

Illness Perceptions of Patients with Advanced Stage Cancer and Their Partners

Doctoral Candidate – July 2010

Statement of Purpose

The proposed research project is designed to understand how patients with advanced stage cancer and their spouses or unmarried partners make sense of and adjust to the illness experience. Specifically, we want to examine how discrepancies in illness perceptions are associated with the physical and psychological health of the patient and their partner. The proposed research brings an interpersonal perspective to Leventhal's common-sense model of self-regulation, which posits that when people are faced with an illness or health threat they form cognitive illness representations to make meaning of their experience (Leventhal et al., 1997). Illness perceptions have been found to predict important illness outcomes within individual patients coping with acute and chronic illnesses (Hagger & Orbell, 2003), but have only recently been examined from a dyadic perspective (e.g., Figueiras & Weinman, 2003). Cancer affects patients and their partners, and discrepant perceptions about cancer between patients and their partners might diminish the quality of their relationship, make adjustment to the illness more difficult, and interfere with completing important tasks related to having an advanced stage illness, such as completing an advance directive (NCI, 2005). The proposed research will examine multiple aspects of illness perceptions including beliefs about the timeline of the illness, negative consequences of the illness, controllability of the illness, integration of the illness into a sense of self, treatment preferences, and family support and communication surrounding illness management. Data will identify discrepant areas of illness perceptions that can guide future interventions to get patients and their partners on the same page about the illness and decrease the level of distress experienced by patients with advanced stage cancer and their partners.

Background and Brief Literature Review

In the United States, approximately 1,480,000 new cancer cases and 570,000 deaths from cancer are estimated to have occurred in 2009. Among women, breast and ovarian cancers are the most common diagnoses (NCCN, 2010). Advanced stage cancer (stage III and IV) is a complex health experience and patients who are diagnosed with a progressed illness often have limited treatment options and receive mixed messages or insufficient information about their prognosis (Zhang et al., 2009). Clinically significant distress including major depressive symptoms, anxiety, and role adjustment problems have been reported in 15-50% of adult patients with advanced stage cancer and their spouses (McLean & Jones, 2007). If not treated, elevated distress levels can impact the patient's quality of life, social functioning, adherence to treatment, and increase overall healthcare costs (NCCN, 2010). There is limited research that focuses on advanced stage cancer patients and the research that does exist tends to emphasize end-of-life decision making (e.g., Wright, 2008) and prognostication (e.g., Christakis & Lamont, 2000). However, patients with advanced cancer are living longer and so it is becoming increasingly important to look at long-term quality of life and psychosocial adjustment to living with a life-limiting illness (Rose et al., 2009).

The perceptions that a patient holds about their illness are a significant predictor of psychosocial outcomes above and beyond disease severity (Buick, 1997). In other words, the way that someone thinks about their illness has a bigger impact than its objective severity. Research with cancer patients has found that negative illness representations are associated with increased distress (e.g., depressed mood and anxiety; Thune-Boyle et al., 2006), less coping flexibility (Buick, 1997), and poorer quality of life (Scharloo et al., 2005). The majority of research about illness perceptions focuses on individual beliefs that a patient has about their

illness. However, cancer is not an individual experience and people often turn to their partners to determine what health care they should seek and to provide support for illness and health behaviors (Leventhal et al., 2003). Partners must adjust to the life changes brought on by the illness (e.g., increased economic burden; Feldman & Broussard, 2006) and identify the meaning of the illness for themselves and for their relationship (Germino, Fife, & Funk, 1995). We know that interventions to facilitate couples coping can be effective (e.g., Manne et al., 2005).

However, dyadic coping research also suggests that couples who have difficulty coping with a cancer diagnosis struggle to develop a common philosophy about the illness and how to approach treatment (Kayser, Watson, & Andrade, 2007).

Several research studies have suggested the importance of looking at illness perceptions in the context of a dyadic relationship. A qualitative study by Salander and Spetz (2002) found that couples dealing with the diagnosis of a brain tumor would often think about the prognosis and their information needs differently, which often resulted in decreased communication and “drifting apart”. Couples who felt that they were “on the same wave length” were able to communicate openly and focus on positive everyday life experiences (Salander & Spetz, 2002). In a study investigating discrepancies in illness perceptions of patients with myocardial infarction (MI), Figueiras and Weinman (2003) found that approximately a third of couples had conflicting illness perceptions and that these couples reported higher symptom severity and worse sexual functioning. Finally, in a study of patients with chronic illnesses and their spouses, Heijmans and colleagues (1999) found that discrepancies in illness perceptions were highly correlated with adaptive outcomes (e.g., psychological functioning and vitality) and the quality of the relationship. In this study, discrepancies were not merely a reflection of poor marital quality (i.e., people reporting satisfaction with marriage still held discrepant illness perceptions).

The proposed research has two broad aims. First, we will determine how the illness perceptions of advanced stage ovarian and breast cancer patients and their partners are independently associated with psychosocial adjustment, relationship quality, and participation in advanced illness planning behaviors, such as completing advanced directives. Second, we will examine how discrepancies between patient and partner illness perceptions are associated with psychosocial adjustment, relationship quality, and advanced illness planning behaviors. We predict that patients and partners with discrepant illness perceptions will report poorer psychosocial adjustment, lower relationship quality, and less advanced illness planning behavior.

Methods

Participants. Participants will include 150 patients with advanced stage (Stage III and IV) breast and ovarian cancer, and their spouses or unmarried partners who have been living together for at least one year. Participants will be recruited during routine outpatient oncology appointments at Baylor Medical Center, Parkland Memorial Hospital, or Simmons Cancer Center. The current study will focus on heterosexual relationships to control for gender effects when looking at the patient-caregiver relationship (Manne, 1998). Participants will be eligible if they have had cancer longer than one month and are able to read/write English.

Procedures. Recruitment will begin at the time of a routine outpatient oncology appointment. Clinic staff will introduce potential participants to a research assistant who will explain the study in more detail and conduct initial screening to verify eligibility. After agreeing to participate and providing informed consent, participants will be asked to complete a packet of questionnaires before leaving their clinic visit. Participants will also provide authorization to access medical records for basic information related to their illness (e.g., diagnosis, duration, current treatment, etc.). If partners are present at the clinic visit, they will also be asked to

participate and to complete a packet of questionnaires in a separate private location. If partners are not present at the time of the clinic appointment, then participants will be asked to provide their partner with a letter explaining the research study and asking for their involvement. Partners will be mailed a packet of questionnaires within a week after the participant's clinic appointment and provided with a return envelope and a number to contact with questions.

Illness Perceptions. Patients and their partners will complete several measures to assess their perceptions about the patient's cancer. First, they will complete the Illness Perceptions Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002). This scale was designed to measure the main components of the illness representations in Leventhal's Self-Regulatory Model (Leventhal et al., 1997). Subscales for this instrument have been found to have adequate internal reliability (alphas > 0.79; Moss-Morris et al., 2002). Additional cancer-specific items used in previous research (Buick, 1997) were included to assess areas not accounted for by the original IPQ-R (e.g., my cancer is terminal). Three additional subscales were added to assess: 1) perceptions of the partner's control over the illness, 2) centrality of the illness to the sense of self, and 3) integration of the illness into daily life. These subscales have been used successfully in research with adolescents who have type 1 diabetes and their parents (Croom et al., in press).

Patients and their partners will also complete the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF; Siminoff et al., 2008). This scale includes 18 items to assess: 1) perceptions about the family's support and communication related to illness management and 2) perceived treatment preferences. Reliability for this scale is low (alpha = 0.49), but that is because this scale is based on individual items rather than subscales. The CCAT-PF has been found to be significantly correlated with patient and caregiver outcome variables (e.g., quality of life and depression).

Quality of Life. Patients will complete two measures to assess how their cancer and its treatment have impacted their quality of life. First, the 36-item Short-Form Health Survey (SF-36) will be used to assess patient's experiences of illness and treatment side effects (Ware & Sherbourne, 1992). The usefulness of the SF-36 in estimating disease burden has been described in articles studying over 200 diseases and conditions (Tsai, Bayliss, & Ware, 1997) and has been validated for serious medical conditions, such as cancer (McHorney, Ware, & Raczek, 1993). This scale measures eight dimensions of health (e.g., bodily pain). Published reliability statistics have exceeded alphas coefficients of 0.70 in more than 25 studies (Tsai et al., 1997). Second, the Functional Assessment of Cancer Therapy General scale (FACT-G) will be used to assess specific facets of quality of life in patients with a cancer diagnosis (Cella et al., 1993; Webster, et al., 1999). This 27-item instrument assesses four primary dimensions of well-being (i.e., physical, social/family, emotional, and functional). Subscales have been shown to have alpha coefficients ranging from 0.63 to 0.89 (Cella et al., 1993; Webster et al., 1999).

Depression and Anxiety. Patients and their partners will complete the Hospital Anxiety and Depression scale (HADS; Moorey et al., 1991; Zigmond & Snaith, 1983). The HADS is a 14-item scale that assesses depression and anxiety by removing symptoms that are generally over-endorsed by medical patients (e.g., fatigue and appetite changes). A recent systematic review of assessment instruments reported that the HADS is the most extensively validated measure of distress in cancer patients and that it has adequate internal consistency (Vodermaier, Linden, & Siu, 2009). Partners will be administered the HADS as a measure of their own depression so that their scores will be comparable with the scores obtained from patients.

Relationship Quality. Patients and their partners will complete the Dyadic Adjustment Scale (DAS) to assess the perceived quality of their relationship (Spanier, 1976). The DAS is a

32-item measure that assesses four dimensions of relationship quality (e.g., satisfaction) without exclusively focusing on the context of marriage, which makes it appropriate for unmarried partners. The DAS has been extensively used in the behavioral sciences literature. Across 91 studies the internal consistency for the DAS has ranged from 0.58 to 0.96 with a mean Chronbach's alpha of 0.92 (Graham, Liu, & Jeziorski, 2006).

Perceived Efficacy. Patients and their partners will complete the Cancer Behavior Inventory (CBI), which is a 33-item instrument designed to measure perceived efficacy to manage cancer and its treatment (Merluzzi & Martinez-Sanchez, 1997). Patients will be asked to rate their level of confidence that they can accomplish different behaviors on a Likert scale from 1 (not at all confident) to 9 (totally confident). Efficacy will be assessed across six domains, such as maintaining activity and independence and coping with treatment-related side effects. Partners will be asked to complete identical items assessing their perceived efficacy to help the patient manage their cancer and its treatment. The CBI has adequate internal consistency (alphas > 0.75) and is correlated with other measures relevant to the process of coping with cancer, such as the Psychosocial Adjustment to Illness Scale (Merluzzi & Martinez-Sanchez, 1997).

Advanced Illness Planning and Decision Making Behaviors. An instrument was created for this study to assess whether or not patients engage in particular advanced illness behaviors and how they make these decisions. Items for this scale were chosen from the National Cancer Institute's booklet on coping with advanced cancer (NCI, 2005). There are nine items that assess: 1) participation in cancer specific activities (e.g., survivorship organizations), 2) preparation for medical decision making (e.g., completing an advance directive), and 3) end-of-life planning (e.g., obtained information about hospice). Patients will be asked if they have or have engaged in these behaviors and how they decided whether to do or not do these behaviors. If they have

engaged in the behavior, they will be asked to identify who helped them (e.g., partner, medical team, friends) and to appraise whether they think that the behavior was just their own, indirectly affected their partner, or was shared with their partner.

Design and Statistical Approach. A cross-sectional design will be used to assess associations with illness perceptions of advanced stage cancer patients and their partners. Control variables to be examined as potential covariates include demographic (age, income, length of relationship, education level, status of medical insurance) and illness variables (illness duration, treatment regimen) reported by participants and through medical record review. To address the first aim, hierarchical regression analyses will be used to determine which dimension(s) of illness perceptions predict variability in the outcome variables. At this stage, analyses will be completed for patient and partner reports separately and will include covariates based on preliminary analyses. To address the second aim, an index of potential adaptiveness of illness perceptions will be developed and dyads will be divided into four groups based on median splits around this index. There will be two concordant groups (i.e., patient and partner both have either high or low scores on illness perception variables) and two discordant groups (i.e., patient and partner have opposing scores on the illness perception variables). Discrepancies will be analyzed using ANOVAs to detect mean differences on outcome variables.

Human Rights, Ethical Considerations, and Informed Consent

The Institutional Review Board at _____ and
Baylor Medical Center will approve all procedures (currently pending; documentation of approval and the approved consent documents will be forwarded once approval is obtained). Additional permissions will be obtained from Parkland Memorial Hospital and Simmons Cancer Center prior to initiating data collection. Eligible patients who are interested in participating in

the study will undergo informed consent procedures as follows. Patients and their partners will be provided detailed information regarding the purpose and procedures of the study. Consent forms will be reviewed before initiating completion of the questionnaires and participants will be provided with a copy. The consent forms will discuss (1) the general overview of the questionnaires and study protocols, (2) the length of time required to complete the protocol, (3) the confidentiality of the research data within the research team, (4) the information that will be obtained through the medical records, (5) the fact that the patient's medical treatment will not be affected by their decision to participate or from withdrawal from the study, and (6) the fact that they will be reimbursed for the study (\$15 for questionnaires per participant). Patients and their partners will receive an explanation of the risks and benefits of participating in the research study and will be given as much time as needed to review the consent forms and ask questions. Once questions and concerns have been sufficiently addressed, informed consent will be documented by signatures on the consent forms and witnessed by the research assistant. Partners who choose to participate through mail will be asked to return a signed consent form with their questionnaires and will be provided with a number to contact with questions or concerns.

Time Frame of Proposed Research

The proposed study will be conducted over a two-year time frame. Data collection will begin in mid-fall of 2010 and will be completed in the fall of 2011. Data will be continuously entered and checked as they become available, facilitating analyses once data are collected. We expect that preliminary results will be produced by spring of 2012, which may be submitted for publication in summer of 2012.

Relationship to the Timberlawn Foundation's Areas of Primary Interest

The proposed research coincides with the Timberlawn Foundation's interest in

understanding connections between interpersonal relationship characteristics and psychological and physical health or dysfunction. The research will enhance our understanding of whether patients with a serious illness and their partners form a mutual understanding of the illness and its treatment at a dyadic level, and the associations of these shared understandings to adjustment.

Scientific Importance of the Project

Previous research has explored connections between illness perceptions and physical and psychological health for individuals. However, our research will be investigating illness perceptions in the context of a long-term relationship. Cancer impacts patients and their partners and both parties form independent perceptions of the illness and its treatment. Discrepancies between how patients and their partners perceive the illness are likely to impact overall adjustment to the illness and might impede the completion of important planning behaviors.

Practical or Applied Importance

We hope to better understand how psychological and physical health is connected to patients and their partners not seeing “eye-to-eye” about illness and treatment. These findings should provide important knowledge for applied psychologists (e.g., couples therapists) and health care professionals to develop interventions that facilitate coming to a mutual understanding about cancer and its treatment, which could improve psychosocial adjustment.

Detailed Budget and Justification

Description	Amount
Personnel	\$21,000
Participant incentives (150 couples x \$30 per couple = \$4,500)	\$4,500
Xeroxing	\$1,500
Mailing, office supplies, and postage	\$1,000
Total	\$28,000

Personnel. Money is requested to fund one full-time (i.e., 20 hrs/wk; \$14,000) and one half-time (10 hrs/wk; \$7,000) graduate research assistants to recruit participants and collect data. Both research assistants (RAs) will be doctoral candidates in the

Funds are requested to approximate the graduate research stipends at

Subject Reimbursement. Participants will be paid \$15 each to complete the study protocol, which will require a time commitment of approximately 30 minutes. We budgeted for 150 patient-partner dyads (300 participants total).

Xeroxing and Supplies. We request \$1,500 for Xeroxing and \$1000 to purchase necessary mailing and office supplies, including postage for mailing packets to partners who are not in attendance at the clinic visit.

Other Funding Sources. None.

Proposed Measures

All measures were selected through careful consideration of reliability and validity issues for patients with cancer. Specific information on the measures is reported in the Method section, and copies are included in the Appendix. References detailing the psychometric properties of the instruments are asterisked in the general references section.

Dissemination of Results

Results will be submitted for presentation at national conferences and for publication in peer-reviewed journals. We anticipate submitting at least two manuscripts for publication. The first will be based on the analyses of associations between patient and partner illness perceptions and psychological and physical health. The second manuscript will be based on the analyses of the predictive power of discrepancies between the dyad's illness perceptions.

Institution Verification

The principle investigator (applicant) and supervising faculty's agency is

which is a public institution as documented in the attached letter.

Individuals Responsible for the Project

The project will be led by (principle investigator, applicant) and

(supervising faculty) at (see attached CVs).

has three years experience as a research assistant and four years experience as a research coordinator. Her research experience has focused on family relationships and how these relationships contribute to learning as well as to coping with chronic illnesses. has expertise in clinical health and pediatric psychology, and has been conducting research on families coping with chronic illness for several years. The proposed research will also be conducted with the support and assistance of faculty members at participating institutions (see attached CVs). is an associate professor of Internal Medicine and

is a professor of

Gynecology at

and

is an assistant professor in the

department of Psychiatry and Clinical Sciences at

with a

primary appointment at Simmons Cancer Center.

Primary Contacts

Appendix

1. References
2. Institutional IRS Determination Letter
3. CVs and Biosketches for Principal Investigator, Supervising Faculty, and Co-Investigators
4. Self-Report Measures

References

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