhelpful thoughts

Many unhelpful thoughts start with “I can’t...” or “I should...,” so be mindful if your thoughts start off with these phrases.

You can use positive self-talk to prepare yourself for a stressful situation, when you’re facing a challenge, and when you’re trying to deal with a fear.

By using positive self-talk, you can turn unhelpful thoughts into positive ones.



And build your confidence to get the information you need and express your concerns when talking with your doctor.

You can even use positive self-talk to congratulate yourself for an achievement!

Now, take a moment to think of positive self-talk that you can use before and during your doctor visit. Write your statements in this space provided in the booklet.



Take a few minutes to write down you positive self-statements that you can use before and during your doctor visit.

For example, "I can tell my doctor what's important to me."

Empowering Yourself

Feeling empowered means having a strong will or belief in yourself that you can actively go after a goal.

- ◆ When you use positive self-talk, you are empowering yourself to reach your goals.



- ◆ Remember, being empowered is being in control.

When you empower yourself, you are building your inner strength. Also, it's like voting for yourself because you think you are #1!

Empower yourself to make the most of your time at your doctor visit.



Barriers during your doctor visit: What to do?

Even when you feel empowered and motivated to get the information you need or tell your doctor your concerns, sometimes barriers or obstacles come up.

These barriers can be intimidating and make you feel less motivated to meet your goals when talking with your doctor.

So, what can you do about these barriers?

- ◆ First take a few minutes to write down any obstacles you've had in talking about your needs and concerns with your doctor.

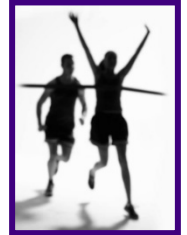


- ◆ Now that you've identified barriers that you have experienced during talks with your doctor, the list below provides some strategies that you can use to overcome these barriers.

Many people express that going to the doctor's office is similar to running a race trying to get to the finish line. The time you spend with your doctor can often seem like a blur. So, we've provided some strategies that can help you stay in the lead and win the race!

- ◆ Ready, set...go! Sometimes going to the doctor can seem like you're in a race to the finish line.

Here are some strategies to use that can help you stay in the lead!



- 1)** Have your question sheet ready before you see the doctor.
- 2)** Make a list of symptoms you want to discuss.
- 3)** Prioritize your questions and concerns.
- 4)** Order your list so that you ask what's important first.
- 5)** Try repeating the question or issue you want to discuss.

If you have other strategies that would help you overcome barriers when seeing your doctor, write them in the space provided.



Use the space below to write down other strategies for barriers that may be helpful to you.

We are nearing the end of the session, so this is a good time to revisit the skills you have learned during the COMPACT program to help get your needs met during doctor visits. It may be helpful to start with the information learned in session 1. Take a minute to quickly write down what you recall.

Recap of Skills



Let's take a few minutes to revisit all the skills you have learned to apply to getting your needs met during doctor visits. Quickly jot them down.

Before we end, let's review today's material.

Summary



- Positive self-talk is a powerful tool that can build your confidence to accomplish any task you set out to do.
- It can turn unhelpful thoughts into positive ones and build your confidence to get the information you need and express concerns when talking with your doctor.
- Feeling empowered means having a strong will or belief in yourself that you can actively go after a goal.
- Being prepared with strategies can help overcome any barriers you may have when talking with your doctor.

Congratulations! You have completed the COMPACT program. Thank you for your participation.

Thank you

**For participating in
COMPACT!**

APPENDIX C

Study Measures

COMPACT

Communication Program to Activate Cancer Survivors

This script is to be used for calling participants to complete the telephone survey.

Date: _____

Participant Name: _____

Phone: _____

Alternate Phone: _____

Best days to call:

Best times to call:

“Hello, my name is _____. I am calling from the COMPACT program. I would like to speak to _____.”

1. If available continue to introduction.
2. If participant is not available, schedule an appointment.
3. If incorrect number, say thank you and end call.
4. If participant is deceased, say “I am very sorry for your loss. Can you please tell me when _____ died?”
Record date or “don’t know” or “refused”: _____. Please note that dates are very important and at least get the month and year.

Introduction:

“You may remember signing a consent form at a recent visit to the Cooper Green Oncology Clinic and being told that you would receive a phone call from someone with the COMPACT study who would ask some questions about your doctor visits.

This survey will take a short time and all information you share with me will be kept private. If I ask any questions you don’t want to answer or can’t remember the answer to, just tell me and we will skip those questions and move on.

Thank you for your time. After completing this survey, you will receive a check for \$15 mailed to you.”

Cancer Type:

Please tell me the first cancer type you were diagnosed with.

DateDx1:

When were you diagnosed? _____ (mm/dd/yyyy)

Cancer Type2:

Have you had a recurrence of your cancer? If yes, please tell me where in your body.

Interviewer: Recurrence means the cancer has come back after it was thought to be gone completely.

DateDX2: [If necessary...]

When were you diagnosed with a recurrence? _____ (mm/dd/yyyy)

Interviewer: Please note that dates are very important and at least get the month and year. If they can't remember enter "don't know."

SECTION 1:
Treatment Types

In this section of the survey, I am going to ask you about treatments you may have had for your cancer.

Surgery:

1. Have you received surgery for your cancer? By surgery, I mean operations that required you to have anesthesia and where all or part of your cancer was removed. Please do not include any biopsies you had as part of your cancer being diagnosed.
 1. Yes
 2. No
 8. Don't Know/Not Sure
 9. Refused

SECTION 2:
Chemotherapy:

Now we are going to talk about chemotherapy you may have received as part of your treatment for your cancer. Chemotherapy is given through a needle in the vein at the Cooper Green Oncology Clinic or other facility specializing in cancer treatment.

1. Have you received chemotherapy for your cancer?
 1. Yes
 2. No
 8. Don't Know/Not Sure
 9. Refused

Skip to Section 3
Skip to Section 3
Skip to Section 3

2. Are you still receiving chemotherapy treatments?
 1. Yes
 2. No
 8. Don't Know/Not Sure
 9. Refused

SECTION 3:
Radiation:

We are now going to talk about Radiation Therapy that you may have received as part of the treatment for your cancer.

Radiation treatments are usually given daily over several weeks using a machine that targets high-energy x-rays to specific areas of the body. You would have had these treatments outside of Cooper Green.

1. Have you received radiation treatments for your cancer?

1. Yes

2. No

8. Don't Know/Not Sure

9. Refused

Skip to Section 4

Skip to Section 4

Skip to Section 4

2. Are you still receiving radiation treatments?

1. Yes

2. No

8. Don't Know/Not Sure

9. Refused

SECTION 4:
Hormone Therapy:

Interviewer: If respondent was not diagnosed with either Breast or Prostate Cancer, Skip to Section 5.

Breast Cancer Patients:

We are now going to talk about Hormone therapy. Women who have breast cancer sometimes get Tamoxifen, a hormone pill taken by mouth once a day, or another hormone such as Arimidex.

Prostate Cancer Patients:

We are now going to talk about hormone therapy. Hormone therapy can be taken by mouth every day such as Eulexin, Nilandron, Casodex, or injected such as Lupron, Viadur or Eligard.

1. Have you been prescribed a hormone treatment?

1. Yes

2. No

8. Don't Know/Not Sure

9. Refused

Skip to Section 5

Skip to Section 5

Skip to Section 5

2. Are you still receiving hormone therapy?

1. Yes

2. No

8. Don't Know/Not Sure

9. Refused

SECTION 5:

Demographics

Now I am going to ask you some questions about yourself and your background.

Demo1:

1. What is your date of birth? _____ (mm/dd/yyyy)

Interviewer: Please note that dates are very important and at least get the month and year.

Demo2:

2. Enter gender of respondent. (Ask only if necessary.)
 1. Male
 2. Female

Demo3:

3. Which of the following best describes your ethnic or racial background?
 1. White
 2. Black or African American
 3. American Indian, Eskimo or Aleut
 4. Asian or Pacific Islander
 5. Other Please Specify: _____
 8. Don't Know/Not Sure
 9. Refused

Demo4:

4. Do you consider yourself to be of Latino or Hispanic descent?
 1. Yes
 2. No
 8. Don't Know/Not Sure
 9. Refused

Demo5:

5. What is your current marital status?
 1. Married or living with a partner
 2. Divorced or separated
 3. Widowed
 4. Single, never been married
 8. Don't Know/Not Sure
 9. Refused

Demo6:

- 6a. What is the highest grade or level of education you have completed?
1. Less than 8th grade
 2. 8th grade through 11th grade
 3. High school diploma or GED
 4. Vocational School or some college
 5. College graduate
 6. Professional or graduate school degree
 8. Don't Know/Not Sure
 9. Refused
- 6b. What is the total number of years of education you have completed?
- _____

Demo7:

7. Which of the following best describes your current employment situation?
1. Full time or part time job
 2. Retired
 3. Receiving disability payments
 4. Unemployed and looking for work
 5. Unemployed and not looking for work
 6. On leave with pay
 7. On leave without pay
 8. Don't Know/Not Sure
 9. Refused
 10. Other Please specify: _____

Demo8:

8. Including income provided by you, your spouse or partner and anyone else living in your household, in what category does your yearly household income from all sources before taxes fall?
1. 0 – 5,000
 2. 5,001 – 10,000
 3. 10,001 – 15,000
 4. 15,001 – 20,000
 5. 20,001 – 25,000
 6. 25,001 – 30,000
 7. 30,001 or higher
 8. Don't know/Not Sure
 9. Refused

Demo9:

9. Are you currently being treated for any medical illness other than cancer?
1. Yes
 2. No
 8. Don't Know/Not Sure
 9. Refused
- [Skip to Demo10](#)
[Skip to Demo10](#)
[Skip to Demo10](#)

Demo9a

- 9a. What is the illness?
-

8. Don't Know/Not Sure
9. Refused

Demo10:

10. If you have medical insurance, please tell me what kind you have.
1. No insurance
 2. Private insurance (e.g., Blue Cross, VIVA)
 3. Medicare
 4. Medicaid
 5. Military or VA benefits
 6. Other specify: _____
 8. Don't Know/Not Sure
 9. Refused

SECTION 6:**Met Needs****Asked at Baseline and 1-month Follow-up**

This section asks about kinds of information you may or may not need as a result of living with a diagnosis of cancer. For each item, decide (yes or no) if you have needed information. If yes, tell me if your level of need was low, moderate, or high. If item does not apply to you, say not applicable. Your response should reflect your needs within the past month.

In the past month, did you need help with... (If yes, was your level of need low, moderate, or high?):

| | No Need | Low Need | Moderate Need | High Need | |
|---|------------|-------------|------------------|--------------|-----|
| 1. Pain | | | | | |
| 2. Lack of energy and tiredness | 1 | 2 | 3 | 4 | n/a |
| 3. Feeling unwell a lot of the time | 1 | 2 | 3 | 4 | n/a |
| 4. Work around the home | 1 | 2 | 3 | 4 | n/a |
| 5. Not being able to do the things you used to do | 1 | 2 | 3 | 4 | n/a |
| 6. Anxiety | 1 | 2 | 3 | 4 | n/a |
| 7. Feeling down or depressed | 1 | 2 | 3 | 4 | n/a |
| 8. Feelings of sadness | 1 | 2 | 3 | 4 | n/a |
| 9. Fears about the cancer spreading | 1 | 2 | 3 | 4 | n/a |
| 10. Worry that the results of treatment are beyond your control | 1 | 2 | 3 | 4 | n/a |
| 11. Uncertainty about the future | 1 | 2 | 3 | 4 | n/a |
| 12. Learning to feel in control of your situation | 1 | 2 | 3 | 4 | n/a |
| 13. Keeping a positive outlook | 1 | 2 | 3 | 4 | n/a |
| 14. Feelings about death and dying | 1 | 2 | 3 | 4 | n/a |
| 15. Changes in sexual feelings | 1 | 2 | 3 | 4 | n/a |
| 16. Changes in your sexual behavior | 1 | 2 | 3 | 4 | n/a |
| 17. Concerns about the worries of those closest to you | 1 | 2 | 3 | 4 | n/a |

In the past month, have you needed... (If yes, was your level of need low, moderate, or high?):

| | No Need | Low Need | Moderate Need | High Need | |
|--|------------|-------------|------------------|--------------|-----|
| 18. More choice about which cancer specialist you see | 1 | 2 | 3 | 4 | n/a |
| 19. More choice about which clinic you attend | 1 | 2 | 3 | 4 | n/a |
| 20. Reassurance by medical staff that the way you feel is normal | 1 | 2 | 3 | 4 | n/a |
| 21. Clinic staff to attend promptly to your physical needs | 1 | 2 | 3 | 4 | n/a |
| 22. Clinic staff to acknowledge and show concern about your feelings and emotional needs | 1 | 2 | 3 | 4 | n/a |
| 23. Written information about the important aspects of your care | 1 | 2 | 3 | 4 | n/a |
| 24. Information about managing you illness and side-effects at home | 1 | 2 | 3 | 4 | n/a |
| 25. Explanations for tests | 1 | 2 | 3 | 4 | n/a |
| 26. To be adequately informed about the benefits and side-effects of treatments before you choose to have them | 1 | 2 | 3 | 4 | n/a |
| 27. To be informed about you test results as soon as possible | 1 | 2 | 3 | 4 | n/a |
| 28. To be informed about cancer remission | 1 | 2 | 3 | 4 | n/a |
| 29. To be informed about things you can do to help yourself get well | 1 | 2 | 3 | 4 | n/a |
| 30. To have access to counseling if you or your family or friends need it | 1 | 2 | 3 | 4 | n/a |
| 31. Information on having sexual relationships | 1 | 2 | 3 | 4 | n/a |
| 32. To be treated like a person, not just another case | 1 | 2 | 3 | 4 | n/a |
| 33. To be treated in a clinic that is pleasant | 1 | 2 | 3 | 4 | n/a |
| 34. To have <u>one</u> member of clinic staff who you talk to your condition, treatment and follow-up | 1 | 2 | 3 | 4 | n/a |

SECTION 7:**Satisfaction with Doctor****Asked at Baseline and 1-month Follow-up**

Now, I'd like to ask you some questions about your relationship with your doctor that you see regularly. Remember, there are no right or wrong answers. I'm going to read you some statements and I'd like for you to tell me if you strongly disagree, disagree, agree or strongly agree with each statement. If the statement does not apply to you, respond not applicable.

| | Strongly Disagree | Disagree | Agree | Strongly Agree | |
|---|----------------------|----------|-------|-------------------|-----|
| Information exchange | | | | | |
| 1. I will follow the doctor's advice because I think he/she is absolutely right. | 0 | 1 | 2 | 3 | n/a |
| 2. I really felt understood by my doctor. | 0 | 1 | 2 | 3 | n/a |
| 3. After my last visit with my doctor, I feel much better about my concerns. | 0 | 1 | 2 | 3 | n/a |
| 4. I understand my illness much better after seeing this doctor. | 0 | 1 | 2 | 3 | n/a |
| 5. This doctor was interested in me as a person and not just my illness. | 0 | 1 | 2 | 3 | n/a |
| 6. I feel I understand pretty well the doctor's plan for helping me. | 0 | 1 | 2 | 3 | n/a |
| 7. After talking with the doctor, I have a good idea of what changes to expect in my health over the next few weeks and months. | 0 | 1 | 2 | 3 | n/a |
| 8. The doctor told me to call back if I had any questions or problems. | 0 | 1 | 2 | 3 | n/a |
| 9. I felt the doctor was being honest with me. | 0 | 1 | 2 | 3 | n/a |
| 10. The doctor explained the reason why the treatment was recommended for me. | 0 | 1 | 2 | 3 | n/a |

| | Strongly Disagree | Disagree | Agree | Strongly Agree | |
|--|----------------------|----------|-------|-------------------|-----|
| Interpersonal skills | | | | | |
| 11. The doctor did not take my problems very seriously. | 0 | 1 | 2 | 3 | n/a |
| 12. The doctor did not give me all the information I thought I should have been given. | 0 | 1 | 2 | 3 | n/a |
| 13. I didn't have a chance to say everything I wanted or to ask all my questions. | 0 | 1 | 2 | 3 | n/a |
| 14. The doctor was not friendly to me. | 0 | 1 | 2 | 3 | n/a |
| 15. I would not recommend this doctor to a friend. | 0 | 1 | 2 | 3 | n/a |
| 16. The doctor seemed to brush off my questions. | 0 | 1 | 2 | 3 | n/a |
| 17. The doctor should have told me more about how to care for my condition. | 0 | 1 | 2 | 3 | n/a |
| 18. It seemed to me that the doctor wasn't really interested in my physical well-being. | 0 | 1 | 2 | 3 | n/a |
| Empathy | | | | | |
| 19. The doctor considered my individual needs when treating my condition. | 0 | 1 | 2 | 3 | n/a |
| 20. There were some things about my visit with the doctor that could have been better. | 0 | 1 | 2 | 3 | n/a |
| 21. It seemed to me that the doctor wasn't really interested in my emotional well-being. | 0 | 1 | 2 | 3 | n/a |
| 22. The doctor seemed rushed during my visit. | 0 | 1 | 2 | 3 | n/a |
| 23. The doctor should have shown more interest. | 0 | 1 | 2 | 3 | n/a |
| 24. There were aspects of my visit with the doctor that I was not very satisfied with. | 0 | 1 | 2 | 3 | n/a |

| | Strongly Disagree | Disagree | Agree | Strongly Agree | |
|---|----------------------|----------|-------|-------------------|-----|
| Quality of time | | | | | |
| 25. The doctor went straight to my medical problem without first greeting me. | 0 | 1 | 2 | 3 | n/a |
| 26. The doctor used words I did not understand. | 0 | 1 | 2 | 3 | n/a |
| 27. There wasn't enough time to tell the doctor everything I wanted. | 0 | 1 | 2 | 3 | n/a |
| 28. I feel the doctor did not spend enough time with me. | 0 | 1 | 2 | 3 | n/a |
| 29. I felt the doctor diagnosed my condition without enough information. | 0 | 1 | 2 | 3 | n/a |
| 30. Overall, I am satisfied with my doctor-patient interaction. | 0 | 1 | 2 | 3 | n/a |

SECTION 8:**Patient self-efficacy****Asked at Baseline, Post-Intervention and 1-month Follow-up**

In this section, I'm going to ask you some questions on how confident or certain you are in your ability to get or give information in your discussions with your doctor. For each question, tell me how confident you are on a scale from 1 – 5, with 1 meaning that you are not at all confident and a 5 meaning that you are very confident that you could accomplish this particular task. Your ratings should reflect the confidence you have in doing these tasks now, whether or not you have done them in the past.

| | Not at all Confident | | | | Very Confident |
|---|-------------------------|---|---|---|-------------------|
| 1. How confident are you in your ability to get a doctor to pay attention to what you have to say? | 1 | 2 | 3 | 4 | 5 |
| 2. How confident are you in your ability to know what questions to ask a doctor? | 1 | 2 | 3 | 4 | 5 |
| 3. How confident are you in your ability to get a doctor to answer all of your questions? | 1 | 2 | 3 | 4 | 5 |
| 4. How confident are you in your ability to ask a doctor questions about your main health concern? | 1 | 2 | 3 | 4 | 5 |
| 5. How confident are you in your ability to make the most of your visit with a doctor? | 1 | 2 | 3 | 4 | 5 |
| 6. How confident are you in your ability to get a doctor to take your main health concern seriously? | 1 | 2 | 3 | 4 | 5 |
| 7. How confident are you in your ability to understand what a doctor tells you? | 1 | 2 | 3 | 4 | 5 |
| 8. How confident are you in your ability to get a doctor to do something about your main health concern? | 1 | 2 | 3 | 4 | 5 |
| 9. How confident are you in your ability to explain your main health concern to a doctor? | 1 | 2 | 3 | 4 | 5 |
| 10. How confident are you in your ability to ask a doctor for more information if you don't understand what he or she said? | 1 | 2 | 3 | 4 | 5 |

SECTION 9:**Patient Trust****Asked at Baseline and 1-month Follow-up**

The next set of questions ask about your level of trust in your doctor. There are no right or wrong answers. Your response should be based on how you feel now. I'm going to read you some statements and I'd like for you to tell me if you strongly disagree, disagree, are neutral, agree or strongly agree with each statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|----------------------|----------|---------|-------|-------------------|
| 1. Your doctor will do whatever it takes to get you all the care you need. | 0 | 1 | 2 | 3 | 4 |
| 2. Sometimes your doctor cares more about what is convenient for him or her than about your medical needs. | 0 | 1 | 2 | 3 | 4 |
| 3. Your doctor's medical skills are not as good as they should be. | 0 | 1 | 2 | 3 | 4 |
| 4. Your doctor is extremely thorough and careful. | 0 | 1 | 2 | 3 | 4 |
| 5. You completely trust your doctor's decisions about which medical treatments are best for you. | 0 | 1 | 2 | 3 | 4 |
| 6. Your doctor is totally honest in telling you about all of the different treatment options available for your condition. | 0 | 1 | 2 | 3 | 4 |
| 7. Your doctor only thinks about what is best for you. | 0 | 1 | 2 | 3 | 4 |
| 8. Sometimes your doctor does not pay full attention to what you are trying to tell him or her. | 0 | 1 | 2 | 3 | 4 |
| 9. You have no worries about putting your life in your doctor's hands. | 0 | 1 | 2 | 3 | 4 |
| 10. All in all, you have complete trust in your doctor. | 0 | 1 | 2 | 3 | 4 |

SECTION 10:**Distress****Asked at Baseline and 1-month Follow-up**

For this next question, think about your level of distress. During the past week, including today, how much distress have you experienced? Rate your response on a scale from 0 to 10, with 0 being no distress and 10 being extreme distress.

Distress score _____

Interviewer: If question is unclear to responder, prompt with, “Distress is an unpleasant emotional experience, including nervousness, sadness, and worry about an area of your life.”

SECTION 11:**Illness Uncertainty****Asked at Baseline and 1-month Follow-up**

For this last section, I am going to ask you some questions on your knowledge of your cancer illness. Your response should be based on how you feel today. I'm going to read you some statements and I'd like for you to tell me if you strongly agree, agree, are undecided, disagree or strongly disagree with each statement.

[Interview: Note that the response category order has been switched below.]

| | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
|---|----------------------|----------|-----------|-------|-------------------|
| 1. I don't know what is wrong with me. | 1 | 2 | 3 | 4 | 5 |
| 2. I have a lot of questions without answers. | 1 | 2 | 3 | 4 | 5 |
| 3. I am unsure if my illness is getting better or worse. | 1 | 2 | 3 | 4 | 5 |
| 4. It is unclear how bad my symptoms will be. | 1 | 2 | 3 | 4 | 5 |
| 5. The explanation they give me about my condition seem hazy to me. | 1 | 2 | 3 | 4 | 5 |
| 6. The purpose of each treatment is clear to me. | 1 | 2 | 3 | 4 | 5 |
| 7. When I have pain, I know what this means about my condition. | 1 | 2 | 3 | 4 | 5 |
| 8. I do not know when to expect procedures will be done to me. | 1 | 2 | 3 | 4 | 5 |
| 9. My symptoms continue to change unpredictably. | 1 | 2 | 3 | 4 | 5 |
| 10. I understand everything explained to me. | 1 | 2 | 3 | 4 | 5 |
| 11. The doctors say things to me that could have many meanings. | 1 | 2 | 3 | 4 | 5 |
| 12. My treatment is too complex to figure out. | 1 | 2 | 3 | 4 | 5 |
| 13. It is difficult to know if the treatments or medications I am getting are helping. | 1 | 2 | 3 | 4 | 5 |
| 14. There are so many different types of staff; it's unclear who is responsible for what. | 1 | 2 | 3 | 4 | 5 |
| 15. Because of the unpredictability of my illness, I cannot plan for the future. | 1 | 2 | 3 | 4 | 5 |

| | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
|--|----------------------|----------|-----------|-------|-------------------|
| 16. The course of my illness keeps changing. I have good and bad days. | 1 | 2 | 3 | 4 | 5 |
| 17. It's vague to me how to manage my care while at home. | 1 | 2 | 3 | 4 | 5 |
| 18. I have been given many differing opinions about what is wrong with me. | 1 | 2 | 3 | 4 | 5 |
| 19. It is not clear what is going to happen to me. | 1 | 2 | 3 | 4 | 5 |
| 20. The results of my tests are inconsistent. | 1 | 2 | 3 | 4 | 5 |
| 21. The effectiveness of the treatment is not known | 1 | 2 | 3 | 4 | 5 |
| 22. It is difficult to determine how long it will be before I can care for myself. | 1 | 2 | 3 | 4 | 5 |
| 23. Because of the treatment, what I can do and cannot do keeps changing. | 1 | 2 | 3 | 4 | 5 |
| 24. The treatment I am receiving is known to have success. | 1 | 2 | 3 | 4 | 5 |
| 25. They have not given me a specific diagnosis. | 1 | 2 | 3 | 4 | 5 |
| 26. I can depend on the nurses to be there when I need them. | 1 | 2 | 3 | 4 | 5 |
| 27. I am aware of the seriousness of my illness. | 1 | 2 | 3 | 4 | 5 |
| 28. The doctors and nurses use everyday language so I can understand what they are saying. | 1 | 2 | 3 | 4 | 5 |

SECTION 12:
Address verification

Thank you for your time today. We will be sending you a \$15 check for this completed survey. Let me make sure we have all the correct information:

Name: _____

Street Address: _____

City, State and Zip Code: _____

Close

Thank you again. Please allow 3-4 weeks to receive your check from UAB.

Interviewer initials: _____

APPENDIX D

IRB Approval



Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on October 26, 2010. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines.

Principal Investigator: PRAYOR-PATTERSON, HEATHER M.

Co-Investigator(s):

Protocol Number: **X081009006**

Protocol Title: *Cognitive-Behavioral Intervention to Enhance Communication Skills for Recurrent Cancer Patients*

The IRB reviewed and approved the above named project on 11-30-09. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 11-30-09

Date IRB Approval Issued: 11-30-09

Marilyn Doss, M.A.
Vice Chair of the Institutional Review
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

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