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the Quality of Life of Prostate Cancer Patients and Their Spouses

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Research on prostate cancer has not, as yet, identified how patients' and their spouses' supportive (e.g., giving advice/emotional support) and non-supportive behaviors (e.g., criticizing/avoiding partner) affect and are affected by their: 1) feelings of illness uncertainty, 2) psychological well-being, and 3) quality of life (QOL). The major aims of this two a half year longitudinal questionnaire study are to address the following questions among 150 early stage prostate cancer patients and their spouses at time of diagnosis and at one, six and twelve month post-initiation of treatment: 1) does illness uncertainty and perceptions of control predict patient and spouse supportive and non-supportive behavior, QOL and psychological well-being/distress? 2) does perceived inadequacy of partner support predict non-supportive behaviors? and 3) to what extent do supportive and non-supportive behaviors mediate the relationship between illness uncertainty and QOL and illness uncertainty and psychological well-being? We have successfully recruited 186 patients and 166 spouses/partners. One preliminary result suggests that patient perceived disease uncertainty at baseline is highly negatively correlated, with the exception of role limitations, with all dimensions of quality life at the one-month follow-up.

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INTRODUCTION

Research on prostate cancer has not, as yet, identified how patients' and their spouses' supportive (e.g., giving advice/emotional support) and nonsupportive behavior (e.g., criticizing/avoiding partner) affect and are affected by their: 1) feelings of disease uncertainty, 2) psychological well-being, 3) perceptions of control, and 4) quality of life (QOL). This two year prospective observational survey study explored these issues among 186 early stage prostate cancer patients and 166 of their spouses. Specifically, early stage prostate cancer patients and their spouses were asked to complete a questionnaire packet before surgery (radical prostatectomy), and at one-, six- and twelve-months post-surgery. The questionnaire packet assessed primary perceptions of disease uncertainty, supportive and unsupportive behaviors, perceptions of control, marital satisfaction, and quality of life.

BACKGROUND AND SIGNIFICANCE

Quality of life among prostate cancer patients.

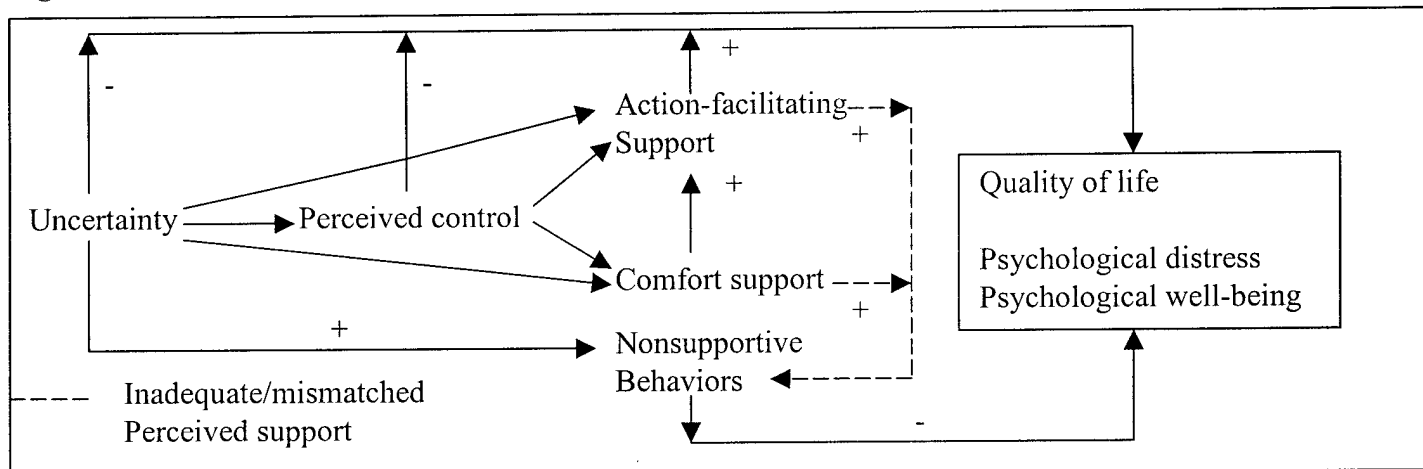
Research on QOL among prostate cancer patients has lagged significantly behind other cancer sites (1). The extant literature shows that prostate cancer patients who undergo radical prostatectomy or radiation therapy often report poorer QOL due to problems in sexual functioning (e.g., impotence) and incontinence, and a sizeable proportion also experience psychological morbidity (e.g., anxiety, depression) and reductions in social/marital functioning (2-12; for reviews, see 1,13-14).

Unlike other cancer sites, noticeably lacking are studies that examine how prostate cancer patients' QOL affects and is affected by their spouses/partners. Spouses of cancer patients often report decrements in physical and psychological well-being. Approximately 20%-30% of spouses suffer from mood-disturbances and psychological impairment (15-18), and between 25%-50% of spouses of newly diagnosed cancer patients report sleep and eating disturbances, headaches, nervousness, and inability to concentrate on work (19). Although these acute symptoms dissipate over time elevated levels, compared to controls, continue to persist as much as one year after diagnosis (16, 20-21).

Evidence from one study shows that spouses of prostate cancer patients exhibit similar physical and psychological distress. In a cross-sectional study, spouses of prostate cancer patients (N= 83) reported decreased sexual enjoyment (49%) and interest (41%), tiredness (56%), worrying (56%), tenseness (35%), sleeping problems (37%), depression (25%), and more psychological distress than the patients (7). Furthermore, spouses' psychological distress tended to predict poorer patient QOL, and patients' poorer QOL predicted significant increases in spousal psychological distress, fatigue/malaise, and overall QOL. These results show that psychological adjustment and QOL of prostate cancer patients and their spouses is an interdependent process and points to the need to research this disease as a problem facing the couple (22-27). Indeed, prostate cancer patients view the disease as a "family affair" (28) and see the spouse as a primary source of instrumental and emotional support (29); similarly, spouses also perceive the cancer patient as the primary source of emotional support (19). Thus, marital interactions play an important role in affecting: 1) stress and health among cancer patients and their spouses, 2) attributions of support, and 3) whether support is ultimately beneficial (30-32).

This proposal explored prospectively how prostate cancer patients' and spouses' levels of illness uncertainty and perceived control affected their social support needs, nonsupportive behaviors, and QOL. The theoretical framework, grounded in Mishel's (33-35) work on illness uncertainty and Cutrona's (36-37) optimal matching hypothesis of social support, is diagrammed below.

Figure 1: Theoretical Framework



The model states that patients and spouses experience different levels of illness uncertainty defined here as the "lack of a cognitive framework to understanding their situations, and an inability to predict outcomes" (38) -- the term uncertainty will heretofore refer to illness uncertainty. Whether uncertainty is viewed as threatening or as a challenge is mediated by perceptions of control (i.e., mastery). Uncertainty and more proximally perceived control predict social support needs. High levels of uncertainty and low perceived control instigate the need for comfort (i.e., emotion-focused) social support; low levels of uncertainty and high perceived control instigate action-facilitating (i.e., problem-solving) social support. Support needs that are matched (i.e., needed support is seen as forthcoming from the partner), rather than mismatched, are predicted to improve QOL and lessen psychological distress. Mismatches in support and high levels of uncertainty are predicted to increase the number and type of nonsupportive behaviors (e.g., criticizing/avoiding partner), which will negatively affect QOL and psychological well-being. The model also predicts that uncertainty and perceived control have direct and indirect effects -- through supportive and/or nonsupportive behaviors -- on QOL and psychological distress. Details of the model are now discussed.

The relationships between illness uncertainty, perceived control, and positive social support.

To date, no studies have examined, from the time of prostrate cancer diagnosis, the relationships between spouses' and patients' levels of uncertainty and perceptions of control, how these two processes affect the social support needs desired from the spouse, and ultimately QOL and psychological well-being. The diagnosis, early treatment and management of prostrate cancer may instill in the patient and spouse uncertainty about how best to cope with the side-effects of treatment (e.g., sexual dysfunctions, incontinence), worries over disease progression and recurrence, and possible changes in life goals, plans and responsibilities (39-42). If inadequately managed, uncertainty contributes to decrements in QOL and psychosocial adjustment to illness, dissatisfaction with family life, and unstable family relationships during cancer treatment (for review, see 43-45).

According to Mishel's (33) theory of illness uncertainty, whether uncertainty leads to these detrimental outcomes is partly affected by uncertainty appraisals that result in perceptions of threat or challenge. Perceptions of threat or challenge are mediated by perceptions of control (i.e., mastery) whereby higher perceived control predicts challenge appraisals and lower perceived control predicts threat appraisals (46-48). Uncertainty is viewed as a precursor to, and is negatively correlated with, control (46-48). Individuals who feel that they can manage uncertainty often resort to problem-focused coping; those who feel they cannot manage uncertainty resort to emotion-focused coping (48-51). Of import, social support can serve as a problem, as an emotion-focused coping strategy (52), and has been related to reductions in illness uncertainty (27, 44, 53-56).

These findings suggest that patients and spouses with high levels of illness uncertainty coupled with lower perceived control should need comfort support (emotional support) from the partner; those with low levels of illness uncertainty coupled with high perceived control should need action-facilitating (i.e., problem-solving) support from the partner. Thus, whether support enhances QOL and psychological well-being depends, in part, on the perception that the partner is available to provide (i.e., match) these needs. Indeed, while social support has been related to improved mental health among cancer patients (57-59), it is the perception of support availability (i.e., perceived support) rather than network size (i.e., structural support) or the receipt of support (received support) that best predicts adjustment (58, 60-62). Consistent with this view, network support does not significantly predict QOL in early or late stage prostate cancer patients (63).

The above reasoning is consistent with the stress-buffering hypothesis that suggests that social support is most beneficial to individuals during times of stress when there is a match between the needs elicited by the stressful event and the type of social support perceived to be available (64-65), and with Cutrona's optimal matching model of support (36-37). According to this model, perceptions of control determine which type of support is most needed. Events perceived by the person as controllable foster informational (e.g., advice, additional views on how to handle the problems) and tangible (e.g., provision of goods and services such as money, transportation, etc.) support needs. Events viewed as uncontrollable elicit the need for three types of support: emotional (e.g., expression of caring, concern, empathy and sympathy), network (e.g., making the person feel as part of a group with similar interests and concerns), and esteem (e.g., acknowledging the individual's worth) -- esteem support also may promote problem-solving coping by enhancing self-efficacy (e.g., making the person feel competent). Thus, findings from the uncertainty literature blend nicely with the stress buffering and optimal matching hypotheses to predict the nature of support needed and provided by couples in the context of prostate cancer.

Relationships between uncertainty, nonsupportive behaviors and QOL and psychological well-being.

This study will be the first to examine prospectively: 1) how prostate cancer patients' and spouses' levels of illness uncertainty and appraisals of support availability affect nonsupportive behaviors (e.g., criticizing/avoiding partner) and 2) whether nonsupportive rather than supportive behaviors are a more powerful mediator between levels of uncertainty and QOL and between uncertainty and psychological well-being. The scant literature suggests that nonsupportive behaviors have a relatively greater detrimental effect on interpersonal functioning (66), psychological distress and well-being (67-71) than supportive behaviors. For example, nonsupportive behaviors from spouses accounted for 16%-20% of the variance in predicting cancer patients' psychological distress; supportive behaviors accounted for 2%-4% of the variance (67). Dow (63) found that patients with localized prostate cancer felt severe distress at not receiving adequate care from their partners, suggesting that nonsupportive behaviors between patients and spouses merit closer scrutiny. Thus, nonsupportive behaviors are critical to study because they: 1) affect more profoundly well-being, perhaps in more domains than supportive behaviors and 2) represent relatively distinct interpersonal processes (69, 71-73).

Studies using cancer patients provide glimpses into the types of nonsupportive behaviors that transpire between a patient and spouse (74-77). Common complaints from patients about spouses and friends include the minimization of their illness and its consequences, forced cheerfulness, and physical avoidance (74). These behaviors may be viewed as failures to provide emotional support by disallowing the patient to discuss personal issues surrounding the disease (58). Among cancer patients, the ability to self-disclose is viewed as a central element of perceived emotional support, and a number of prostate cancer patients report problems in communicating personal issues surrounding the disease with family and friends (8, 63). This is unfortunate since the ability of men to share their experiences about prostate cancer has been shown to alleviate anxiety, provide reassurance, enhance coping, and provide a more positive outlook (28, 78).

The proposed theoretical model suggests that uncertainty and inadequacies in perceived partner support, especially in the areas most needed, will increase the number and types of nonsupportive behaviors. Individuals

distracted by their own uncertainties may be less attentive to their partners needs, which over time, are likely to solidify perceptions of inadequate partner support. Interestingly, dissatisfaction in network support increases feelings of uncertainty (79) which: 1) enhances one's feelings of being poorly integrated into a social network (54) and 2) may diminish interest in obtaining social support (80). In addition to uncertainty, interpersonal processes that contribute to perceived inadequacies in partner social support (e.g., poor communication, marital conflict) may also be symptoms that contribute to nonsupportive behaviors (81). As Coyne and Downey argue, "low support may signify the presence of a negative, conflictual relationship" (82). Over time, nonsupportive behaviors may further erode perceptions of positive partner support. In sum, some evidence exists to support the model's hypothesized relationships between illness uncertainty, perceived inadequacies in partner support, and nonsupportive behaviors.

Hypothesis/purpose

As outlined in Figure 1, this study tested the following main predictions, which unless otherwise specified, apply equally to patients and their spouses:

H1: Greater levels of illness uncertainty among prostate cancer patients and their spouses will predict significantly lower perceptions of perceived control (i.e., mastery).

H2: Patients and spouses with low levels of uncertainty and/or high perceived control will need primarily informational and instrumental support; individuals with high levels of illness uncertainty and/or low perceived control will need emotional, network and esteem support. However, given the premium that cancer patients place on emotional support from their spouses (58), it is hypothesized that illness uncertainty and perceived control will be less important in predicting the need for emotional, network and esteem support (i.e., comfort support) than in predicting informational and instrumental support (i.e., action-facilitating support).

H3: Greater illness uncertainty and perceived inadequacies in social support, especially in areas most needed, will correlate positively with frequency and types of nonsupportive behaviors. However, perceived inadequacies in emotional social support will most strongly predict nonsupportive behaviors compared to inadequacies in information/tangible support.

H4: Social support and nonsupportive behaviors will mediate the relationship between illness uncertainty and QOL and between illness uncertainty and psychological well-being.

Corollary A: Patients and spouses who perceive their partners as being available rather than unavailable to provide for their needs will have high QOL (especially in the social/emotional domains) and psychological well-being scores.

Corollary B: Partner's nonsupportive behaviors will more powerfully predict QOL and psychological well-being than appraisal of partner's support. Thus, nonsupportive behaviors will be a more powerful mediator between uncertainty, QOL and psychological well-being than supportive behaviors.

H5: Higher levels of uncertainty and lower perceived control will predict poorer QOL and psychological well-being especially in the short-term -- up to 6 months post-treatment. However, as individuals adapt to living with uncertainty, uncertainty will be weakly or positively related to QOL and psychological well-being.

H6: Spouses will experience poorer QOL and psychological well-being than patients, and these variables will be moderately correlated (.30 to .40) between patients and spouses across time.

Technical Objectives

The aims of the proposal are to examine the following processes at time of diagnosis and at one-, six- and twelve-months post-initiation of treatment:

- I. To examine relationships between prostate cancer patients' and spouses' levels of uncertainty, perceived control, support and nonsupportive behaviors, QOL and psychological well-being.

- II. To examine how well patients' and spouses' levels of illness uncertainty and perceptions of control predict their social support needs.
- III. To examine the extent to which levels of illness uncertainty and matches/mismatches in social support predict nonsupportive behaviors.
- IV. To examine the extent to which supportive and nonsupportive behaviors affect QOL and psychological well-being among prostate cancer patients and their spouses, and whether these behaviors mediate the relationship between uncertainty and QOL and between uncertainty and psychological well-being.
- V. To assess over a year, stability and change in levels of illness uncertainty, perceived control, supportive and nonsupportive behaviors among prostate cancer patients and their spouses, and to examine whether stability and change affects QOL and psychological well-being.

BODY

Task 1: Plan and develop a tracking system with the Duke Department of Urology to recruit study participants.

Early stage (i.e., 1&2) prostate cancer patients, who were yet to undergo treatment (i.e., radical prostatectomy) at Duke University Medical Center, were identified by a research assistant through urologists' medical appointment calendars. Once identified, the research assistant obtained prior approval from the specific urologist to discuss the upcoming study. All urologists in the Duke Clinic gave permission to approach their patients and spouses/partners. Upon gaining approval, the research assistant, when at all possible, contacted the patient by phone up to a week in advance of their scheduled appointment and explained the purpose of the study and the possibility of having to complete a 30 to 45 minute questionnaire during the clinic visit. Permission was also asked of the patient to contact his spouse/partner to provide an explanation of the study. In the further discussion, the term "partner" will be used to represent both spouses and persons deemed not married, yet significantly associated with the patient.

Eligibility of the patients was determined by the following inclusion criteria: 1) spoke English, 2) were literate, 3) had early-stage biopsy-proven prostate cancer diagnosed within the preceding year, 4) chose as a treatment option radical prostatectomy or watchful waiting at DUMC, 5) were mentally competent and capable of understanding the questionnaire and consent form, 6) had no psychiatric illness that interfered with answering the questionnaire, and 7) had no evidence of other primary malignancies for at least 5 years prior, excluding basal cell carcinoma.

At the time of the patients clinic visit or after having made the decision to undergo surgery, patients and their partners were asked to read and sign the study consent form and to complete a 30 to 45 minute baseline question independently at the clinic (see measures below). However, several patients and their partners opted to complete the questionnaire at home either when they were approached at the clinic or when contacted by phone prior to their visit. When this occurred, the research assistant gave or mailed to them the questionnaire in a self-addressed stamped envelope, along with a copy of the written consent form. Specific instructions included that they complete the questionnaire without getting help from, or sharing their answers with, their partner. In addition, they were informed that their completed questionnaire and signed consent form needed to be returned prior to surgery. The same battery of questions was distributed to patients and partners at one-, six- and twelve-months post-surgery. If the questionnaire was not received a week after the one-, six-, and twelve-month post-surgery date, the research assistant contacted the patient and/or partner as a reminder to complete the questionnaire. Participants were paid \$10 for each questionnaire that they completed.

This system of recruitment was highly successful. We were able to recruit 80% of eligible, newly-diagnosed, early-stage prostate cancer patients from the Duke Urology Clinic. A total of 331 patients were tracked through our recruitment system. The recruitment took place over two time periods: October 1998

through November of 1999 and June to November, 2000. The second recruitment period was added after the approval of our one-year, no-cost extension and enabled us to more closely complete our recruitment goals. Of these 331 patients: 99 were ineligible (72 chose treatment other than surgery, 11 had a diagnoses of another cancer within less than five years, 5 were mentally incompetent, and 11 were due to extenuating circumstances (i.e. surgical complications, recurrent prostate cancer, etc.). A total of 232 eligible patients were contact about the study. Of these 232, 22 refused to participate, 24 gave verbal agreement but never sent back their questionnaire after all reasonable efforts were made, and 186 were enrolled in the study. A total of 169 eligible partners were identified during recruitment. Of these eligible partners, 3 refused or did not return either the baseline or any follow-up questionnaire and 166 are enrolled in the study.

Task 2: Develop and test study questionnaire with 10 prostate cancer patients and their spouses.

The baseline questionnaire was developed by the research team and pilot tested in Duke's Urology Clinic. The pilot test determined that the questionnaire was readable, understandable and included the measures needed to complete the study.

Elements of the baseline questionnaire included gathering information on demographics (age, sex, education, etc.), perceived health (excellent, good, fair, poor), and preexisting illnesses. Stage of illness and treatment information were obtained by the research assistant from the patients' medical records. Except where otherwise noted, patients and partners completed the following, mostly standardized, measures during the baseline and at each follow-up time point. Copies of the questionnaires for patient and partner at each time point are included in Appendix A - D. For purposes of analyses, a participant was deemed to have a nonmissing response to a standardized scale if she or he completed at least 80% of all scale items.

Illness Uncertainty: Patients completed the 33-item version of Mishel Uncertainty in Illness Scale (83) which provides a total score based on four domains of uncertainty: ambiguity concerning the state of the illness, complexity concerning treatment and system of care, inconsistency concerning information, and unpredictability of the course of illness and outcomes. Alphas for the total scale score and subscales range from .67 to .90 (84). Partners completed the analogous 31-item uncertainty scale for family members. Alphas for the total scale score and subscales range from .66 to .89 (84). For purposes of this report, higher numbers represent less illness uncertainty.

Perception of Control: was assessed by the eight-item Balanced Mastery Scale (85). Alpha for this scale is .67. This scale is an improved version of Pearlin and Schooler's (86) mastery scale that has been used to test assumptions of Mishel's uncertainty model of illness (46, 47). Participants were asked to respond to the eight-item scale by considering how the experience of prostate cancer has affected perceptions of control in their lives.

Social Support: The shortened, 10-item version of the 24-item spouse version of the Social Provisions Scale was used to assess satisfaction with perceived social support (87). This scale measures two categories of support: action-facilitating and comfort support. Action-facilitating support includes guidance (providing advice and information) and reliable alliance (the assurance that others can be counted on for tangible assistance). Comfort support consists of attachment (the emotional closeness from which one derives a sense of security), social integration (sense of belonging to a group that shares similar interests, concerns, and recreational activities) and reassurance of worth (making the person feel worthwhile, competent). Alphas for the subscales range from .64 to .86 with an overall scale alpha of .92 (87). The scale has been used across diverse samples including married couples (87-88). Higher scores represent greater perceived support.

Nonsupportive Behaviors: A 13-item scale by Manne and colleagues assessed overtly negative (e.g., shouts or yells at you) and withdrawal/avoidant responses among cancer patients and their spouses (67). Thus, this scale measured how nonsupportively the individual in question acted towards the other. Alphas for the

subscales are .77 and .82 for the criticism and avoidance subscales, respectively (67). Higher scores represent acting in more nonsupportive ways.

Quality of Life: General health-related QOL was assessed with the Rand 36-item Health Survey 1.0 SF-36 (89). This scale measures QOL in eight domains: physical and emotional role constraints, emotional well-being, social well-being, fatigue/energy, perceived pain, and general perceived health. In addition, the eight domains can be combined to create two summary standardized scores reflecting physical and mental well-being. All the scales are scored separately from 0 to 100, with a higher score representing better QOL. Overall, the SF-36 has been shown to be very reliable with a test-retest of .78 or greater and alphas between .78 and .93 in various populations (9, 89). Both the patient and partner completed the entire global QOL measures. In addition, the patient completed a measure on prostate specific QOL using the 20-item University of California Los Angeles Prostate Cancer Index (90). This scale measures three domains related prostate cancer: urinary, bowel and sexual functioning. The urinary, bowel and sexual function scales focus on incontinence, proctitis, and sexual difficulties. The scales are scored from 0 to 100, with a higher score representing a better outcome. Test retest of the scale ranges from .77 and greater and has an alpha from .65 to .93 in populations of men with and without prostate cancer (9, 90-92).

Of note, for purposes of this report, since we were interested in being able to assess how uncertainty, perceptions of control and social support affected similar QOL outcomes, in line with the main predictions, we only report mean changes in specific prostate cancer of life domains. A more in-depth assessment of relations with prostate specific QOL will be forthcoming in future publications.

Marital satisfaction: Participants with a partner completed the six-item Marital Quality Index (93). Alphas for this scale range from .72 to .86. This scale is regarded as an excellent measure of marital satisfaction (94). This was assessed at all time points. Since none of the main predictions included marital satisfaction, it will not be discussed further.

Task 3: Mail out study questionnaires to 150 prostate cancer patients and their spouses along with reminder notices and phone calls.

A total of 186 patients and 166 partners were recruited and enrolled over the course of the study. Of the patients, 169 had an eligible partner; 17 had no significant other but were still enrolled in the study. The partners consisted of 165 women and one man. The baseline questionnaire was completed by 179 patients and 156 partners and resulted in 154 dyads at baseline. Seven patients and 10 partners were enrolled in the study at the one-month time point instead of at baseline. This was due to the fact that they did not have time to complete the baseline before the patients' surgery but were still very interested in participating in the study. One of the greatest factors affecting the rate of retention from baseline to the one-month follow-up came as a result of the post-surgical pathology reports which revealed the patient's prostate cancer to be in a more advanced stage of the disease (e.g. T3 or T4). As a result, 33 patients (18%) and 28 partners (18%) were not eligible to participate in the follow-up portion of this study; however, all data from their baseline questionnaire was used because they were completed under the clinical diagnosis of early stage cancer. The one-, six- and twelve-month post-surgical surveys were completed by 132, 128, and 129 patients, respectively. The one-, six- and twelve-month post-surgical surveys were completed by 121, 115, and 113 partners, respectively. The retention rate at the one-month time point was 87% for patients and 85% for partners. These numbers were calculated after first removing the number of subjects that were no longer qualified or refused post-baseline and those that were enrolled at the one-month time point. The retention rate for the patients who qualified to participate post-baseline was 90% and 91% at the six- and twelve-month time points, respectively. For partners the retention rate was 90% and 90% at the six- and twelve-month time points, respectively. A total of 113 patients and 99 partners completed questionnaires at all 4 time points, resulting in complete data collection on 98 dyads. (See Table 1 for demographic information on study participants)

Task 4 - 7: Conduct analyses on baseline and the one-, six-, and twelve-month data.

Data analysis is ongoing for all time points. What follows is a comprehensive discussion of the research findings and accomplishments along with tables representing these findings.

Demographic Information

The baseline demographic information is presented in Table 1 for all patients and partners that completed a baseline questionnaire – note, these data include 10 patients and partners who did not complete the baseline questionnaire but completed the one-month questionnaire. In addition, baseline data for all the patients and partners who completed all four waves of data collection are also presented in Table 1. In general, the sample was primarily white and well-educated, at least half graduated from college. The age range for patients and partners was 43 to 81 and 44 to 80, respectively.

Descriptive Statistics

Table 2 presents the means and alphas for the main measures to be discussed for patients and partner who completed all four waves of data, respectively. Overall, across all four time points, the alphas for the measures had adequate levels of internal consistency (i.e., cronbach's alpha). Moreover, as discussed below, there were significant changes across measures and time points within and between patients and partners.

Changes in Measures within Patients and Partners across Time

As shown in Table 2, patients and partners had significant changes across time and measures. We discuss these changes within specific domains.

Illness uncertainty: Both patients and partners reported the most amount of uncertainty prior to surgery – note, in the table, higher numbers represent greater certainty. The degree of uncertainty decreased significantly across all time periods, with both patients and partners expressing the most certainty at twelve-months post-surgery.

Perceived control (mastery): For patients, perceptions of control were highest at twelve-months post-surgery and least at one-month post-surgery. Perceived control was roughly the same at baseline and at six-months post-surgery, and these levels were significantly lower than at twelve-months post-surgery but higher than at one-month post-surgery. For partners, perceived control was lowest at one-month post-surgery and significantly lower than at any other time point. Perceived control did not differ between baseline, six- and twelve-months post-surgery.

Social support: For patients and partners, overall perceived social support and its subcomponents, action-facilitating and comfort support, varied across time points. Patients viewed their partner as providing equal amounts of comfort, action-facilitating and overall support pre- and one-month post-surgery, that were significantly higher than the support levels perceived at six- and twelve-months post-surgery. Perceived comfort, action-facilitating and overall support did not differ between the six- and twelve-months post-surgery.

Partners exhibited a different pattern of results. Partners perceived the patient as providing the most overall support prior to surgery than at any other time point, which did not differ from each other. This same pattern held for comfort support. Partners viewed the patient as providing the least amount of action-facilitating support at one-month post-surgery relative to six- and twelve-months post-surgery and prior to surgery. In addition, partners viewed the patient as providing more action-facilitating support prior to surgery than at six- and twelve-months post-surgery, which did not differ.

Nonsupportive behaviors: Patients acted in more nonsupportive ways towards the partner at six- and twelve-months post-surgery than prior to surgery and one-month post-surgery. The degree of nonsupportive

behaviors did not differ between pre- and one-month post-surgery; nor did it differ between six- and twelve-months post-surgery. Patients exhibited the least amount of avoidant behavior prior to surgery that at any other time. Furthermore, they were less avoidant of the partner at one-month post-surgery than at six-months post-surgery. Patients' level of avoidant behaviors did not differ between six- and twelve-months post-surgery.

Partners had a more complex pattern of non-supportive behaviors. Overall, they behaved in the least nonsupportive fashions prior to surgery relative to any other time point. Further, they behaved in less nonsupportive ways one-month post-surgery than at six- and twelve-months post-surgery, which did not differ. Partners acted the least avoidant towards the patient prior to surgery than at any other time point. They also acted less avoidant towards the patient at one-month post-surgery than at six- and twelve-months post-surgery, which did not differ. Lastly, partners acted the least critically toward the patient prior to surgery than at any other time point, which did not differ.

QOL: Patients exhibited changes in all domains of QOL except two: emotional well-being and perceived general health. With the exception of perceived pain, the pattern of results was consistent throughout the remaining five domains. Patients reported the poorest physical functioning, role limitations due to physical and emotional reasons, less energy/more fatigue, and exhibited poorer social functioning at one-month post-surgery than at any other time point. These domains reverted back to their pre-surgical levels by six-months post-surgery and remained at the same pre-surgical levels at twelve-months post-surgery. With respect to pain perceptions, the same pattern was followed as the other domains except that improvement in pain perception reverted back to pre-surgical levels at twelve-months post-surgery rather than at six-months post-surgery.

Partners reported changes in QOL in two domains only: role limitations due to emotional reasons and social functioning. Partners reported a greater inability to perform various roles at one-month post-surgery than at six- and twelve-months post-surgery, which did not differ. However, role limitations reverted back to their improved pre-surgical levels by six-months post-surgery. Partners also reported poorer levels of social functioning at one-month post-baseline than at any other time point. Improved levels of social functioning reverted back to their pre-surgical levels by six-months post-surgery. No other effects were found.

Changes in Measures between Patients and Partners across Time

There were significant mean differences among dyads who completed all time points across the majority of constructs (see Table 3). The differences are reported for each domain below.

Illness uncertainty: Patients reported less uncertainty than partners across all time points.

Perceptions of control: Patients perceived less support than partners at the one-month time-point only. Levels of perceived control were similar across all other time points.

Social support: Patients viewed the partner as providing more action-facilitating, comfort and overall support at one-month post-surgery than partners' perceptions of patient support. This pattern continued to be maintained throughout the six- and twelve-month assessment points.

Nonsupportive behaviors: Prior to surgery, patients acted more avoidant, critical and nonsupportive towards the partner than the partner acted towards the patient. This pattern continued to be maintained for avoidant and overall nonsupportive behaviors throughout the remaining assessment points.

QOL: In general, patients reported better QOL than partners in all domains, other than general perceived health, at one-month post-surgery. Otherwise, patients reported better QOL. Specifically, patients reported better physical functioning, more energy/less fatigue, and emotional well-being than the partner prior to surgery and at six- and twelve-months post-surgery – with the reverse pattern at one-month post-surgery. In addition, patients reported better social function at twelve-months post-baseline than the partner. No other significant differences were found.

Prostate-specific QOL: Patients' reports of incontinence and sexual dysfunction (e.g., erectile) were poorest at one-month post-surgery and improved significantly at each assessment. However, they never reverted

back to their pre-surgical levels. Dysfunctions of the bowel followed a similar pattern, except that by twelve-months post-surgical, QOL in this domain reverted back to its higher pre-surgical level.

Tests of the Major Hypotheses

I. *What is the relationship between illness uncertainty and control?* Hypothesis 1 predicts that greater levels of illness uncertainty among prostate cancer patients and their partners will predict significantly lower perceptions of perceived control (i.e., mastery). The correlations between uncertainty and control for patients and partner and the relationships (i.e., Spearman correlations) among these constructs within patients and partners are presented in Tables 4 and 5, respectively. The prediction was strongly supported in both patients and partners. For patients and partners, less perceived illness uncertainty was significantly related to greater perceived control on all occasions (i.e., 16 out of 16 correlations were significant). Overall, greater levels of certainty were strongly related to greater perceived control.

As additional analyses, we inspected how uncertainty and control correlated within dyads. The Spearman correlations are presented in Tables 6 and 7. Patients reported less illness uncertainty if their partner felt more in control (13 out 16 correlations significant), with the same pattern holding for partners. In sum, in cross-sectional and prospective analyses, less illness uncertainty was associated with greater feelings of control within patients, partners and dyads. In general, patients and partners reported less illness uncertainty if their counterpart also reported less uncertainty (14 out of 16 correlations significant); the same pattern held for perceived control (15 out of 16 correlations significant).

II. *How do uncertainty and control individually and jointly affect perceptions of social support?* Hypothesis 2 predicts that patients and partners with low levels of uncertainty and/or high perceived control will need primarily informational and instrumental support (i.e., action facilitating support); individuals with high levels of illness uncertainty and/or low perceived control will need emotional support (i.e., comfort support). Further, it is hypothesized that illness uncertainty and perceived control will be less important in predicting the need for comfort support than in predicting the need for action-facilitating support. Thus, these hypotheses tested how control and uncertainty interact to predict forms of perceived support. As before, these predictions hold for patients and partners separately and not for the dyad.

To initially test this relationship, we divided the Social Provisions Scale into two categories of support: action-facilitating and comfort support (see measures section under task 2). Spearman correlations were then computed between the subscales of the Social Provision Scale, overall perceived support, perceived control and uncertainty. Overall, for patients, greater perceived certainty was related consistently, cross-sectionally and prospectively to perceiving the partner as providing more action-facilitating support (14 out of 16 correlations significant) and comfort support (15 out of 16 correlations significant) (see Table 8). For partners, greater perceived certainty was related consistently, cross-sectionally and prospectively, to viewing the patient as providing more action-facilitating support (14 out of 16 correlations significant) and comfort support (15 out of 16/16 correlations significant) (see Table 9).

Similarly, albeit weaker and less consistent, relations were found between perceived control domains of support. For patients, greater control was related to viewing the partner as providing more action-facilitating (11 out of 16 correlations significant) and comfort support (10 out of 16 correlations significant) (See Table 8). Among partners, those who perceived themselves as having more control viewed the patient as providing more action-facilitating support (8 out of 16 correlations significant) and comfort support (6 out of 16 correlations significant) (See Table 9). Thus, the relation between control and support was shown to be more consistent among patients than partners and certainly less consistent than perceptions of illness uncertainty.

In addition, Spearman correlations were computed between patients' perceptions of partner support and partners' perceived illness uncertainty and control. The same correlations were computed between partners' perceptions of patient support and patients' perceived illness uncertainty and control. Overall, patients viewed

the partner as providing more action-facilitating (13/16 correlations significant) and comfort support (12/16 correlations significant) when the partner expressed less illness uncertainty (see Table 10). Similarly, partners viewed the patient as providing more action-facilitating (11/16 correlations significant) and comfort support (13/16 correlations significant) when the patient expressed less illness uncertainty (see Table 11). Further, patients viewed the partner as providing more action-facilitating (11/16 correlations significant) and comfort support (10/16 correlations significant) when the partner felt greater control (see Table 10). Conversely, partners' perceptions of patient support in either domain were not significantly and consistently related to patients' control (1/16 and 5/16 correlations significant for action-facilitating and comfort support, respectively, see Table 11). In sum, patients'/partners' perceptions of support was more consistently related to the counterpart's illness perceptions.

To fully test the hypothesis, we ran regression models for patients and partners predicting at each time point action-facilitating and comfort support from the main effects of perceived control, uncertainty, and their interactions. In none of these models for either patients or partners did perceptions of control interact with uncertainty to affect action-facilitating or comfort support. Hence a new series of regression models were run predicting action-facilitating and comfort support separately from only the main effects of control and illness uncertainty in cross-sectional and prospective analyses. In the cross-sectional analyses, control and uncertainty were used to predict domain of support during the same assessment time point. In the prospective analyses, we used prior control and uncertainty scores to predict domains of support during only the subsequent assessment. In all these models, we controlled for prior type of support (e.g., controlling for baseline comfort support when predicting one-month comfort support). The results of the regression analyses for patients and partners are reported below.

Regression results for patients: Across all time points, less illness uncertainty was related to perceiving the partner as providing more action-facilitating support (betas = .34, .21, .41, and .32, $ps < .04$ for baseline to twelve-month, respectively) and comfort support (betas = .29, .30, .35, .35 for baseline to twelve-month, respectively). In addition, patients who reported less illness uncertainty at six-months post-surgery perceived their partner as providing more action-facilitating support at twelve-months post-surgery only (beta = .29, $p < .05$). In all these models, prior levels of support predicted subsequent support.

Regression analyses for partners: For partners, in cross-sectional analyses, less perceived illness uncertainty was related to viewing the patient as providing more action-facilitating support across all time points (betas = .31, .44, .77, and .93, $ps < .05$ for baseline to twelve-month, respectively). Similarly, with the exception at baseline, less perceived illness uncertainty was related to seeing the patient as providing more comfort support (betas = .22, .66, .69, .78, for baseline to twelve-month, respectively; $ps < .0001$ except for baseline, which was nonsignificant). In addition, partners who reported less illness uncertainty at six-months post-surgery viewed the patient at twelve-month as providing more action-facilitating support (beta = .23, $p < .05$) and comfort support (beta = .32, $p < .001$). Interestingly, those partners who felt in greater control at six-month perceived the patient as providing less comfort support at twelve-months post-surgery (beta = -.20, $p < .01$). In all these models, prior levels of support predicted subsequent support.

Regression analyses for dyads: As a set of exploratory analyses, we regressed patients' perceptions of partner action-facilitating and comfort support onto partner perceived illness uncertainty and control. The same analyses were conducted regressing partners' perceptions of patient action-facilitating and comfort support onto patient perceived illness uncertainty and control. In these models, we controlled for patients'/partners' prior levels of action-facilitating and comfort support.

For patients, only two significant effects were found. In cross-sectional analyses, patients with a partner who had greater feelings of control prior to surgery viewed the partner as providing more action-facilitating (beta = .26, $p < .01$) and comfort support (beta = .27, $p < .05$). For partners, those who had a patient who expressed less illness uncertainty at one-month post-surgery viewed the patient as providing more action-facilitating (beta = .23, $p < .05$) and comfort support (beta = .26, $p < .05$). No other effects were found for control or uncertainty.

In sum, there was no evidence to support the prediction that uncertainty and control interact to affect the type of perceived social support needed. In the bivariate correlations, uncertainty, rather than control, was more strongly associated with both types of perceived support. This was further confirmed in the cross-sectional multivariate analyses. Furthermore, inspection of the beta weights did not indicate consistently that uncertainty, or control, would have a stronger relationship with comfort than with action-facilitating support. Inspection within dyads revealed no support in the multivariate analyses that patients'/partners' perceptions of social support was influenced by the counterpart's perceptions of illness uncertainty or control while controlling for previous levels of support. However, there was some support in the bivariate analyses for these associations.

III. *Do uncertainty and perceived social support affect nonsupportive behaviors?* Hypothesis 3 predicts that greater illness uncertainty and perceived inadequacies in social support, especially in areas most needed, will correlate positively with frequency and types of nonsupportive behaviors (ie. critical and avoidant behaviors). However, perceived inadequacies in emotional social support will most strongly predict nonsupportive behaviors compared to inadequacies in information/tangible support. Note that these predictions hold for patients and partners separately and not as a dyad. We first computed Spearman correlations between uncertainty, action-facilitating and comfort support, and avoidant and critical behaviors.

With respect to the relationship between uncertainty and avoidant behaviors, out of 16 possible correlations, 13 were significant within patients and 14 were significant within partners (see Tables 12 and 13). Similarly, for relations with critical behaviors, 13 were significant within patients and eight were significant within partners (see Tables 12 and 13). In general, the more certainty the patient and partner expressed, the less likely they were to behave in a critical or avoidant manner towards the partner or patient, respectively. However, the overall pattern of relationships suggested that uncertainty was related more consistently with critical behaviors among patients than among partners.

In addition, we examined the extent to which patients'/partners' critical and avoidant behaviors correlated with the counterpart's illness uncertainty. In general, patients were less likely to act avoidant (12/16 correlations significant) and critical (11/16 correlations significant) towards the partner if the partner expressed less illness uncertainty (see Table 14). Similarly, partners also tended to be less avoidant of the patient (10/16 correlations significant) if the patient expressed less illness uncertainty. However, unlike patients, the association between partners' critical behaviors were largely unrelated to patients' uncertainty (3/16 correlations significant) (see Table 15). Thus, patients'/partners' avoidant behaviors were more consistently related to the counterpart's illness uncertainty.

Perceptions of social support were consistently and significantly related to nonsupportive behaviors across time points for patients and partners. The prediction holds that comfort, rather than action-facilitating, support should correlate more powerfully and consistently with nonsupportive behaviors. Across assessment points, patients who viewed the partner as providing more action-facilitating, comfort and overall support behaved less avoidantly and critically towards the partner (i.e., 143 out of 144 correlations were significant, see Table 16). Partners exhibited an almost identical pattern of correlations (see Table 17). Thus, there was no support that comfort support would correlate more consistently with nonsupportive behaviors. Noteworthy, while all the correlations between support and nonsupportive behaviors were negative, as expected, the magnitude of the correlations did not suggest that the perceptions of social support are the exact opposite of acting nonsupportively. Indeed, for patients, the most amount of shared variance between social support (e.g., comfort) and nonsupportive behaviors (e.g., avoidance) was 46%. For partners, the most amount of shared variance between social support (e.g., comfort) and nonsupportive behaviors (e.g., avoidance) was 42%.

In addition, we examined the extent to which patients'/partners' overall and domains of social support correlated with the counterpart's critical and avoidant behaviors. In general, across all time points, patients who had a partner who viewed them as providing more action-facilitating, comfort and overall support were less likely to act avoidant and critical towards the partner (all 144 correlations significant) (see Table 18). Similarly,

partners who had a patient that perceived them as providing more action-facilitating, comfort and overall support were less likely to act avoidant towards the partners throughout (43/48 correlations significant) and critical towards the patient after the surgery (35/48 correlations significant) (See Table 19). In sum, both patients and partners were less likely to act avoidantly and critically towards their counterpart if the counterpart viewed them as providing more support.

A series of regression analyses was performed to ascertain whether domains of nonsupportive behaviors were predicted jointly by uncertainty and domains of support within patients and partners only and then within dyads. In the initial analyses, patients' baseline, one-, six- and twelve-month critical and avoidant behaviors were regressed onto patients' perceived illness uncertainty, action-facilitating and comfort support at the same corresponding time point (i.e., cross-sectional analyses). In a separate series of analyses, we regressed patients' one-, six- and twelve-month critical and avoidant behaviors onto patients' perceived illness uncertainty, action-facilitating and comfort support from the previous assessment only (i.e., prospective analyses) (the argument being that if the relations do not hold for the next proximal time point, they are not likely to be seen readily at a more distant time point). In both the cross-sectional and prospective analyses, patients' previous critical and avoidant behaviors were used as covariates (e.g., controlling for one-month avoidant behaviors while predicting six-month avoidant behaviors). A similar set of analyses was conducted for partners (i.e., predicting outcomes from patients' reports). We report below the regression results first for patients than for partners.

Regression results for patients: As shown in Table 20, there were inconsistent findings between patient avoidant behaviors and uncertainty and domains of support. In the cross-sectional analyses, patients who perceived the partner as providing more comfort support reported less avoidant behaviors prior to surgery and at six-months post-surgery. Furthermore, patients who reported less illness uncertainty at twelve-months post-surgery were less likely to avoid their partner. In the prospective analyses, patients who perceived their partner as providing more comfort support at one-month post-surgery were less avoidant of their partner at six-months post-surgery, while those who reported less illness uncertainty at six-months post-surgery were less avoidant of their partner at twelve-months post-surgery. In all cases, prior avoidant behaviors served as a significant covariate.

The results for predicting critical behaviors were more consistent (see Table 21). In cross-sectional analyses, patients who perceived their partner as providing more comfort support prior to surgery and at one- and six-months post-surgery were less likely to act critically towards their partner. In addition, patients who perceived their partner as providing more comfort support prior to surgery were less likely to act critically towards their partner at one-month post-surgery only. In all cases, prior critical behaviors served as a significant covariate.

Regression results for partners: Partners' avoidant behaviors were related rather consistently with perceptions of patient comfort support (see Table 22). Specifically, prior to surgery and at one- and twelve-months post-surgery, partners who perceived the patient as providing more comfort support were less avoidant of the patient. Moreover, greater perceptions of patient-provided comfort support at six-month predicted less avoidant behaviors at twelve-months post-surgery. In addition, partners who viewed the patient as providing more action-facilitating support at six-months reported being less avoidant of the patient during the same period. Perceived action-facilitating support at one-month predicted less avoidant behaviors at six-months post-surgery only. In all cases, prior avoidant behaviors served as a significant covariate.

A similar pattern of findings held for critical behaviors, with two exceptions. Comfort support was not related significantly with partner critical behaviors prior to surgery, but rather action-facilitating support now served as a significant correlate (see Table 23). In all cases, prior critical behaviors served as a significant covariate.

Regression analyses for dyads: We ran a series of regression analyses predicting patients' avoidant and critical behaviors from partners' perceptions of illness uncertainty and partners' perception of patient action-facilitating and comfort support. A similar series of analyses was conducted for partners. The results are

presented in Tables 24-27. With the exception of previous assessments of avoidant and critical behaviors being correlated with subsequent reports of avoidant and critical behaviors, there was little evidence to show that either uncertainty, action-facilitating or comfort support were uniquely associated with avoidant or critical behavior in cross sectional or prospective analyses.

In sum, there was strong support in the bivariate analyses that greater perceived support and less illness uncertainty (especially for patients) were associated with acting less nonsupportive towards the partner. However, in multivariate analyses, uncertainty did not contribute any unique variance in its relation to avoidant and critical behaviors. Within patients and partners, there was some, albeit inconsistent, support that perception of comfort support was related to acting in less avoidant and critical ways than action-facilitating support. Of these two domains, comfort support was more consistently related with engaging in less critical behaviors.

IV. Do supportive and nonsupportive behaviors mediate the relationship between illness uncertainty and QOL? Hypothesis 4 states that social support and nonsupportive behaviors will mediate the relationship between illness uncertainty and QOL and between illness uncertainty and psychological well-being. It also has two corollaries. Corollary A states that patients and partners who perceive their partners as being available, rather than unavailable, to provide for their needs will have high QOL (especially in the social/emotional domains) and psychological well-being scores. Corollary B states that partners' nonsupportive behaviors will more powerfully predict QOL and psychological well-being than will appraisal of partners' support. Thus, nonsupportive behaviors will be a more powerful mediator between uncertainty and QOL and psychological well-being than supportive behaviors.

To test for full mediation, three requirements need to be fulfilled (95). First, uncertainty needs to be related to QOL, especially in the area of mental (i.e., psychological) well-being. Second, social support and nonsupportive behaviors need to be related to QOL. Third, uncertainty needs to be related to both social support and nonsupportive behaviors. If the relations between uncertainty and QOL become non-significant with the inclusion of either or both social support and nonsupportive behaviors, but either or both social support and nonsupportive behaviors continue to predict QOL, this would provide evidence for full mediation. In prior analyses, the rather consistent relationship between illness uncertainty and social support and nonsupportive behaviors was established. We report below the other relations needed to *apriori* establish mediation.

Relations between uncertainty and QOL: To begin to initially test these predictions, we computed Spearman correlations between patients' illness uncertainty and their scores on the two, global-standardized measures of mental (i.e., psychological) well-being and physical well-being. The two standardized measures capture the differential contributions (i.e., weights) of each of the eight domains towards mental and physical well-being and were used as summary scores. Note that hypothesis 4 does not make a specific prediction which of the eight QOL of domains would be most affected, other than to state general mental (i.e., psychological) well-being; hence using two, global-summary scores was deemed appropriate. Spearman correlations were also computed for partners between these constructs.

The prediction that less illness uncertainty would correlate positively with QOL was strongly supported within both patients and partners. Indeed, for patients, less illness uncertainty was related to better physical and mental well-being across all time points (16 out of 16 correlations significant for both QOL domains) (See Table 28). Similarly, partners who reported less illness uncertainty reported better mental, and to a lesser extent, physical well-being. For mental well-being, 12 out of 16 correlations were significant, while for physical well-being, only 9 out of 16 were significant (see Table 29). In sum, the first step for testing mediation was strongly supported for patients and partners, especially in the area of mental well-being.

Relations between nonsupportive behaviors and QOL: It was expected that patients and partners who engaged in nonsupportive behaviors would report poorer physical and especially mental well-being. Spearman correlations were computed between overall nonsupportive behaviors, its two subcomponents of avoidant and critical behaviors, and physical and mental well-being. Among patients, those who were more critical, avoidant

and more nonsupportive of their partners overall reported consistently poorer mental well-being (see Table 30). These relationships were substantially weaker and, virtually, all nonsignificant between unsupportive behaviors and physical well-being. An almost identical pattern existed for partners (see Table 31).

The mediational analyses take into consideration the extent to which patients'/partners' nonsupportive behaviors affect the counterpart's QOL. Hence, Spearman correlations were computed between patients' QOL and partners' nonsupportive behaviors and between partners' QOL and patients' nonsupportive behaviors. There was weak support for the prediction that patients' overall mental and physical well-being was related adversely by their partner's avoidant, critical and overall nonsupportive behaviors (see Table 32). However, among the two nonsupportive domains, partners' avoidant behaviors were more likely to be related to less patient mental well-being – six of sixteen relations were significant.

A rather different pattern emerged between partners' QOL and patients' nonsupportive behaviors (see Table 33). Overall, patients who acted more critical, avoidant and more nonsupportive towards the partner had partners who reported rather consistently poorer overall mental well-being. These relations did not generalize to overall physical well-being.

Relations between social support and QOL: Spearman correlations were computed for patients between overall social support, its two domains of comfort and action-facilitating support, and physical and mental well-being. Spearman correlations were also computed for partners between these constructs. Among patients, those who perceived the partner as providing more action-facilitating, comfort and overall support consistently reported better mental well-being. For example, at a minimum, 14 out of 16 correlations were significant within each social support domain (see Table 34). However, the relations between perceived social support and physical well-being were substantially weaker and less consistent than for physical well-being. For example, at most only 7 of 16 correlations were significant relating action-facilitating support and physical well-being. Among partners, virtually the same patterns held (see Table 35).

Although hypothesis four does not explicitly make the prediction that patients' QOL behavior would be related to partners' perceptions of patient social support, or vice versa, for purposes of completeness and to compare with the results using nonsupportive behaviors, we computed Spearman correlations between: 1) patients' QOL and partners' perceptions of patient social support and 2) partners' QOL and patients' perceptions of partner support. As shown in Table 36, there was good support for the prediction that patients that had a partner who viewed them as providing more action-facilitating, comfort or overall support would report better physical, and especially, psychological well-being. Similarly, partners who had a patient who viewed them as providing more action-facilitating, comfort and overall support reported better mental well-being, especially at one-month and twelve-months post-surgery (see Table 37). These results did not generalize consistently to physical well-being.

Summary and status of precursors to the mediational analyses: Overall, there was good correlational support showing that illness uncertainty is related to mental and physical well-being, social support and nonsupportive behaviors. There was good support that social support and nonsupportive behaviors were related to QOL, but only in the mental health domain. Furthermore, and rather unexpectedly, patients' QOL in either domain was not related consistently with partner nonsupportive behaviors. Rather, only partners' mental well-being was more consistently related to patients' supportive and nonsupportive behaviors. In view of these correlational findings, any close approximation to mediational analyses could be performed on mental well-being, especially predicting partner mental well-being.

Acknowledging these shortcomings to conduct a true full mediational analyses on all outcomes of interest and given that the pattern of correlations differed between patient and partners, we ran a series of cross-sectional and prospective regression analyses that differed slightly in predicting patients' and partners' mental well-being. For patients, mental well-being was predicted from their own perceptions of illness uncertainty, that included in the model, either individually or jointly, their perceptions of partner support and own nonsupportive behaviors. In the cross-sectional analyses (i.e., predicting outcomes using the same time frame), we controlled

for patients' prior mental well-being score (i.e., using baseline mental well-being as a covariate for the analyses predicting one-month post-surgical well-being). In the prospective analyses, we examined how a previous assessment time point predicted the next time point only. Since there was no strong correlational evidence showing that partners' nonsupportive behaviors were related consistently and significantly with patient QOL, we did not examine these relations in multivariate regression analyses.

Overall, a similar series of regression analyses was conducted for partners. However, because patients' perceptions of partner support and nonsupportive behaviors were related to partners' mental well-being, these were examined in multivariate regression analyses. Hence, in a series of cross-sectional and prospective regression analyses, partners' mental well-being was predicted from their own perceptions of illness uncertainty that included in the model, either individually or jointly, their perception of patient support and own nonsupportive behaviors. In a second set of cross-sectional and prospective regression analyses, partners' mental well-being was predicted from their own perceptions of illness uncertainty that included in the model, either individually or jointly, patients' perception of partner support and patients' nonsupportive behaviors.

Because overall perceived social support and overall nonsupportive behaviors paralleled the findings using their subdomains, the overall scores were used in the analyses without loss of information. Further, all the regression models included uncertainty because we wanted to test whether either supportive or nonsupportive behaviors could account for some of the variance in the relations between uncertainty and QOL. The results of these analyses for patients and partners are reported below.

Regression analyses for patients:

Predicting patient mental well-being from uncertainty and social support: As shown in Table 38, less illness uncertainty was significantly related to better overall mental well-being cross-sectionally at baseline and at one- and six-months post-surgery. However, uncertainty was not a significant predictor of mental well-being at the next subsequent assessment time point (prospective analyses). In the cross-sectional analyses, patients who viewed their partners as providing more social support reported better mental well-being at baseline and at six- and twelve-months post-surgery. Social support was not a significant predictor of mental well-being at any subsequent assessment point (prospective analyses). At all time points, patients' prior mental well-being score predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting patient mental well-being from uncertainty and own nonsupportive behaviors: As shown in Table 39, less illness uncertainty was significantly related to better overall mental well-being cross-sectionally at baseline and at one- and six-months post-surgery. However, baseline uncertainty was only a significant predictor of mental well-being at one-month post-surgery (prospective analyses). In the cross-sectional analyses, patients who acted nonsupportively towards their partner reported poorer mental well-being at baseline and at six- and twelve-months post-surgery. However, baseline nonsupportive behaviors predicted only poorer mental well-being at one-month post-surgery (prospective analyses). At all time points, patients' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting patient mental well-being from uncertainty, perception of partner support and own nonsupportive behaviors: As shown in Table 40, partners with less illness uncertainty reported better overall mental well-being cross-sectionally at baseline and at one- and six-months post-surgery. However, uncertainty was only a significant predictor of mental well-being at any subsequent assessment point (prospective analyses). In the cross-sectional analyses, patients who acted nonsupportively towards their partner reported poorer mental well-being at baseline and at six-months post-surgery. However, nonsupportive behaviors were not a significant predictor of mental well-being at any subsequent assessment point (prospective analyses). Perception of partner support was not related to mental well-being in any analyses. At all time points, patients' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting patient mental well-being from uncertainty and perception of partners' perceptions of patient support: As shown in Table 41, in cross-sectional analyses, patients who reported less illness uncertainty prior to surgery and at one- and six-months post-surgery reported better mental well-being. Further, less illness uncertainty at one-month predicted better mental well-being at six-months post-surgery. Further, in cross-sectional analyses, patients who had a partner that viewed the patient as providing more support reported better mental well-being prior to surgery. At all time points, patients' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Regression analyses for partners:

Predicting partner mental well-being from uncertainty and perception of patient social support: As shown in Table 42, partners with less illness uncertainty reported better overall mental well-being cross-sectionally prior to surgery. Further, less illness uncertainty at six-months post-surgery predicted better mental well-being at twelve-months post-surgery. In the cross-sectional analyses, partners who viewed the patient as providing more social support reported better mental well-being at one-, six-, and twelve-months post-surgery. In addition, partners who viewed the patient as providing more social support prior to surgery reported better mental well-being at one-month post-surgery. At all time points, partners' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting partner mental well-being from uncertainty and own nonsupportive behaviors: As shown in Table 43, partners with less illness uncertainty had better overall mental well-being cross-sectionally prior to surgery and at one- and twelve-months post-surgery. Further, illness uncertainty at baseline and at six-months post-baseline predicted better mental well-being at one- and twelve-months post-surgery (prospective analyses). In the cross-sectional analyses, partners who acted nonsupportively towards the patient reported poorer mental well-being across all time points. However, these nonsupportive behaviors did not predict mental well-being at any subsequent assessment point (prospective analyses). At all time points, patients' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting partner mental well-being from uncertainty, perception of patient support and own nonsupportive behaviors: These regression analyses differed from those previously reported in that both partners' perceptions of patient support and partners' nonsupportive behaviors were included in the analyses. As shown in Table 44, partners with less illness uncertainty had better overall mental well-being cross-sectionally prior to surgery only. Less illness uncertainty at six-months post-surgery predicted better mental well-being at twelve-months post-surgery (prospective analyses). In the cross-sectional analyses, partners' nonsupportive behaviors towards the patient contributed to poorer mental well-being prior to surgery and at one- and twelve-months post-surgery. However, nonsupportive behaviors were not a significant predictor of mental well-being at any subsequent assessment point (prospective analyses). Perception of greater patient support was related to greater mental well-being only at one- and six-months post-surgery. At all time points, patients' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting partner mental well-being from uncertainty and patients' perception of partner support: In these analyses, patients' perceptions of partner support, rather than partners' perceptions of patient support, was used in the model containing partners' illness uncertainty. As shown in Table 45, less illness uncertainty was significantly related to better overall mental well-being cross-sectionally prior to surgery and at one- and twelve-months post-surgery. Further, less illness uncertainty at six-months post-surgery predicted better mental well-being at twelve-months post-surgery. In the cross-sectional analyses, patients' perceptions of greater partner support contributed to partners' improved mental well-being at one- and twelve-months post-surgery. Patients' perceptions of partner support at baseline predicted better partner mental well-being at one-month

post-baseline only (prospective analyses). At all time points, partners' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting partner mental well-being from uncertainty and patients' nonsupportive behaviors: In these analyses, patients' nonsupportive behaviors towards the partner, rather than partners' nonsupportive behaviors towards the patient, were used in the model containing partners' illness uncertainty. As shown in Table 46, less illness uncertainty contributed to better overall mental well-being cross-sectionally prior to surgery and at one- and twelve-months post-surgery. Further, less illness uncertainty at six-months post-surgery predicted better mental well-being at twelve-months post-surgery. In the cross-sectional analyses, patients' nonsupportive behaviors towards the partner contributed to partners' poorer mental well-being across all time points. Further, patients' nonsupportive behaviors prior to surgery contributed to patients' poorer mental well-being at one-month post-baseline only (prospective analyses). At all time points, partners' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

Predicting partner mental well-being from uncertainty and patients' perception of patient support and patient nonsupportive behaviors: In these analyses, we examined how both the patients' perceptions of partner support and patients' nonsupportive behaviors contributed to partners' mental well-being beyond partner illness uncertainty. As shown in Table 47, in cross-sectional analyses, less illness uncertainty at twelve-months post-surgery contributed to improved mental well-being. Furthermore, less illness uncertainty at six-months post-surgery contributed to better well-being at twelve-months post-surgery. In cross-sectional analyses, patients' nonsupportive behaviors contributed to poorer partner mental well-being prior to surgery and at six-months post-surgery. Patients' nonsupportive behaviors at one-month predicted poorer partner mental well-being at six-months post-surgery. In addition, in cross-sectional analyses, patients' perceptions of greater partner support at one-month post-surgery were related to partners' better well-being and these perceptions at baseline contributed to better well-being at one-month post-surgery. At all time points, partners' prior mental well-being scores predicted positively mental well-being at the subsequent assessment point. No other significant effects were found.

In sum, the bivariate relations, especially within patients and partners, strongly supported the predicted relations between QOL and uncertainty and perceived social support and nonsupportive behaviors. Of import, uncertainty was related to both mental and physical well-being, while perceptions of social support and nonsupportive behaviors were more consistently related to mental (i.e., psychological) well-being. Hence, the mediational roles of social support and uncertainty could only be tested predicting mental well-being. In general, in the multivariate analyses controlling for prior level of mental well-being, the most consistent correlate was nonsupportive behaviors. Patients' nonsupportive acts contributed to their own and their partners' poorer mental well-being. Similarly, partners' own nonsupportive behaviors contributed to their own poorer well-being.

V. *Do the relations between uncertainty and QOL and control and QOL diminish over time?* Hypothesis 5 states that higher levels of uncertainty and lower perceived control will predict poorer QOL and psychological well-being, especially in the short-term -- up to 6 months post-treatment. However, as individuals adapt to living with uncertainty, uncertainty will be weakly or positively related to QOL and psychological well-being. Thus, at the most basic level, this prediction states that one or two things may occur: 1) the relations between these constructs and QOL do not remain consistent across time (i.e., correlations are significant early but not later) and 2) the direction of the relations may change.

As revealed in Table 28 for the relations between patient illness uncertainty and mental and physical well-being, less illness uncertainty continued to be associated with better mental and physical well-being across all time points (32/32 correlations significant). Further the magnitude of these relationships for the six- and twelve-month assessment points were similar to those found prior to and one-month post-surgery. For partners,

while the relationships were less consistent, especially for physical well-being, there was still evidence indicating that less illness uncertainty was related to better mental and physical well-being, especially at six-months post-surgery, and rather consistently prior to the six-month assessment point for mental well-being (see Table 29).

The relations between perceptions of control and mental and physical well-being are presented in Tables 48 and 49. In general, patients who felt in control reported better mental (13/16 correlations significant) and physical well-being (15/16 correlations significant) across assessments (see Table 48). For partners, these relations were less consistent, especially for mental well-being. As shown in Table 49, partners who felt more in control experienced better mental well-being (9/16 correlations significant) and physical well-being (14/16 correlations significant). Interestingly, baseline perceived control was the most consistent correlate of mental well-being across all time points.

In sum, for patients, there was little support for the prediction that the relations between illness uncertainty and mental and physical well-being between perceptions of control and mental and physical well-being diminish over time. For partners, the relations between illness uncertainty and mental well-being, as well as the relation between perceived control and physical well-being remained consistent throughout. There was no evidence to suggest a reversal in the nature of these relations (i.e., going from positive to negative).

VI. Do partners experience poorer QOL than patients and is QOL related between patients and partners?
Hypothesis 6 states that partners will experience poorer QOL and psychological well-being than patients, and that these variables will be moderately correlated (.30 to .40) between patients and partners across time. The means for the QOL domains comparing patients and partners who completed all time points were presented previously in Table 3. As discussed, patients consistently reported better QOL in all domains except general, perceived health at one-month post-surgery. With these exceptions, patients reported better QOL, especially in the domains of physical functioning, emotional well-being, more energy/less fatigue, and to a lesser extent, social functioning.

The QOL domains between patients and partners were indeed related in most cases. Spearman correlations were computed between the patient and partner across time for all eight QOL domains. Here we report on the range of scores for each domain and how many correlations were significant out of a possible 16, placed in parenthesis. Correlations for physical functioning ranged from .14 to .43 (15/16). Correlations for role limitations due to physical and emotional reasons ranged from .06 to .27 (11/16) and .03 to .27 (8/16), respectively. Correlations for energy and fatigue ranged from .14 to .42 (13/16). Correlations for emotional well-being ranged from .21 to .41 (16/16), while that of social functioning ranged from .08 to .44 (10/16). The range for perceptions of pain was .02 to .43, and for general perceived health, .23 to .48 (16/16). Thus, the prediction that the upper limit of the correlations would be around .40 was supported for seven out of eight domains.

In sum, there was good support indicating that partners' were experiencing poorer QOL than patients, especially in certain areas. Furthermore, the most consistent relations between patients' and partners' QOL were in the domains of physical functioning, energy and fatigue, emotional functioning and perceived general health.

Summary

The main aim of the project was to ascertain how a modified version of Mishel's illness uncertainty models predicted ultimately QOL in prostate cancer patients and their partners. In this section, we summarize the main findings, especially in relations to illness uncertainty, social support and unsupportive behaviors. The summary begins with some general observations.

In general, there were significantly more changes in the QOL of men than of the partner. Men experienced the poorest QOL during the one-month post-surgical assessment. However, this finding was the exception rather than the rule. Indeed, in general partners reported poorer quality relative to the patient across

several domains (e.g., physical functioning, role limitations, energy/fatigue, and to a lesser extent social functioning). Thus, as found in other studies, it is the caregiver, in this case most often the spouse, who experienced poorer QOL.

There were several elements that could have contributed to the poorer QOL of the partner. In general, partners tended to report more illness uncertainty across times points than the patient. Further, partners perceived the patient as providing less support than the patient viewed the partner as providing. Partners were also more likely to be the recipient of patients' nonsupportive behaviors. In total, the poorer QOL among partners in several domains could reflect their greater illness uncertainty, poorer perceptions of patient support, and being the target of more nonsupportive behaviors.

In part, these associations held true, especially at a bivariate level. Indeed, greater illness uncertainty, lower perceived support, and being the target of nonsupportive behaviors contributed to the poorer mental well-being of partners and the patient (i.e., within patient/partner associations). Of perhaps greater significance, patients' perceptions of illness uncertainty, perceived support provided by the partner, and their own critical and avoidant behaviors were related in the predicted direction with partners' mental well-being. Similarly, partners' perceptions of illness uncertainty and perception of support provided by the partner were related in the predicted direction with patients' mental well-being. These relations provide evidence of the importance of studying the QOL of the patient and the partner in unison. Indeed, there existed several positive relationships between patient and partner QOL in various domains across the assessment points.

In general, while the main study predictions were upheld at the bivariate level, support for the study predictions were not as strongly and consistently supported, especially in the prospective, multivariate analyses. In part, this may be due to the rather stringent and conservative set of analyses posed. Specifically, in each of the multivariate regression models, the prior level of the outcome of interest served as a covariate (e.g., predicting one-month mental health controlling for baseline mental health). Thus, in essence, our models predicted changes in the outcome of interest rather than absolute levels. Nonetheless, several noteworthy trends were found in these multivariate analyses. For example, within patients, and even more within partners, nonsupportive behaviors were more consistently related to perceptions of support than illness uncertainty (i.e., more perceived support was related to less nonsupportive behaviors). Further, the mental health of the patient and especially that of the partner were most consistently related to level of own nonsupportive behaviors (patient and partner) as well as being the target of nonsupportive behaviors (for partners only). Less consistent relations were found for illness uncertainty.

Table 1: Demographics.

	Baseline (total participants)				All 4 timepoints			
Variable	Patients (n=186)		Partners n=166)		Patients (n=113)		Partners (n=99)	
<u>Education Level</u>								
Grade school	5	2.7%	2	1.2%	3	2.7%	0	0.0%
Some high school	20	10.8%	12	7.2%	10	8.8%	7	7.1%
High school graduate	33	17.7%	33	19.9%	19	16.8%	22	22.2%
Some college	31	16.7%	59	35.5%	22	19.5%	37	37.4%
College graduate	45	24.2%	36	21.7%	34	30.1%	20	20.2%
Graduate education	51	27.4%	24	14.5%	25	22.1%	13	13.1%
Blank	1	0.5%	0	0.0%	0	0.0%	0	0.0%
 <u>Race/ethnicity</u>								
White, not Hispanic	160	86.1%	145	87.4%	101	89.4%	88	88.9%
Black/African-American	21	11.3%	15	9.0%	11	9.7%	10	10.1%
Hispanic	1	0.5%	2	1.2%	0	0.0%	0	0.0%
American Indian/Alaskan	3	1.6%	4	2.4%	1	0.9%	1	1.0%
Asian/Pacific Islander	1	0.5%	0	0.0%	0	0.0%	0	0.0%
Hawaiian native	0	0.0%	0	0.0%	0	0.0%	0	0.0%
 <u>Marital Status</u>								
Never married	6	3.2%	1	0.6%	2	1.8%	0	0.0%
Married	158	84.9%	158	95.2%	101	89.4%	96	96.9%
Separated	4	2.2%	0	0.0%	1	0.9%	0	0.0%
Divorced	11	5.9%	5	3.0%	5	4.4%	2	2.0%
Widowed	7	3.8%	2	1.2%	4	3.5%	1	1.1%
 <u>Socioeconomic Status</u>								
\$0-\$4,000	1	0.5%	2	1.2%	0	0.0%	2	2.0%
\$4,001-\$9,000	5	2.7%	4	2.4%	3	2.7%	2	2.0%
\$9,001-\$18,000	11	5.9%	17	10.3%	5	4.4%	13	13.1%
\$18,001-\$30,000	22	11.8%	18	10.9%	14	12.4%	10	10.1%
\$30,001-\$40,000	22	11.8%	15	9.0%	11	9.7%	9	9.1%
\$40,001-\$50,000	17	9.2%	21	12.7%	13	11.5%	14	14.2%
\$50,001-\$60,000	24	12.9%	19	11.4%	20	17.7%	15	15.2%
Above \$60,000	77	41.4%	62	37.3%	45	39.8%	31	31.3%
Blank	7	3.8%	8	4.8%	2	1.8%	3	3.0%
 <u>Age</u>								
Mean	63.0		60.5		63.1		60.0	
Min	43.8		33.5		44.5		33.5	
Max	80.9		87.2		80.9		75.2	
Max2 (exc. WW patients)	76.8		87.2		76.1		75.2	

Table 2: Means and Alphas for Main Study Variables for Patients Across Time Points.

Variable	Baseline	Scale Mean			F	Base	Scale Alpha		
		1-month	6-Months	12-Months			1M	6M	12M
Uncertainty (n=107)	115.6 _a	120.9 _b	124.4 _c	127.6 _d	24.6***	.91	.94	.92	.94
Perceived Control (n=111)	5.4 _a	1.4 _b	5.2 _a	6.3 _c	46.0***	.64	.62	.62	.68
<u>Social Support</u>									
Overall (n=102)	40.2 _a	39.6 _a	37.8 _b	38.3 _b	9.9***	.85	.87	.88	.90
Action-Facilitating (n=103)	7.0 _a	7.2 _a	6.7 _b	6.8 _b	8.9***	.80	.82	.88	.88
Comfort (n=103)	10.0 _a	9.8 _a	9.3 _b	9.4 _b	8.3***	.54	.69	.65	.85
<u>Negative Behaviors</u>									
Overall (n=101)	19.8 _a	20.5 _a	21.8 _b	21.6 _b	5.7**	.85	.87	.88	.90
Avoidant (n=101)	9.9 _a	10.7 _{bd}	11.5 _c	11.2 _{cd}	9.1	.63	.75	.80	.84
Critical (n=101)	6.9	6.9	7.1	7.2	0.4	.65	.77	.74	.66
<u>Quality of Life (domains)</u>									
Physical Functioning (n=113)	90.5 _a	60.1 _b	87.0 _c	88.7 _{ac}	81.2***	.93	.88	.92	.93
Role Limitations (physical) (n=112)	75.4 _a	10.9 _b	69.9 _{ac}	71.6 _{ac}	120.3***	.90	.71	.90	.89
Role Limitations (emotional) (n=110)	72.0 _a	28.5 _b	78.5 _{ac}	78.8 _{ac}	74.3***	.86	.58	.81	.82
Energy/Fatigue (n=112)	35.1 _a	23.8 _b	34.4 _{ac}	35.0 _{ac}	21.6***	.90	.84	.90	.91
Perceived Pain (n=112)	89.5 _a	58.6 _b	86.0 _c	87.2 _{ac}	71.6***	.85	.84	.84	.88
Social Integration (n=111)	83.9 _a	54.8 _b	87.4 _{ac}	89.0 _{ac}	55.0***	.89	.82	.93	.86
Emotional Well-being (n=113)	76.9	77.3	78.7	80.6	2.6	.85	.85	.87	.87
General Health (n=112)	71.4	72.8	71.9	73.6	1.6	.84	.86	.89	.88
<u>Prostate-Specific QOL</u>									
Incontinence (n=109)	91.2 _a	43.1 _b	72.6 _c	79.2 _d	111.6***	.74	.85	.87	.90
Bowel Dysfunction (n=109)	88.8 _a	74.8 _b	84.7 _c	87.2 _{ac}	22.0***	.76	.58	.68	.72
Sexual Dysfunction (n=109)	61.0 _a	10.5 _b	19.0 _c	24.8 _d	113.5***	.92	.83	.86	.89

Note. Means are for patients who completed all time points. Means with different lettered subscripts differ at $p < .05$.

* $p < .05$, ** $p < .01$, *** $p < .001$.

Table 2 (continued): Means and Alphas for Main Study Variables for Partners Across Time Points.

Variable	Baseline	Scale Mean		12-Month	F	Base	Scale Alpha		
		1-month	6-Month				1M	6M	12M
Uncertainty (n=95)	111.0 _a	115.2 _b	118.8 _c	121.9 _d	22.6***	.88	.92	.94	.93
Perceived Control (n=93)	4.8 _a	3.4 _b	5.3 _a	5.5 _a	9.0***	.57	.70	.76	.62
Social Support									
Overall (n=93)	39.4 _a	36.9 _b	36.5 _b	36.7 _b	14.4***	.88	.92	.94	.93
Action-Facilitating (n=99)	6.9 _a	6.3 _b	6.6 _c	6.6 _c	8.9***	.82	.83	.89	.87
Comfort (n=99)	10.0 _a	9.1 _b	9.2 _b	9.2 _b	16.0***	.74	.82	.87	.85
Negative Behaviors									
Overall (n=94)	16.6 _a	18.3 _b	19.8 _c	19.6 _c	12.9***	.76	.86	.88	.88
Avoidant (n=95)	8.3 _a	9.1 _b	10.0 _c	10.1 _c	11.1***	.80	.78	.84	.82
Critical (n=97)	5.8 _a	6.6 _b	6.9 _b	6.8 _b	10.3***	.74	.80	.78	.78
<u>Quality of Life (domains)</u>									
Physical Functioning (n=96)	82.5	79.7	79.0	79.5	2.2	.92	.93	.93	.93
Role Limitations (physical) (n=95)	69.2	65.8	63.7	65.0	0.6	.84	.86	.87	.89
Role Limitations (emotional) (n=96)	74.3 _{ab}	65.6 _a	74.3 _b	77.4 _b	2.8*	.76	.75	.71	.82
Energy/Fatigue (n=96)	31.0	31.0	29.0	29.2	2.3	.88	.90	.91	.93
Perceived Pain (n=95)	73.1	70.9	69.8	70.7	0.8	.90	.88	.91	.92
Social Integration (n=95)	80.6 _a	75.0 _b	81.4 _{ac}	79.7 _{ac}	2.8*	.85	.89	.93	.95
Emotional Well-being (n=97)	71.3	72.1	73.2	74.7	2.2	.85	.84	.90	.88
General Health (n=96)	68.7	68.2	67.0	66.7	0.4	.87	.88	.90	.87

Note. Means are for partners who completed all time points. Means with different lettered subscripts differ at $p < .05$.

* $p < .05$, ** $p < .01$, *** $p < .001$.

Table 3: Means and Alphas for Main Study Variables for Dyads Across Time Points.

Variable	Scale Mean								F
	Baseline	t	1-month	t	6-Month	t	12-Month	t	
<u>Uncertainty (n=96)</u>									
Patients	116.0 _a	2.9***	120.7 _a	3.6***	124.1 _a	2.7**	127.0 _a	2.6*	17.5***
Spouse/partner	111.7 _b		115.7 _b		119.7 _b		122.8 _b		
<u>Perceived Control (n=93)</u>									
Patients	5.4	1.2	1.3 _a	4.7***	5.2	<1.0	6.2	1.1	16.2***
Spouse/partner	4.8		3.5 _b		5.5		5.7		
<u>Social Support</u>									
<u>Overall (n=91)</u>									
Patients	40.5	1.4	40.0 _a	5.5***	38.2	2.3*	38.7 _a	3.0**	11.5***
Spouse/partner	39.4		37.1 _b		36.8 _b		37.0 _b		
<u>Action-Facilitating (n=98)</u>									
Patients	7.0	1.0	7.2	8.0***	6.7	-1.0	6.8	-1.4	12.7***
Spouse/partner	6.9		6.3		6.6		6.7		
<u>Comfort (n=98)</u>									
Patients	10.1	<1.0	9.8	3.8***	9.4	<1.0	9.4	1.2	10.0***
Spouse/partner	10.1		9.2		9.2		9.2		
<u>Nonsupportive Behaviors</u>									
<u>Overall (n=92)</u>									
Patients	19.6	6.1***	20.4	3.2**	21.5	2.6*	21.6	2.8**	12.1***
Spouse/partner	16.6		18.4		19.7		19.7		
<u>Avoidant (n=93)</u>									
Patients	9.8	4.8***	10.6	3.9***	11.4	3.2**	11.2	2.6*	11.7***
Spouse/partner	8.3		9.2		10.0		10.2		
<u>Critical (n=95)</u>									
Patients	6.9	4.9***	6.8	<1.0	7.1	<1.0	7.2	2.0*	8.1***
Spouse/partner	5.9		6.6		6.9		6.8		

Note. Means with different lettered subscripts within time point are significantly different.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 3 (continued): Means and Alphas for Main Study Variables for Dyads Across Time Points.

Variable	Baseline	t	Scale Mean						F	
			1-month	t	6-Month	t	12-Month	t		
<u>Quality of life (domains)</u>										
<u>Physical Functioning (n=95)</u>										
Patients	90.7	3.2**	60.8	6.8***	88.1	3.5***	89.0	4.0***	32.8***	
Spouse/partner	82.9		79.9		79.1		79.6			
<u>Role limitations (physical) (n=94)</u>										
Patients	75.5	1.2	10.6	12.9***	71.5	1.5	71.3	1.2	57.8***	
Spouse/partner	69.9		66.5		64.1		64.9			
<u>Role limitations (emotional) (n=93)</u>										
Patients	72.6	<1.0	25.8	8.9***	79.2	<1.0	80.6	<1.0	44.9***	
Spouse/partner	75.3		66.3		75.3		78.1			
<u>Energy/Fatigue (n=95)</u>										
Patients	35.4	3.1**	24.0	4.0***	35.1	4.2***	34.9	4.2***	11.2***	
Spouse/partner	30.9		31.1		28.8		29.3			
<u>Perceived Pain (n=94)</u>										
Patients	89.2	6.2***	57.8	4.2***	86.1	5.4***	87.9	6.8***	39.8***	
Spouse/partner	72.9		71.2		70.2		70.9			
<u>Social Integration (n=93)</u>										
Patients	84.6	1.3	55.8	6.3***	88.2	1.9	90.2	3.8***	21.4***	
Spouse/partner	81.6		76.3		82.9		81.2			
<u>Emotional well-being (n=96)</u>										
Patients	77.2	3.1**	77.6	2.8**	79.1	2.6*	81.2	3.0**	3.7**	
Spouse/partner	71.8		72.7		73.9		75.1			
<u>General health (n=95)</u>										
Patients	70.9	<1.0	72.5	1.52	72.0	1.9	73.8	3.0	1.9	
Spouse/partner	69.2		68.8		67.8		67.2			
<u>Overall Mental (n=88)</u>										
Patients	49.6	-1.0	45.2	1.85	53.3	-1.7	53.0	-1.9	13.5***	
Spouse/partner	48.4		47.3		50.3		50.6			
<u>Overall Physical (n=88)</u>										
Patients	52.8	-3.4***	38.4	7.81***	50.7	-3.3**	51.3	-4.2***	62.6***	
Spouse/partner	48.9		47.8		46.7		46.5			

Note. Means with different lettered subscripts within time point are significantly different.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 4: Correlation of Patients' Level of Uncertainty and Perceived Control.

Patient Uncertainty	Baseline	Patient Perceived Control		
		1-month	6-month	12-month
Baseline	.49***	.36***	.36***	.39***
1-month	.37***	.54***	.42***	.36***
6-month	.24**	.35***	.56***	.53***
12-month	.38***	.31***	.57***	.63***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 5: Correlation of Partners' Level of Uncertainty and Perceived Control.

Partner Uncertainty	Baseline	Partner Perceived Control		
		1-month	6-month	12-month
Baseline	.41***	.34***	.42***	.29**
1-month	.41***	.51***	.39***	.36***
6-month	.44***	.38***	.56***	.50***
12-month	.36***	.27**	.45***	.52***

* $p < .05$, ** $p < .01$, *** $p < .001$

Tables 6: Correlations Between Patients' Uncertainty and Partners' Perceived Control.

	Baseline	Patients' Uncertainty		
		1-month	6-month	12-month
<u>Partner Control</u>				
<u>Baseline</u>	.22**	.27**	.24*	.27**
<u>1-month</u>	.39***	.40***	.33***	.24*
<u>6-month</u>	.18	.29**	.28**	.26**
<u>12-month</u>	.14	.12	.27**	.31***

* $p < .05$, ** $p < .01$, *** $p < .001$

Tables 7: Correlations Between Partners' Uncertainty and Patients' Perceived Control.

	Baseline	Partners' Uncertainty		
		1-month	6-month	12-month
<u>Patient Control</u>				
<u>Baseline</u>	.31***	.28**	.31**	.32***
<u>1-month</u>	.18	.34***	.17	.18
<u>6-month</u>	.20*	.31***	.32***	.25**
<u>12-month</u>	.28**	.34***	.39***	.38***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 8:

Relations Between Patient Perceptions of Control, Uncertainty, and Domains of Social Support.

Patient	Patient Perception of Partner Support							
	Action-facilitating				Comfort			
	Baseline	1-month	6-month	12-month	Baseline	1-month	6-month	12-month
<u>Baseline</u>								
Control	.29***	.18	.32***	.20*	.32***	.03	.29**	.28**
Uncertainty	.37***	.23*	.29**	.17	.39***	.19	.29**	.26**
<u>1-month</u>								
Control	-.05	.07	.15	-.02	.09	.12	.15	.06
Uncertainty	.32***	.28**	.30**	.13	.35***	.33***	.31***	.29**
<u>6-month</u>								
Control	.23*	.19*	.34***	.20*	.34***	.18	.41***	.38***
Uncertainty	.39***	.45***	.37***	.34***	.36***	.41***	.46***	.43***
<u>12-month</u>								
Control	.22*	.21*	.21*	.29**	.25**	.20	.27**	.41***
Uncertainty	.30**	.38***	.38***	.31***	.28**	.29**	.36***	.43***

* $p < .05$, ** $p < .01$, *** $p < .001$ **Table 9:**

Relations Between Partner Perceptions of Control, Uncertainty, and Domains of Social Support.

Partner	Partner Perception of Patient Support							
	Action-facilitating				Comfort			
	Baseline	1-month	6-month	12-month	Baseline	1-month	6-month	12-month
<u>Baseline</u>								
Control	.31***	.34***	.33***	.28**	.36***	.33***	.38***	.23*
Uncertainty	.19*	.33***	.38***	.41***	.27***	.34***	.43***	.40***
<u>1-month</u>								
Control	-.09	.12	.06	-.07	-.02	.11	.10	-.06
Uncertainty	.16	.42***	.40***	.22*	.19*	.37***	.42***	.28**
<u>6-month</u>								
Control	.17	.18	.20*	.06	.23*	.13	.25***	.10
Uncertainty	.19	.38***	.34***	.24*	.23*	.31***	.37***	.28**
<u>12-month</u>								
Control	.10	.18	.16	.15	.20*	.13	.23*	.12
Uncertainty	.25*	.25**	.33***	.25**	.31**	.21*	.33***	.28**

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 10:

Relations Between Patients' Domains of Social Support and Partners' Perceptions of Control and Uncertainty.

Patient Perception of Partner Support								
Partner	Baseline	Action-facilitating			Baseline	Comfort		
		1-month	6-month	12-month		1-month	6-month	12-month
Baseline								
Control	.28***	.16	.32**	.15	.30***	.19*	.17	.21*
Uncertainty	.28***	.17	.22*	.17	.24**	.15	.17	.22*
1-month								
Control	.27**	.26**	.29**	.14	.31***	.20*	.20*	.16
Uncertainty	.31***	.18*	.29**	.19	.33***	.23*	.29**	.32***
6-month								
Control	.27**	.27**	.18	.14	.24*	.16	.08	.14
Uncertainty	.35***	.35***	.30**	.27**	.35***	.31***	.29**	.36***
12-month								
Control	.19*	.22*	.23*	.24*	.22*	.14	.20*	.26**
Uncertainty	.18*	.21*	.23*	.20*	.21*	.18	.17	.31**

* $p < .05$, ** $p < .01$, *** $p < .001$ **Table 11:**

Relations Between Partners' Domains of Social Support and Patients' Perceptions of Control and Uncertainty.

Partner Perception of Patient Support								
Patient	Baseline	Action-facilitating			Baseline	Comfort		
		1-month	6-month	12-month		1-month	6-month	12-month
<u>Baseline</u>								
Control	.11	.08	.10	.11	.21*	.11	.18	.13
Uncertainty	.06	.22*	.16	.13	.17*	.13	.13	.07
<u>1-month</u>								
Control	-.09	.12	.06	-.07	-.02	.11	.10	-.06
Uncertainty	.16	.42***	.40***	.22***	.19*	.37***	.42***	.28**
<u>6-month</u>								
Control	.17	.18	.20*	.06	.23*	.13	.25**	.10
Uncertainty	.19	.38***	.34***	.24*	.23*	.31***	.37***	.28**
<u>12-month</u>								
Control	.10	.18	.16	.15	.20*	.13	.23*	.12
Uncertainty	.25*	.25**	.33***	.25**	.31**	.21*	.33***	.28**

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 12: Correlation Between Patients' Level of Uncertainty and Nonsupportive Behaviors.

<u>Patient Uncertainty</u>	<u>Patients' Nonsupportive Behaviors Towards Partner</u>							
	<u>Baseline</u>		<u>1-month</u>		<u>6-month</u>		<u>12-month</u>	
	<u>Avoid</u>	<u>Critical</u>	<u>Avoid</u>	<u>Critical</u>	<u>Avoid</u>	<u>Critical</u>	<u>Avoid</u>	<u>Critical</u>
<u>Baseline</u>	-.14	-.19*	-.17	-.24*	-.15	-.16	-.20*	-.24*
<u>1-month</u>	-.22*	-.27**	-.23*	-.26**	-.21*	-.25**	-.29**	-.32**
<u>6-month</u>	-.33***	-.29**	-.34***	-.31**	-.33***	-.37***	-.51***	-.38***
<u>12-month</u>	-.24*	-.18	-.24*	-.13	-.30**	-.25**	-.44***	-.32***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 13: Correlation Between Partners' Level of Uncertainty and Nonsupportive Behaviors.

<u>Partner Uncertainty</u>	<u>Partners' Nonsupportive Behaviors Toward Patient</u>							
	<u>Baseline</u>		<u>1-month</u>		<u>6-month</u>		<u>12-month</u>	
	<u>Avoid</u>	<u>Critical</u>	<u>Avoid</u>	<u>Critical</u>	<u>Avoid</u>	<u>Critical</u>	<u>Avoid</u>	<u>Critical</u>
<u>Baseline</u>	-.17*	.00	-.22*	-.19	-.45***	-.30**	-.41***	-.23*
<u>1-month</u>	-.13	-.07	-.26**	-.21*	-.37***	-.25*	-.36***	-.26**
<u>6-month</u>	-.24*	-.06	-.26**	-.09	-.41***	-.28**	-.37***	-.34***
<u>12-month</u>	-.19	.02	-.21*	.02	-.34***	-.19	-.37***	-.25*

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 14: Correlation Between Patients' Nonsupportive Behaviors and Partners' Uncertainty.

Partner Uncertainty	Patients' Nonsupportive Behaviors Toward Partner							
	Baseline		1-month		6-month		12-month	
	Avoid	Critical	Avoid	Critical	Avoid	Critical	Avoid	Critical
<u>Baseline</u>	-.08	-.14	-.22*	-.22*	-.15	-.15	-.26**	-.30**
<u>1-month</u>	-.21*	-.27**	-.28**	-.27**	-.23*	-.30**	-.33***	-.32***
<u>6-month</u>	-.27**	-.19	-.25**	-.25**	-.27**	-.31**	-.39***	-.37***
<u>12-month</u>	-.17	-.02	-.11	-.06	-.21*	-.21*	-.33***	-.27**

Note. Nonsupportive behaviors refer to patients' acts towards the partner.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 15: Correlation Between Partners' Nonsupportive Behaviors and Patients' Uncertainty.

Patient Uncertainty	Partners' Nonsupportive Behaviors Towards Patient							
	Baseline		1-month		6-month		12-month	
	Avoid	Critical	Avoid	Critical	Avoid	Critical	Avoid	Critical
<u>Baseline</u>	-.11	-.10	-.03	-.09	-.24*	-.09	-.14	-.08
<u>One-month</u>	-.12	-.04	-.21*	-.18	-.36***	-.17	-.27**	-.22*
<u>Six-month</u>	-.17	-.03	-.15	-.11	-.31**	-.21*	-.22*	-.09
<u>Twelve-month</u>	-.23*	-.07	-.20*	-.06	-.31**	-.20*	-.27**	-.09

Note. Nonsupportive behaviors refer to patients' acts towards the partner.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 16:

Correlations Between Patients' Overall and Domains of Social Support and Domains of Nonsupportive Behaviors.

Patient Variables	Patient Nonsupportive Behaviors Toward Partner							
	Baseline		1-month		6-month		12-month	
	Avoid	Critical	Avoid	Critical	Avoid	Critical	Avoid	Critical
<u>Baseline (support)</u>								
Overall	-.42***	-.35***	-.35***	-.43***	-.46***	-.47***	-.55***	-.48***
Action-facilitating	-.32***	-.34***	-.25**	-.38***	-.31***	-.41***	-.44***	-.44***
Comfort	-.39***	-.33***	-.35***	-.44***	-.46***	-.44***	-.52***	-.46***
<u>1-month</u>								
Overall	-.44***	-.37***	-.48***	-.51***	-.52***	-.46***	-.44***	-.39***
Action-facilitating	-.35***	-.30**	-.45***	-.45***	-.47***	-.42***	-.43***	-.38***
Comfort	-.45***	-.41***	-.49***	-.56***	-.51***	-.47***	-.43***	-.40***
<u>6-month</u>								
Overall	-.52***	-.36***	-.47***	-.38***	-.62***	-.57***	-.59***	-.45***
Action-facilitating	-.45***	-.38***	-.42***	-.31***	-.53***	-.50***	-.51***	-.37***
Comfort	-.48***	-.36***	-.48***	-.44***	-.64***	-.60***	-.57***	-.45***
<u>12-month</u>								
Overall	-.45***	-.28**	-.36***	-.29**	-.62***	-.55***	-.63***	-.48***
Action-facilitating	-.39***	-.28**	-.26**	-.18	-.53***	-.47***	-.60***	-.40***
Comfort	-.48***	-.31**	-.45***	-.38***	-.68***	-.62***	-.63***	-.54***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 17:

Correlations Between Partners' Overall and Domains of Social Support and Domains of Nonsupportive Behaviors.

Partner Variables	Partner's Nonsupportive Behaviors Towards Patient							
	Baseline		1-month		6-month		12-month	
	Avoid	Critical	Avoid	Critical	Avoid	Critical	Avoid	Critical
<u>Baseline (support)</u>								
Overall	-.44***	-.30***	-.32**	-.30**	-.50***	-.38***	-.43***	-.30**
Action-facilitating	-.39***	-.31***	-.20*	-.25**	-.40***	-.28**	-.34***	-.34***
Comfort	-.43***	-.22**	-.36***	-.28**	-.51***	-.37***	-.45***	-.28**
<u>1-month</u>								
Overall	-.42***	-.32***	-.52***	-.50***	-.56***	-.49***	-.50***	-.35***
Action-facilitating	-.44***	-.35***	-.46***	-.40***	-.55***	-.46***	-.47***	-.29**
Comfort	-.35***	-.24*	-.54***	-.51***	-.56***	-.43***	-.51***	-.35***
<u>6-month</u>								
Overall	-.41***	-.33***	-.33***	-.21*	-.59***	-.45***	-.55***	-.44***
Action-facilitating	-.40***	-.24*	-.25**	-.14	-.54***	-.40***	-.43***	-.36***
Comfort	-.41***	-.33***	-.42***	-.25**	-.62***	-.46***	-.57***	-.45***
<u>12--month</u>								
Overall	-.41***	-.30**	-.36***	-.28**	-.61***	-.46***	-.63***	-.52***
Action-facilitating	-.43***	-.27**	-.32***	-.24**	-.58***	-.43***	-.62***	-.47***
Comfort	-.38***	-.30**	-.40***	-.30**	-.64***	-.47***	-.65***	-.55***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 18:

Correlations between Patients' Nonsupportive Behaviors and Partners' Overall and Domains of Social Support.

Partner Variables	Patients' Nonsupportive Behaviors Toward Partner							
	Baseline		1-month		6-month		12-month	
	Avoid	Critical	Avoid	Critical	Avoid	Critical	Avoid	Critical
<u>Baseline (support)</u>								
Overall	-.23**	-.21**	-.28**	-.25*	-.35***	-.37***	-.40***	-.44***
Action-facilitating	-.27***	-.28***	-.27**	-.28**	-.37***	-.37***	-.33***	-.40***
Comfort	-.22**	-.20*	-.22*	-.23*	-.31**	-.32***	-.38***	-.41***
<u>1-month</u>								
Overall	-.28**	-.33***	-.37***	-.44***	-.23*	-.35***	-.36***	-.36***
Action-facilitating	-.31***	-.37***	-.31***	-.41***	-.25**	-.38***	-.33***	-.36***
Comfort	-.26**	-.32***	-.35***	-.41***	-.25**	-.33***	-.39***	-.35***
<u>6-month</u>								
Overall	-.31**	-.29**	-.31**	-.32***	-.38***	-.45***	-.42***	-.45***
Action-facilitating	-.23*	-.26**	-.23*	-.26**	-.25**	-.37***	-.29**	-.37***
Comfort	-.31**	-.29**	-.34***	-.33***	-.40***	-.44***	-.45***	-.44***
<u>12-month</u>								
Overall	-.31**	-.21*	-.33***	-.31**	-.39***	-.45***	-.42***	-.41***
Action-facilitating	-.31**	-.27**	-.27**	-.26**	-.38***	-.44***	-.42***	-.40***
Comfort	-.31**	-.25**	-.34***	-.36***	-.35***	-.43***	-.42***	-.46***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 19:

Correlations between Partners' Nonsupportive Behaviors and Patients' Overall and Domains of Social Support.

Patient Variables	Partners' Nonsupportive Behavior Toward Patient							
	Baseline		1-month		6-month		12-month	
	Avoid	Critical	Avoid	Critical	Avoid	Critical	Avoid	Critical
<u>Baseline (support)</u>								
Overall	-.19*	-.10	-.20*	-.25**	-.35***	-.29**	-.33***	-.30**
Action-facilitating	-.19*	-.07	-.17	-.27**	-.25*	-.23*	-.26**	-.20*
Comfort	-.18*	-.13	-.24*	-.29**	-.41***	-.32***	-.36***	-.30**
<u>1-month</u>								
Overall	-.33***	-.14	-.33***	-.26**	-.41***	-.36***	-.34***	-.26**
Action-facilitating	-.36***	-.14	-.26**	-.27**	-.41***	-.33***	-.29**	-.21*
Comfort	-.35***	-.20*	-.32***	-.26**	-.44***	-.37***	-.36***	-.28**
<u>6-month</u>								
Overall	-.25*	-.14	-.21*	-.30**	-.42***	-.41***	-.40***	-.29**
Action-facilitating	-.28**	-.15	-.18	-.21*	-.33***	-.29**	-.34***	-.25*
Comfort	-.20*	-.14	-.25**	-.33***	-.46***	-.41***	-.40***	-.28**
<u>12-month</u>								
Overall	-.29**	-.15	-.15	-.16	-.39***	-.44***	-.43***	-.32**
Action-facilitating	-.25*	-.10	-.03	-.11	-.26**	-.34***	-.34***	-.28**
Comfort	-.32**	-.18	-.24*	-.23*	-.48***	-.45***	-.47***	-.35***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 20:

Regression Analyses Predicting Patients' Avoidant Behaviors from Illness Uncertainty and Domains of Social Support

Model	Patient Avoidant Behaviors Toward Partner							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Avoidant behaviors (baseline)	---	.15***	.56***	.38***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	-.37		---		---		---	
1-month								
Avoidant behaviors (baseline)	---	---	.51	.44***	---	.39***	---	---
Avoidant behaviors (1-month)	---		---		-.48***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		-.28*		---	
6-month								
Avoidant behaviors (1-month)	---	---	---	---	---	.51***	---	.54***
Avoidant behaviors (6-months)	---		---		.38***		.41***	
Uncertainty	---		---		---		-.37***	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		-.43***		---	
12-month								
Avoidant behaviors (6-months)	---	---	---	---	---	---	.30***	.58***
Uncertainty	---		---		---		-.33***	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 21:

Regression Analyses Predicting Patients' Critical Behaviors from Illness Uncertainty and Domains of Social Support.

Model	Patients' Critical Behaviors Toward Partner							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Critical behaviors (baseline)	---	.13***	.38***	.34***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	-.27*		-.27*		---		---	
1-month								
Critical behaviors (baseline)	---	---	.35***	.41***	---	.37***	---	---
Critical behaviors (1-month)	---		---		.47***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		-.26*		---		---	
6-month								
Critical behaviors (1-month)	---	---	---	---	.41***	.48***	---	.55***
Critical behaviors (6-months)	---		---		---		.71***	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		-.30**		---	
12-month								
Critical behaviors (6-months)	---	---	---	---	---	---	.64***	.57***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	

Note. Only significant relationships are reported.

*p<.05, **p<.01, ***p<.001

Table 22:

Regression Analyses Predicting Partners' Avoidant Behaviors from Illness Uncertainty and Domains of Social Support.

Model	Partners' Avoidant Behaviors Toward Patient							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Avoidant behaviors (baseline)	---	.18***	.40***	.10**	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	-.16*		---		---		---	
1-month								
Avoidant behaviors (baseline)	---	---	.31*	.26***	---	.43***	---	---
Avoidant behaviors (1-month)	---		---		.50***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		-.22*		---	
Comfort support	---		-.31**		---		---	
6-month								
Avoidant behaviors (1-month)	---	---	---	---	.51***	.52***	---	.50***
Avoidant behaviors (6-month)	---		---		---		.64***	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		-.26**		---	
Comfort support	---		---		---		-.28*	
12-month								
Avoidant behaviors (6-months)	---	---	---	---	---	---	.49***	.56***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		-.35**	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 23:

Regression Analyses Predicting Partners' Critical Behaviors from Illness Uncertainty and Perceptions of Patient Support

Model	Partners' Critical Behaviors Toward Patient							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Critical behaviors (baseline)	---	.05*	.43***	.15***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	-.24*		---		---		---	
Comfort support	---		---		---		---	
1-month								
Critical behaviors (baseline)	---	---	.38***	.30***	---	.44***	---	---
Critical behaviors (1-month)	---		---		.51***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		-.27**		---	
Comfort support	---		-.54***		---		---	
6-month								
Critical behaviors (1-month)	---	---	---	---	.49***	.48***	---	.40***
Critical behaviors (6-month)	---		---		---		.54	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	
12-month								
Critical behaviors (6-months)	---	---	---	---	---	---	.48***	.46***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		-.26*	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 24:

Regression Analyses Predicting Patients' Avoidant Behaviors from Partners' Illness Uncertainty and Partners' Perception of Patients' Action-facilitating and Comfort Support.

Model (Partner variables)	Baseline	Adj R ²	Patients' Avoidant Behaviors Toward Partner					
			1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Avoidant behaviors (baseline)	---	.12***	.66***	.40***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	-.21*		---		---		---	
Comfort support	---		---		---		---	
1-month								
Avoidant behaviors (baseline)	---	---	.56***	.44***	---	.34***	---	---
Avoidant behaviors (1-month)	---		---		.65***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	
6-month								
Avoidant behaviors (1-month)	---	---	---	---	.52***	.42***	-.50***	.47***
Avoidant behaviors (6-months)	---		---		---		-.21*	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		.25*		---	
Comfort support	---		---		-.45***		---	
12-month								
Avoidant behaviors (6-months)	---	---	---	---	---	---	.50***	.47***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	

Note. Only significant relationships are reported.

*p<.05, **p<.01, ***p<.001

Table 25:

Regression Analyses Predicting Patients' Critical Behaviors from Partners' Illness Uncertainty and Partners' Perceptions of Patients' Action-facilitating and Comfort Support.

Model (Partner variables)	Baseline	Adj R ²	Patients' Critical Behaviors Toward Partner					
			1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
<u>Baseline</u>								
Critical behaviors (baseline)	---	.08**	.48***	.28***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	-.25*		---		---		---	
Comfort support	---		---		---		---	
<u>1-month</u>								
Critical behaviors (baseline)	---	---	.38***	.38***	---	.36***	---	---
Critical behaviors (1-month)	---		---		.49***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		-.26*		---		---	
<u>6-month</u>								
Critical behaviors (1-month)	---	---	---	---	.45***	.43***	---	.56***
Critical behaviors (6-months)	---		---		---		.69***	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		-.31*		---	
<u>12-month</u>								
Critical behaviors (6-months)	---	---	---	---	---	---	.69***	.56***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 26:

Regression Analyses Predicting Partners' Avoidant Behaviors from Patients' Illness Uncertainty and Patients' Perceptions of Partner Action-facilitating and Comfort Support.

Model (Patient variables)	Baseline	Adj R ²	Partners'	Avoidant	Behaviors	Toward	Patient	Adj R ²
			1-month	Adj R ²	6-month	Adj R ²	12-month	

Baseline								
Avoidant behaviors (baseline)	---	.04*	.67***	.40***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	
1-month								
Avoidant behaviors (baseline)	---	---	.36**	.14***	---	.34***	---	---
Avoidant behaviors (1-month)	---		---		.65***		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	
6-month								
Avoidant behaviors (1-month)	---	---	---	---	.65***	.41***	---	.47***
Avoidant behaviors (6-month)	---		---		---		.50***	
Uncertainty	---		---		---		-.20*	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		-.21*		---	
12-month								
Avoidant behaviors (6-months)	---	---	---	---	---	---	.64***	.51***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 27:

Regression Analyses Predicting Partners' Critical Behaviors from Patients' Illness Uncertainty and Patients' Perceptions of Partner Action-facilitating and Comfort Support.

Model (Patient variables)	Partners' Critical Behaviors Toward Patient							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Critical behaviors (baseline)	---	.02	.48***	.27***	---	---	---	---
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	
1-month								
Critical behaviors (baseline)	---	---	.40***	.22***	---	.36***	---	---
Critical behaviors (1-month)	---		---		.49		---	
Uncertainty	---		---		---		---	
Action-facilitating support	---		-.31*		---		---	
Comfort support	---		---		---		---	
6-month								
Critical behaviors (1-month)	---	---	---	---	.55***	.44***	---	.56***
Critical behaviors (6-month)	---		---		---		.69***	
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	
12-month								
Critical behaviors (6-months)	---	---	---	---	---	---	.58***	.40***
Uncertainty	---		---		---		---	
Action-facilitating support	---		---		---		---	
Comfort support	---		---		---		---	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 28:Spearman Correlations Between Patient Uncertainty and Overall Mental and Physical Well-being (standardized).

<u>Patient</u>	<u>Patient Mental Well-being</u>				<u>Patient Physical Well-being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Uncertainty</u>								
<u>Baseline</u>	.32***	.35***	.37***	.20*	.36***	.31***	.34***	.32***
<u>1-month</u>	.44***	.54***	.38***	.34***	.28**	.39***	.36**	.34***
<u>6-months</u>	.35***	.35***	.48***	.43***	.33***	.21*	.47***	.38***
<u>12-months</u>	.28**	.28**	.43***	.38***	.44***	.28**	.48***	.55***

* $p < .05$, ** $p < .01$, *** $p < .001$ **Table 29:**Spearman Correlations Between Partner Uncertainty and Overall Mental and Physical Well-being (standardized).

<u>Partner</u>	<u>Partner Mental Well-being</u>				<u>Partner Physical Well-being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Uncertainty</u>								
<u>Baseline</u>	.34**	.38***	.47***	.52***	.16	.20*	.33***	.26*
<u>1-month</u>	.22*	.33***	.26**	.29***	.17	.16	.25**	.15
<u>6-months</u>	.24*	.26**	.18	.39***	.06	.14	.25**	.16
<u>12-months</u>	.08	.14	.16	.34***	.27**	.24*	.40***	.25**

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 30:

Spearman Correlations Between Patient Nonsupportive Behaviors and Overall Mental and Physical Well-being (standardized).

<u>Patient Nonsupportive Behaviors</u>	<u>Patient Mental Well-being</u>				<u>Patient Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Nonsupportive</u>								
Baseline	-.49***	-.40***	-.45***	-.45***	-.11	.07	-.05	-.02
1-month	-.39***	-.39***	-.42***	-.42***	-.02	.05	-.02	.05
6-months	-.39***	-.32***	-.57***	-.51***	-.10	.00	-.13	.07
12-months	-.38***	-.33***	-.47***	-.55***	-.07	.01	-.19	-.17
<u>Avoidant</u>								
Baseline	-.45***	-.37***	-.43***	-.48***	-.08	.14	-.04	.01
1-month	-.35***	-.32***	-.39***	-.45***	-.01	.05	-.06	.02
6-months	-.34***	-.29**	-.52***	-.49***	-.09	.03	-.16	-.06
12-months	-.39***	-.34***	-.47***	-.58***	-.07	.02	-.22*	-.18
<u>Critical</u>								
Baseline	-.47***	-.37***	-.37***	-.32***	-.12	.02	-.04	-.01
1-month	-.37***	-.40***	-.40***	-.32***	-.04	.03	.02	.06
6-months	-.37***	-.33***	-.56***	-.45***	-.06	-.01	-.07	-.07
12-months	-.27**	-.23**	-.39**	-.41***	-.11	-.06	-.10	-.19*

Note. Nonsupportive behaviors represent patients' acts toward the partner.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 31:

Spearman Correlations Between Partners' Nonsupportive Behaviors and Overall Mental and Physical Well-being (standardized).

<u>Partner Nonsupportive Behaviors</u>	<u>Partner Mental Well-being</u>					<u>Partner Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>		<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Nonsupportive</u>									
Baseline	-.30***	-.27**	-.27**	-.21*		-.06	.00	-.06	-.04
1-month	-.29**	-.48***	-.20*	-.22*		.10	.16	.09	.07
6-months	-.33***	-.50***	-.33***	-.44***		-.09	-.04	-.15	-.14
12-months	-.24*	-.48***	-.27**	-.49***		.01	.06	-.02	.01
<u>Avoidant</u>									
Baseline	-.22**	-.27**	-.19	-.19		-.08	-.06	-.11	-.15
1-month	-.26**	-.40***	-.22*	-.22*		.05	.16	.02	-.02
6-months	-.27**	-.45***	-.28**	-.35***		-.14	-.07	-.16	-.17
12-months	-.29**	-.47***	-.30**	-.49***		-.09	.03	-.11	-.07
<u>Critical</u>									
Baseline	-.25**	.22*	.26**	-.17		.05	.11	.06	.12
1-month	-.25**	-.48***	.18	-.23*		.15	.19*	.15	.13
6-months	-.30	-.44***	-.29**	-.41***		.00	-.03	-.10	-.06
12-months	-.26**	-.40***	-.23*	-.40***		.12	.07	.03	.04

Note. Nonsupportive behaviors represent partners' acts toward the patient.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 32:

Spearman Correlations Between Patients' Overall Mental and Physical Well-being (standardized) and Partners' Nonsupportive Behaviors.

<u>Partner</u>	<u>Patient Mental Well-being</u>				<u>Patient Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Nonsupportive</u>								
Baseline	-.15	-.04	-.12	-.19	-.12	.03	-.05	-.05
1-month	-.21*	-.14	-.19	-.09	.06	-.10	-.01	-.07
6-months	-.29	-.18	-.28	-.25	-.14	-.17	-.15	-.21*
12-months	-.21*	-.12	-.12	-.15	-.07	-.09	-.10	-.11
<u>Avoidant</u>								
Baseline	-.19*	-.06	-.13	-.19	-.22**	-.03	-.15	-.16
1-month	-.18	-.17	-.15	-.07	-.02	-.11	-.10	-.15
6-months	-.26**	-.17	-.21*	-.24*	-.16	-.14	-.17	-.20*
12-months	-.21*	-.15	-.18	-.20*	-.08	-.03	-.10	-.12
<u>Critical</u>								
Baseline	-.10	-.02	-.12	-.16	.01	.06	.04	.07
1-month	-.19*	-.08	-.16	-.11	.14	-.05	.06	.03
6-months	-.18	-.09	-.29**	-.20*	-.04	-.13	-.06	-.15
12-months	-.19	-.05	-.12	-.12	.02	-.10	-.08	-.11

Note. Partner nonsupportive behaviors refer to partners' acts toward the patient.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 33:

Spearman Correlations Between Patients' Nonsupportive Behaviors and Partners' Overall Mental and Physical Well-being (standardized).

<u>Patient</u>	<u>Partner Mental Well-being</u>				<u>Partner Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Nonsupportive</u>								
Baseline	-.31***	-.33***	-.21*	-.31**	.04	-.03	.02	-.13
1-month	-.32***	-.39***	-.34***	-.35***	.07	.02	-.05	-.03
6-months	-.20*	-.26**	-.32**	-.34***	-.14	-.12	-.10	-.18
12-months	-.24*	-.32***	-.26**	-.43***	-.13	-.17	-.18	-.18
<u>Avoidant</u>								
Baseline	-.30***	-.26**	-.22*	-.27**	.00	-.02	-.02	-.13
1-month	-.32***	-.39***	-.33***	-.34***	.04	.02	-.06	-.02
6-months	-.16	-.24*	-.32**	-.32**	-.17	-.10	-.10	-.17
12-months	-.24*	-.32***	-.28**	-.43***	-.14	-.15	-.18	-.19
<u>Critical</u>								
Baseline	-.29***	-.34***	-.17	-.28**	.10	-.04	.07	-.09
1-month	-.26**	-.32***	-.23*	-.27**	.15	.05	.00	.00
6-months	-.25*	-.27**	-.27**	-.39***	-.08	-.16	-.10	-.16
12-months	-.18	-.29**	-.20*	-.38***	-.16	-.22*	-.20*	-.19*

Note. Patient nonsupportive behaviors refer to patients' acts toward the partner.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 34:

Spearman Correlations Between Patient Social Support and Overall Mental and Physical Well-being (standardized).

<u>Patient Social Support</u>	<u>Patient Mental Well-being</u>				<u>Patient Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Support</u>								
Baseline	.36***	.34***	.41***	.42***	.08	.07	.20*	.20*
1-month	.31***	.39***	.38***	.26**	.15	.09	.20*	.04
6-months	.40***	.34***	.51***	.49***	.11	.09	.16	.12
12-months	.36***	.23*	.45***	.52***	.11	.10	.32***	.24*
<u>Action-facilitating</u>								
Baseline	.29***	.26**	.31**	.26**	.06	.01	.12	.19*
1-month	.26**	.29**	.39***	.27**	.15	.06	.19*	.07
6-months	.45***	.36***	.49***	.43***	.22*	.20*	.21*	.17
12-months	.30**	.16	.37	.42***	.11	.06	.29*	.20*
<u>Comfort-support</u>								
Baseline	.36***	.34***	.41***	.42***	.10	.10	.20*	.19*
1-month	.34***	.35***	.38***	.31**	.12	.07	.20*	.04
6-months	.37***	.34***	.51***	.49***	.10	.08	.16	.11
12-months	.38***	.26**	.53***	.57***	.11	.11	.31**	.24*

*p<.05, **p<.01, ***p<.001

Table 35:

Spearman Correlations Between Partner Social Support and Overall Mental and Physical Well-being (standardized).

Partner Social Support	Partner Mental Well-being				Partner Physical Well-Being			
	Baseline	1-month	6-month	12-month	Baseline	1-month	6-month	12-month
<u>Overall Support</u>								
Baseline	.11	.32***	.34***	.27**	.07	.08	.11	.20*
1-month	.23*	.43***	.33***	.29**	.08	.06	.16	.12
6-months	.18	.36***	.39***	.38***	.19	.20*	.23*	.22*
12-months	.16	.36***	.32***	.46***	.12	.09	.20*	.11
<u>Action-facilitating</u>								
Baseline	.21**	.28**	.35***	.28**	.08	.10	.04	.17
1-month	.27**	.36***	.31***	.29**	.02	.09	.13	.12
6-months	.20*	.32***	.33***	.32***	.08	.13	.16	.17
12-months	.22*	.36***	.34***	.51***	.13	.14	.25**	.16
<u>Comfort-support</u>								
Baseline	.10	.31***	.33***	.27**	.04	.08	.17	.24*
1-month	.24*	.51***	.33***	.30**	.08	.05	.15	.12
6-months	.20*	.41***	.40***	.39***	.18	.19	.27**	.22*
12-months	.17	.38***	.31**	.45***	.12	.10	.22*	.10

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 36:

Spearman Correlations Between Patients' Overall Mental and Physical Well-being (standardized) and Partner Perception of Social Support.

<u>Partner Social Support</u>	<u>Patient Mental Well-being</u>				<u>Patient Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Support</u>								
Baseline	.27***	-.01	.31**	.40***	.09	.09	.20*	.24**
1-month	.33***	.27**	.30**	.23*	.21*	.19*	.22*	.18
6-months	.32***	.27**	.39***	.30**	.26**	.24*	.31***	.30**
12-months	.26**	.14	.26**	.32***	.08	.07	.14	.15
<u>Action-facilitating</u>								
Baseline	.26**	.04	.28**	.34***	.05	.06	.14	.17
1-month	.31***	.28**	.30**	.26**	.22*	.14	.25**	.17
6-months	.30**	.23*	.36***	.20*	.18	.18	.25**	.26**
12-months	.28**	.14	.26**	.30**	.17	.10	.18	.23*
<u>Comfort-support</u>								
Baseline	.31***	.04	.35***	.43***	.16*	.12	.24*	.32**
1-month	.34***	.32***	.30**	.22*	.18	.25**	.18	.19*
6-months	.36***	.31***	.45***	.33***	.24*	.23*	.32***	.31**
12-months	.27**	.18	.30**	.33***	.10	.12	.16	.20*

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 37:

Spearman Correlations Between Partners' Overall Mental and Physical Well-being (standardized) and Patients' Perceptions of Partner Social Support.

<u>Patient Social Support</u>	<u>Partner Mental Well-being</u>				<u>Partner Physical Well-Being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Overall Support</u>								
Baseline	.07	.36***	.15	.35***	.06	.02	.04	.15
1-month	.14	.29**	.20*	.21*	-.06	-.08	-.01	.06
6-months	.26**	.34***	.28**	.36***	.12	.18	.17	.21*
12-months	.12	.20*	.20*	.32***	.23	.19	.19	.22*
<u>Action-facilitating</u>								
Baseline	.06	.30***	.00	.29**	.04	.03	.10	.10
1-month	.15	.36***	.26**	.31***	-.03	.02	.08	.17
6-months	.25*	.31***	.32***	.37***	.16	.15	.14	.24*
12-months	.15	.18	.19	.35***	.21*	.20*	.19*	.20*
<u>Comfort-support</u>								
Baseline	.05	.37***	.19**	.32***	.04	.00	.00	.16
1-month	.11	.25**	.17	.20*	-.11	-.12	-.04	.00
6-months	.19	.31**	.22*	.30**	.10	.16	.16	.20*
12-months	.11	.24*	.22*	.32***	.21*	.18	.19	.25**

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 38:

Regression Analyses Predicting Patients' Overall Mental Well-being (QOL) Across Time From Uncertainty and Patients' Perceptions of Overall Partner Support.

Model	Patient Mental Well-being							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
<u>Baseline</u>								
Mental well-being (baseline)	---	.17***	.32***	.31***	---	---	---	---
Uncertainty	5.1**		---		---		---	
Overall social support	6.6***		---		---		---	
<u>1-month</u>								
Mental well-being (baseline)	---	---	.26***	.50***	---	.23***	---	---
Mental well-being (1-month)	---		---		.46***		---	
Uncertainty	---		6.7***		---		---	
Overall social support	---		---		---		---	
<u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.32**	.40***	---	.54***
Mental well-being (6-months)	---		---		---		.64	
Uncertainty	---		---		5.2**		---	
Overall social support	---		---		6.1***		---	
<u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.64***	.59***
Uncertainty	---		---		---		---	
Overall social support	---		---		---		3.3**	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 39:

Regression Analyses Predicting Patients' Overall Mental Well-being (QOL) Across Time From Uncertainty and Own Nonsupportive Behaviors.

Model	Baseline	Adj R ²	Patient Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
<u>Baseline</u>								
Mental well-being (baseline)	---	.28***	.27***	.33***	---	---	---	
Uncertainty	5.6***		2.8*		---		---	
Nonsupport behaviors	-10.5***		-3.3*		---		---	
<u>1-month</u>								
Mental well-being (baseline)	---	---	.24***	.49	---	.26***	---	
Mental well-being (1-month)	---		---		.42		---	
Uncertainty	---		7.0***		---		---	
Nonsupport behaviors	---		---		-4.1*		---	
<u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.34***	.41***	---	.54***
Mental well-being (6-months)	---		---		---		.66***	
Uncertainty	---		---		5.8***		---	
Nonsupport behaviors	---		---		-5.5***		---	
<u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.63***	.58***
Uncertainty	---		---		---		---	
Nonsupport behaviors	---		---		---		-3.2*	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 40:

Regression Analyses Predicting Patients' Overall Mental Well-being (QOL) Across Time From Uncertainty, Patients' Perceptions of Overall Partner Support and Own Nonsupportive Behaviors.

Model	Patient Mental Well-being							
	Baseline	Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
Baseline								
Mental well-being (baseline)	---	.28***	.27***	.33***	---	---	---	---
Uncertainty	4.7**		---		---		---	
Overall social support	---		---		---		---	
Nonsupport behaviors	-9.4***		---		---		---	
1-month								
Mental well-being (baseline)	---	---	.25	.51***	---	.24***	---	---
Mental well-being (1-month)	---		---		.42**		---	
Uncertainty	---		6.6***		---		---	
Overall social support	---		---		---		---	
Nonsupport behaviors	---		---		---		---	
6-month								
Mental well-being (1-month)	---	---	---	---	.31**	.42***	---	.54***
Mental well-being (6-months)	---		---		---		.64***	
Uncertainty	---		---		.49**		---	
Overall social support	---		---		---		---	
Nonsupport behaviors	---		---		-3.7*		---	
12-month								
Mental well-being (6-months)	---	---	---	---	---	---	.62	.59**
Uncertainty	---		---		---		---	
Overall social support	---		---		---		---	
Nonsupport behaviors	---		---		---		---	

Note. Only significant relationships are reported.

*p<.05, **p<.01, ***p<.001

Table 41:

Regression Analyses Predicting Patients' Overall Mental Well-being (QOL) Across Time From Uncertainty and Partners' Perceptions of Overall Patient Support.

Model	Baseline	Adj R ²	Patient Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
<u>Baseline</u>								
Mental well-being (baseline)	---	.17***	.34***	.32***	---	---	---	---
Uncertainty	7.5***		2.9*		---		---	
Overall social support (partner)	5.7**		---		---		---	
<u>1-month</u>								
Mental well-being (baseline)	---	---	.27	.30***	---	.22***	---	---
Mental well-being (1-month)	---		---		.42**		---	
Uncertainty	---		6.6***		---		---	
Overall social support (partner)	---		---		---		---	
<u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.36***	.36***	---	.54***
Mental well-being (6-months)	---		---		---		.64***	
Uncertainty	---		---		6.5***		---	
Overall social support (partner)	---		---		---		---	
<u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.65	.57***
Uncertainty	---		---		---		---	
Overall social support (partner)	---		---		---		---	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 42:

Regression Analyses Predicting Partners' Overall Mental Well-being (QOL) Across Time from Uncertainty and Partners' Perceptions of Overall Patient Support.

Model (Partner Variables)	Baseline	Partner Mental Well-being						
		Adj R ²	1-month	Adj R ²	6-month	Adj R ²	12-month	Adj R ²
<u>Baseline</u>								
Mental well-being (baseline)	---	.12***	.45***	.40***	---	---	---	---
Uncertainty	8.1***		---		---		---	
Overall social support	---		5.5**		---		---	
<u>1-month</u>								
Mental well-being (baseline)	---	---	.45***	.50***	---	.40***	---	---
Mental well-being (1-month)	---		---		.51***		---	
Uncertainty	---		---		---		---	
Overall social support	---		7.0***		---		---	
<u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.47***	.47***	---	.56***
Mental well-being (6-months)	---		---		---		.60***	
Uncertainty	---		---		---		7.1***	
Overall social support	---		---		6.1***		---	
<u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.54***	.55***
Uncertainty	---		---		---		---	
Overall social support	---		---		---		5.3***	

Note. Only significant relationships are reported.

*p<.05, **p<.01, ***p<.001

Table 43:

Regression Analyses Predicting Partners' Overall Mental Well-being (QOL) Across Time From Uncertainty and Partners' Nonsupportive Behaviors Towards the Patient.

Model (Partner variables)	Baseline	Adj R ²	Partner Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
<u>Baseline</u>								
Mental well-being (baseline)	---	.17***	.46***	.36***	---	---	---	---
Uncertainty	8.2***		4.3*		---		---	
Nonsupport behaviors	-8.1**		---		---		---	
<u>1-month</u>								
Mental well-being (baseline)	---	---	.45***	.49***	---	.40***	---	---
Mental well-being (1-month)	---		---		.61***		---	
Uncertainty	---		4.6**		---		---	
Nonsupport behaviors	---		-7.9***		---		---	
<u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.49***	.42***	---	.56***
Mental well-being (6-months)	---		---		---		.56***	
Uncertainty	---		---		---		6.1***	
Nonsupport behaviors	---		---		-4.1*		---	
<u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.57***	.57***
Uncertainty	---		---		---		3.8*	
Nonsupport behaviors	---		---		---		-6.5***	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 44:

Regression Analyses Predicting Partners' Overall Mental Well-being (QOL) Across Time From Uncertainty, Partners' Perceptions of overall Patient support and Partners' Nonsupportive Behaviors Toward Patient.

Model (Partner variables)	Baseline	Adj R ²	Partner Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
Baseline								
Mental well-being (baseline)	---	.17***	.46***	.40***	---	---	---	---
Uncertainty	8.4***		---		---		---	
Overall social support	---		5.8**		---		---	
Nonsupport behaviors	-9.1**		---		---		---	
1-month								
Mental well-being (baseline)	---	---	.41***	.53***	---	.41***	---	---
Mental well-being (1-month)	---		---		.56***		---	
Uncertainty	---		---		---		---	
Overall social support	---		4.9**		---		---	
Nonsupport behaviors	---		-5.9**		---		---	
6-month								
Mental well-being (1-month)	---	---	---	---	.46***	.46***	---	.56***
Mental well-being (6-months)	---		---		---		.59***	
Uncertainty	---		---		---		6.8***	
Overall social support	---		---		5.7**		---	
Nonsupport behaviors	---		---		---		---	
12-month								
Mental well-being (6-months)	---	---	---	---	---	---	.53***	.58***
Uncertainty	---		---		---		---	
Overall social support	---		---		---		---	
Nonsupport behaviors	---		---		---		-4.5*	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 45:

Regression Analyses Predicting Partners' Overall Mental Well-being (QOL) Across Time From Uncertainty and Patients' Perceptions of Overall Partner Support.

Model (includes Patients)	Baseline	Adj R ²	Partner Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
<u>Baseline</u>								
Mental well-being (baseline)	---	.13***	.43***	.40***	---	---	---	---
Uncertainty (partner)	8.1***		---		---		---	
Overall support (patient)	---		6.1**		---		---	
<u>1-month</u>								
Mental well-being (baseline)	---	---	.44***	.41***	---	.36***	---	---
Mental well-being (1-month)	---		---		.53***		---	
Uncertainty (partner)	---		3.7*		---		---	
Overall support (patient)	---		6.4***		---		---	
<u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.48***	.35***	---	.54***
Mental well-being (6-months)	---		---		---		.59***	
Uncertainty (partner)	---		---		---		6.4***	
Overall support (patient)	---		---		---		---	
<u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.60	.53***
Uncertainty (partner)	---		---		---		4.4**	
Overall support (patient)	---		---		---		3.1*	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 46:

Regression Analyses Predicting Partners' Overall Mental Well-being (QOL) Across Time From Uncertainty and Patients' Nonsupportive Behaviors Towards the Partner.

Model	Baseline	Adj R ²	Partner Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
<u>Baseline</u>								
Mental well-being (baseline)	---	.23***	.39***	.38***	---	---	---	---
Uncertainty (partner)	7.4***		---		---		---	
Nonsupport behaviors (patient)	-7.7***		-5.02*		---		---	
 <u>1-month</u>								
Mental well-being (baseline)	---	---	.40***	.42***	---	.36***	---	---
Mental well-being (1-month)	---		---		.45***		---	
Uncertainty (partner)	---		3.4*		---		---	
Nonsupport behaviors (patient)	---		-5.8**		-3.6*		---	
 <u>6-month</u>								
Mental well-being (1-month)	---	---	---	---	.46***	.38***	---	.54***
Mental well-being (6-months)	---		---		---		.60***	
Uncertainty (partner)	---		---		---		6.7***	
Nonsupport behaviors (patient)	---		---		-3.9*		---	
 <u>12-month</u>								
Mental well-being (6-months)	---	---	---	---	---	---	.59*	.54***
Uncertainty (partner)	---		---		---		4.0**	
Nonsupport behaviors (patient)	---		---		---		-3.8*	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 47:

Regression Analyses Predicting Partners' Overall Mental Well-being (QOL) Across Time From Uncertainty, Patients' Perceptions of Overall Partner Support and Patients' Nonsupportive Behaviors Towards the Partner.

Model (Partner variables)	Baseline	Adj R ²	Partner Mental Well-being		6-month	Adj R ²	12-month	Adj R ²
			1-month	Adj R ²				
Baseline								
Mental well-being (baseline)	---	.23***	.38***	.40***	---	---	---	---
Uncertainty (partner)	7.8***		---		---		---	
Overall social support (patient)	---		5.1*		---		---	
Nonsupport behaviors (patient)	-8.6***		---		---		---	
1-month								
Mental well-being (baseline)	---	---	.41***	.42***	---	.40***	---	---
Mental well-being (1-month)	---		---		.48***		---	
Uncertainty (partner)	---		---		---		---	
Overall social support (patient)	---		4.7*		---		---	
Nonsupport behaviors (patient)	---		---		-5.2**		---	
6-month								
Mental well-being (1-month)	---	---	---	---	.47***	.37***	---	.54***
Mental well-being (6-months)	---		---		---		.59***	
Uncertainty (partner)	---		---		---		6.5***	
Overall social support (patient)	---		---		---		---	
Nonsupport behaviors (patient)	---		---		-4.2*		---	
12-month								
Mental well-being (6-months)	---	---	---	---	---	---	.59***	.54***
Uncertainty (partner)	---		---		---		3.9*	
Overall social support (patient)	---		---		---		---	
Nonsupport behaviors (patient)	---		---		---		---	

Note. Only significant relationships are reported.

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 48:

Spearman Correlations Between Patient Perceived Control and Overall Mental and Physical Well-being (standardized).

<u>Control</u>	<u>Patient Mental Well-being</u>				<u>Patient Physical Well-being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Baseline</u>	.16*	.27**	.24**	.17	.28***	.27**	.32***	.42***
<u>1-month</u>	.26**	.43***	.11	.12	.19*	.36***	.29**	.20*
<u>6-months</u>	.27**	.26**	.42***	.39***	.21*	.15	.42***	.38***
<u>12-months</u>	.18*	.18	.36***	.38***	.32***	.25**	.42***	.50***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 49:

Spearman Correlations Between Partner Perceived Control and Overall Mental and Physical Well-being (standardized).

<u>Control</u>	<u>Partner Mental Well-being</u>				<u>Partner Physical Well-being</u>			
	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>	<u>Baseline</u>	<u>1-month</u>	<u>6-month</u>	<u>12-month</u>
<u>Baseline</u>	.22**	.24*	.41***	.43***	.18*	.22*	.24*	.28**
<u>1-month</u>	.30**	.20*	.17	.18	.09	.24**	.14	.29**
<u>6-months</u>	.23*	.18	.18	.32***	.22*	.32***	.38***	.40***
<u>12-months</u>	.16	.11	.23	.32***	.33***	.39***	.42***	.38***

* $p < .05$, ** $p < .01$, *** $p < .001$

Key Research Accomplishments

- Among all the variables examined, only illness uncertainty had a consistent relationship with both mental and physical well-being; the other constructs, such as social support and nonsupportive behaviors, were related primarily to mental well-being.
- Study results suggest that the partner is more adversely affected by the cancer experience than the patient.
- Within patients, and even more within partners, nonsupportive behaviors were more consistently related to perceptions of support than illness uncertainty (i.e., more perceived support was related to less nonsupportive behaviors).
- The mental health of the patient, and especially that of the partner, was most consistently related to level of own nonsupportive behaviors (patient and partner) as well as being the target of nonsupportive behaviors (for partners only).

Reportable Outcomes

To date the only completed reportable outcome is a meeting abstract entitled: "Correlates of Quality of Life Among Prostate Cancer Patients and Their Spouses" presented at the Pan American Congress of Psychosocial and Behavioral Oncology Conference held October 20th – 23rd in New York City (See appendix E).

A total main outcomes paper is planned for completion by August of 2002.

Conclusions

Several of the study findings have implications for interventions that target the patient and the partner. We offer two here. First, among all the variables examined, only illness uncertainty had a consistent relationship with both mental and physical well-being; the other constructs, such as social support and nonsupportive behaviors were related primarily to mental well-being. Thus, there is a continuing need to understand and modify perceptions of illness uncertainty given its rather generalizable effects in several domains of the patients' and partners' lives. In particular, it is the patient's partner who might need the most support to decrease illness uncertainty.

Second, these results suggest that the partner is more adversely affected by the cancer experience than the patient. To date, the majority of observational and intervention studies have targeted the patient. However, it is the partner who may be in need of more support. Although the present findings may reflect women's tendency to self-disclose more negative thoughts and feelings than patients, this in itself does not negate the need to focus on the partner. In particular, based on our findings, patients need to be made aware that their own nonsupportive acts may have a profound and consistent effect on the QOL of the partner. Similarly, patients and partners need to be informed that their own nonsupportive behaviors can adversely affect their own mental well-being.

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Appendices

- A) Baseline Questionnaires
- B) One-month Questionnaires
- C) Six-month Questionnaires
- D) Twelve-month Questionnaires
- E) Meeting Abstract
- F) List of Personnel

Isaac M. Lipkus
Principal Investigator

Appendix A:
Baseline Questionnaires

Patient with a Spouse Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage paid envelope before your treatment for prostate cancer begins.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your wife, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at 919-956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / _____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. _____ Living with spouse or partner
2. _____ In a significant relationship, but not living together
3. _____ Not in a significant relationship

A9. What is your current marital status?

1. _____ Never married
2. _____ Married
3. _____ Separated
4. _____ Divorced
5. _____ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. _____ Your husband/wife
2. _____ Your mother
3. _____ Your father
4. _____ Your children 18 or under → How many? _____
5. _____ Your children over 18 → How many? _____
6. _____ Sister(s) → How many? _____
7. _____ Brother(s) → How many? _____
8. _____ Grandchildren → How many? _____
9. _____ Grandparent(s) → How many? _____
10. _____ Other relatives → How many? _____
11. _____ Other non-relatives → How many? _____
12. _____ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. _____ 0 - \$4,000
2. _____ \$4,001 - \$9,000
3. _____ \$9,001 - \$18,000
4. _____ \$18,001 - \$30,000
5. _____ \$30,001 - \$40,000
6. _____ \$40,001 - \$50,000
7. _____ \$50,001 - \$60,000
8. _____ Above \$60,000

A13. Altogether, how many people live on this income?

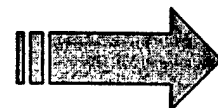
_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.		
Example: Asthma		No	Yes	Not At All	A Little	A Great Deal
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



The following statements are about your thoughts and feelings **since your diagnosis of prostate cancer**. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each Treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my pain will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have pain, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who's responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care after I leave the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I'm certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My physical distress is predictable; I know when it is going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the nurses to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



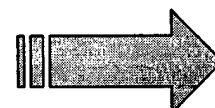
The following statements are about your sense of control over your life since your diagnosis of prostate cancer. Please circle the response that best describes how you think and feel since your diagnosis.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: Most of my problems are due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	There is no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	The really good things that happen to me are mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	I am responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	I can do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	Most of my problems are due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	I have little control over the bad things that happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	My misfortunes are a result of the mistakes I have made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	I am responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree



The next questions ask about marital attitudes and behaviors. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: Our marriage is strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	We have a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	My relationship with my partner is very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	Our marriage is strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	My relationship with my partner makes me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	I really feel like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, indicate the point which best describes the degree of happiness, everything considered, in your marriage. Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10			
Very unhappy		Happy	Perfectly happy



In the space below, please answer the following questions.

F1. Since your diagnosis of prostate cancer, what has your wife said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way?

F2. Since your diagnosis of prostate cancer, what have you wished that your wife had done or said to help you cope with cancer that she did not do?

The statements below are possible reactions that you may have had towards your wife since your diagnosis of prostate cancer. Please tell us how often you have responded this way **since your diagnosis with prostate cancer.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: Since your diagnosis, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	Since your diagnosis, you've acted impatient with her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	Since your diagnosis, you've seemed angry or upset with her when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	Since your diagnosis you've complimented the way she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	Since your diagnosis, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	Since your diagnosis, you've made her wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	Since your diagnosis, you've made it comfortable for her to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	Since your diagnosis, you've avoided being around her when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	Since your diagnosis, you've given her the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

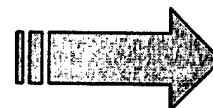
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	Since your diagnosis, you've shouted or yelled at her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	Since your diagnosis, you have made it a point to spend time with her when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	Since your diagnosis, you've not seemed to respect her feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	Since your diagnosis, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	Since your diagnosis, you've acted uncomfortable talking to her about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	Since your diagnosis, you've criticized the way she was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	Since your diagnosis, you have been affectionate with her when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	Since your diagnosis, you've acted less accepting of her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	Since your diagnosis, you've not been emotionally supportive of her when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The next questions concern your relationship with your wife **since your diagnosis of prostate cancer**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: Since my diagnosis, I have not been able to turn to my wife for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree	
H1	Since my diagnosis, I have been able to depend on my wife to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H2	Since my diagnosis, I have not been able to turn to my wife for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H3	Since my diagnosis, my wife has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H4	Since my diagnosis, I have felt personally responsible for my wife's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H5	Since my diagnosis, I have not thought that my wife respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H6	Since my diagnosis, if something went wrong my wife would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H7	Since my diagnosis, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H8	Since my diagnosis, my wife has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H9	Since my diagnosis, my wife has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree	

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
H10	Since my diagnosis, my wife has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H11	Since my diagnosis, my wife has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H12	Since my diagnosis, I have lacked a feeling of intimacy with my wife.	Strongly Disagree	Disagree	Agree	Strongly Agree	

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE		
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No	
I11. Cut down on the amount of time you spent on work or other activities	Yes	No	
I12. Accomplished less than you would like	Yes	No	
I13. Were limited in the kind of work or other activities	Yes	No	
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No	

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE		
I15. Cut down on the amount of time you spent on work or other activities	Yes	No	
I16. Accomplished less than you would like	Yes	No	
I17. Didn't do work or other activities as carefully as usual	Yes	No	

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
The time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS.**

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.	

J2. Which of the following best describes your urinary control **during the last 4 weeks**? Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.	

J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.	

How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem	
J5. Urine leakage interfering with your sexual activity.	No problem	Very small problem	Small problem	Moderate problem	Big problem	

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Please circle your response.

1	2	3	4	5
No problem	Very small problem	Small problem	Moderate problem	Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS**.

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
Once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
Distress Distress Distress Distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
Times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
Problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.

J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.

J17. How often have you awakened in the morning or night with an erection? Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)

J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response.

No	Yes, once	Yes, more than once

J19. Overall, how would you rate your ability to function sexually during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
No Very Small Moderate Big
Problem small problem problem problem problem

J21. Overall, how satisfied are you with the treatment you received for your prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Extremely Dissatisfied Dissatisfied Uncertain Satisfied Extremely
Dissatisfied satisfied

J22. Do your erections require chemical assistance? Please mark your response.

1. _____ No
2. _____ Yes If yes, please indicate which method you use.

- ☐ Viagra
☐ Injections
☐ Suppositories (MUSE)
☐ Vasomax
☐ Other Please specify: _____

Please answer the following questions related to your prostate cancer diagnosis.

K1. When did you **first** hear of the Prostate Specific Antigen (PSA) test or prostate blood test?

1. ☐ I have never heard of the PSA test.
2. ☐ I heard about it from the media (T.V., radio, newspaper, magazine).
3. ☐ I heard about it from my spouse.
4. ☐ I heard about it from my friends or relatives.
5. ☐ I heard about it from my primary care physician.
6. ☐ I heard about it from my urologist.
7. ☐ I heard about it today while in the clinic.

K2. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5
 None A little A moderate amount A lot A great deal

K3. Has a doctor ever talked to you about your PSA level? Please mark your response.

1. ☐ No (go to question K5).
2. ☐ Yes (go to question K4).
3. ☐ Don't know (go to question K5).

K4. How satisfied were you with the discussion that you had with your doctor about your PSA Level? Please circle your response.

1-----2-----3-----4-----5
 Not at all Slightly Moderately Quite a lot Completely
 Satisfied satisfied satisfied satisfied satisfied

K5. Do you know your last PSA value?

1. ☐ YES If Yes, please write it here: _____ PSA value (ng/ml)
2. ☐ NO If No, please mark one of the following options:
 - 2a. ☐ I don't remember my last PSA value.
 - 2b. ☐ I have never been told my PSA value.

K6. Do you know what different PSA levels mean? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Unsure

K7. How concerned were you when your doctor **first told you** that your PSA level was elevated or high? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite Extremely
Concerned concerned concerned concerned concerned

K8. Has a doctor ever talked to you about how your PSA level will be used to follow your treatment of prostate cancer? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Don't know.

K9. What do you think is the chance that you will have a recurrence of prostate cancer after your treatment? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance likely to happen

Did anyone assist you with the completion of this questionnaire?

No ☐ _____
Yes ☐ _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the second questionnaire one month after you begin your treatment for prostate cancer.

P:\DODPROST\MATERIAL\Revised9_98 PIS Questionnaire.doc September 23, 1998

Spouse Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage paid envelope before your spouse's treatment for prostate cancer begins.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your husband, and views of your husband's illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / _____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. ☐ Living with spouse or partner
2. ☐ In a significant relationship, but not living together
3. ☐ Not in a significant relationship

A9. What is your current marital status?

1. ☐ Never married
2. ☐ Married
3. ☐ Separated
4. ☐ Divorced
5. ☐ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. ☐ Your husband/wife
2. ☐ Your mother
3. ☐ Your father
4. ☐ Your children 18 or under → How many? _____
5. ☐ Your children over 18 → How many? _____
6. ☐ Sister(s) → How many? _____
7. ☐ Brother(s) → How many? _____
8. ☐ Grandchildren → How many? _____
9. ☐ Grandparent(s) → How many? _____
10. ☐ Other relatives → How many? _____
11. ☐ Other non-relatives → How many? _____
12. ☐ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. ☐ 0 - \$4,000
2. ☐ \$4,001 - \$9,000
3. ☐ \$9,001 - \$18,000
4. ☐ \$18,001 - \$30,000
5. ☐ \$30,001 - \$40,000
6. ☐ \$40,001 - \$50,000
7. ☐ \$50,001 - \$60,000
8. ☐ Above \$60,000

A13. Altogether, how many people live on this income?

_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.		
Example: Asthma		No	Yes	Not At All	A Little	A Great Deal
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



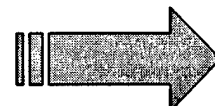
The following statements are about your thoughts and feelings since your husband was diagnosed with prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment for my husband is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my husband's illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my husband's pain will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my husband's condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment for my husband is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	I do not know when to expect things will be done to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	My husband's symptoms continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE					
C11	I can predict how long my husband's illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C12	My husband's treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C13	It is difficult to know if the treatments or medications my husband is getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C14	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C15	Because of the unpredictability of my husband's illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C16	The course of my husband's illness keeps changing. He has good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C17	It's vague to me how I will manage my husband's care after he leaves the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C18	It is not clear what is going to happen to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C19	I usually know if my husband is going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C20	The results of my husband's tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C21	The effectiveness of my husband's treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C22	It is difficult to determine how long it will be before I can care for my husband by myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C23	I can generally predict the course of my husband's illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	Because of the treatment, what my husband can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I am certain they will not find anything else wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	They have not given my husband a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	My husband's physical distress is predictable; I know when it is going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	My husband's diagnosis is definite and will not change.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	I can depend on the nurses to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	The seriousness of my husband's illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

Please continue to the next page of the questionnaire.

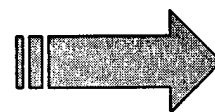


The following statements are about your sense of control over your life since your husband's prostate cancer diagnosis. Please circle the response that best describes how you think and feel about each statement.

SENSE OF CONTROL		CIRCLE RESPONSE				
Example: Most of my problems are due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	There is no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	The really good things that happen to me are mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	I am responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	I can do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	Most of my problems are due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	I have little control over the bad things that happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	My misfortunes are a result of the mistakes I have made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	I am responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best describes your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: Our marriage is strong.		Strongly Disagree	1-----2-----3-----4----- <u>5</u> -----6-----7 Strongly Agree
E1	We have a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	My relationship with my partner is very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	Our marriage is strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	My relationship with my partner makes me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	I really feel like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6 On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			



In the space below, please answer the following questions.

F1. Since your husband's diagnosis of prostate cancer, what has your husband said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way?

F2. Since your husband's diagnosis of prostate cancer, what have you wished that your husband had done or said to help you cope with his cancer that he did not do?

The statements below are possible reactions that you may have had towards your husband since his diagnosis of prostate cancer. Please tell us how often you have responded this way **since his diagnosis**.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: Since your husband's diagnosis, you seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	Since your husband's diagnosis, you've acted impatient with him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	Since your husband's diagnosis, you've seemed angry or upset with him when he needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	Since your husband's diagnosis, you've complimented the way he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	Since your husband's diagnosis, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	Since your husband's diagnosis, you've made him wait a long time for help when he needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	Since your husband's diagnosis, you've made it comfortable for him to share with you how he was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	Since your husband's diagnosis, you've avoided being around him when he was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G8	Since your husband's diagnosis, you've given him the idea you really did not want to talk about a problem he was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G9	Since your husband's diagnosis, you've shouted or yelled at him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	Since your husband's diagnosis, you've made it a point to spend time with him when you thought he was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	Since your husband's diagnosis, you haven't seemed to respect his feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	Since your husband's diagnosis, you've complained about his illness or about helping him with a task he found difficult to do by himself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	Since your husband's diagnosis, you've acted uncomfortable talking to him about his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	Since your husband's diagnosis, you've criticized the way he was coping with his disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	Since your husband's diagnosis, you've been affectionate with him when you thought he needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	Since your husband's diagnosis, you've acted less accepting of him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	Since your husband's diagnosis, you haven't been emotionally supportive of him when he expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The next set of questions concern your relationship with your husband **since his diagnosis of prostate cancer**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
Example: My husband does not view me as competent.		Strongly Disagree	Disagree	Agree	Strongly Agree	
H1	Since my husband's diagnosis, I have been able to depend on him to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H2	Since my husband's diagnosis, I have not been able to turn to him for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H3	Since my husband's diagnosis, he has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H4	Since my husband's diagnosis, I have felt personally responsible for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H5	Since my husband's diagnosis, I have not thought that he respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H6	Since my husband's diagnosis, if something went wrong he would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H7	Since my husband's diagnosis, I have had a close relationship with him that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H8	Since my husband's diagnosis, he has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H9	Since my husband's diagnosis, he has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree	

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
H10	Since my husband's diagnosis, he has not really relied on me for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H11	Since my husband's diagnosis, he has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H12	Since my husband's diagnosis, I have lacked a feeling of intimacy with him.	Strongly Disagree	Disagree	Agree	Strongly Agree	

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE		
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No	
I11. Cut down on the amount of time you spent on work or other activities	Yes	No	
I12. Accomplished less than you would like	Yes	No	
I13. Were limited in the kind of work or other activities	Yes	No	
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No	

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE		
I15. Cut down on the amount of time you spent on work or other activities	Yes	No	
I16. Accomplished less than you would like	Yes	No	
I17. Didn't do work or other activities as carefully as usual	Yes	No	

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
The time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

Please answer the following questions related to your husband's prostate cancer diagnosis.

K1. When did you **first** hear of the Prostate Specific Antigen (PSA) test or prostate blood test?

1. ☐ I have never heard of the PSA test.
2. ☐ I heard about it from the media (T.V., radio, newspaper, magazine).
3. ☐ I heard about it from my husband.
4. ☐ I heard about it from my friends or relatives.
5. ☐ I heard about it from my primary care physician.
6. ☐ I heard about it from my husband's urologist.
7. ☐ I heard about it today while in the clinic.

K2. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5
None A little A moderate amount A lot A great deal

K3. Has a doctor ever talked to you about your husband's PSA level? Please mark your response.

1. ☐ No (go to question K5).
2. ☐ Yes (go to question K4).
3. ☐ Don't know (go to question K5).

K4. How satisfied were you with the discussion that you had with your husband's doctor about his PSA level? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a lot Completely
Satisfied satisfied satisfied satisfied satisfied

K5. Do you know your husband's last PSA value?

1. ☐ YES If Yes, please write it here: _____ PSA value (ng/ml)

2. ☐ NO If No, please mark one of the following options:

2a. ☐ I don't remember his last PSA value.

2b. ☐ I have never been told my husband's PSA value.

K6. Do you know what different PSA levels mean? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Unsure

K7. How concerned were you when your doctor **first told your husband** that his PSA level was elevated or high? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite Extremely
Concerned concerned concerned concerned concerned

K8. Has a doctor ever talked to you about how your husband's PSA level will be used to follow his treatment of prostate cancer? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Don't know.

K9. What do you think is the chance that your husband will have a recurrence of prostate cancer after his treatment? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance likely to happen

Did anyone assist you with the completion of this questionnaire?

No ☐ _____
Yes ☐ _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the second questionnaire one month after your spouse begins his treatment for prostate cancer.

PROSTATECANCERRESEARCHPROGRAM
DODPROSTMATERIAL
Revised 9/98 S Questionnaire.doc
September 23, 1998

Isaac M. Lipkus
Principal Investigator

Appendix B:
One-Month Questionnaires

Patient with a Spouse One-Month Follow-Up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____
Street Apt. #

City State Zip Code

A4. Home Phone Number: (____) _____ - _____



The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.** Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have impotence, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care now that I've left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

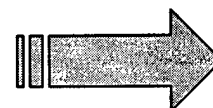
THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment's side effects, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I am certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life **during the past month**. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our marriage has been strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our marriage has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u> . Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			



In the space below, please answer the following questions.

F1. During the past month, what has your wife said or done that you experienced as most annoying or That upset you, made you angry, or just somehow rubbed you the wrong way?

F2. During the past month, what have you wished that your wife had done or said to help you cope with recovering from cancer that she did not do?

The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way during the past month.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with her when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made her wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for her to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around her when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given her the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with her when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect her feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to her about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way she was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with her when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of her when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your wife during the past month. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my wife for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my wife to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my wife for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my wife has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my wife's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my wife respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my wife would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my wife has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my wife has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H10	During the past month, my wife has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my wife.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	Yes	No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of the time Most of the time Some of the time A little of the time None of the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS.**

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day

About once a week.

Less than once a week.

Not at all.

J2. Which of the following best describes your urinary control **during the last 4 weeks?** Please circle your response.

No control whatsoever.

Frequent dribbling.

Occasional dribbling.

Total control.

J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks?** Please circle your response.

3 or more pads per day.

1-2 pads per day.

No pads.

How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.

No problem

Very small problem

Small problem

Moderate problem

Big problem

J5. Urine leakage interfering with your sexual activity.

No problem

Very small problem

Small problem

Moderate problem

Big problem

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks?** Please circle your response.

1-----2-----3-----4-----5
 No problem Very Small problem Small problem Moderate problem Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS.**

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the Last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
distress distress distress distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.

J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.

J17. How often have you awakened in the morning or night with an erection? Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)

J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response.

No	Yes, once	Yes, more than once

J19. Overall, how would you rate your ability to function sexually during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
No Very Small Moderate Big
problem small problem problem problem problem

J21. Overall, how satisfied are you with the treatment you received for your prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Extremely Dissatisfied Uncertain Satisfied Extremely
dissatisfied satisfied

J22a. Have you had erections since your treatment for prostate cancer?

1. _____ No If no please go to question K1.
2. _____ Yes If yes, please go to question J22b.

J22b. Do your erections require assistance? Please mark your response.

1. _____ No If no, please go to question K1.
2. _____ Yes If yes, please indicate which method you use.

- ☐ Viagra
☐ Vasomax
☐ Penile Injections
☐ Urethral Suppositories (MUSE)
☐ Vacuum Device
☐ Constriction Ring
☐ Other Please specify: _____

Please answer the following questions related to your prostate cancer diagnosis.

K1. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5 None
A little A moderate A lot A great deal
amount

K2. Did a doctor ever talk to you about your PSA level after surgery? Please mark your response.

1. ☐ Yes (**Go to K3a**)

K3a. How satisfied were you with the discussion that you had with your doctor about your PSA level after surgery? Please circle your response; then go to question K4.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a lot Completely
satisfied satisfied satisfied satisfied satisfied

2. ☐ No (**Go to K3b**)

K3b. Do you wish you'd had the opportunity to talk to your doctor about your PSA level after surgery? ☐ YES ☐ NO

3. ☐ Don't know

K4. Do you know your last PSA value?

1. ☐ YES If Yes, please write it here: _____ PSA value (ng/ml)

2. ☐ NO If No, please mark one of the following options:

2a. ☐ I don't remember my last PSA value.

2b. ☐ I have never been told my PSA value.

K5. Do you know what different PSA levels mean? Please mark your response.

1. ☐ No
2. ☐ Yes
3. ☐ Unsure

K6. Has a doctor ever talked to you about how your PSA level will be used to follow your treatment of prostate cancer? Please mark your response.

1. ☐ No
2. ☐ Yes
3. ☐ Don't know

K7. What do you think is the chance that you will have a recurrence of prostate cancer after your treatment? Please circle your response.

1-----2-----3-----4-----5-----6-----7						
No	Very	Unlikely	Moderate	Likely	Very	Certain
chance	unlikely		chance		likely	to happen

K8. How worried are you that you will have a recurrence of prostate cancer? Please circle your response.

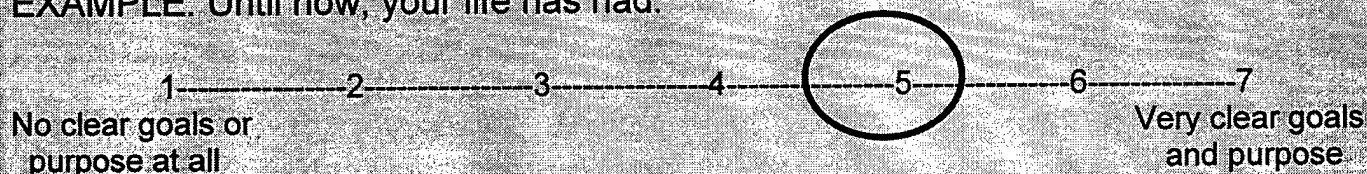
1-----2-----3-----4-----5				
Not at all	Slightly	Moderately	Very	Extremely
worried	worried	worried	worried	worried

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

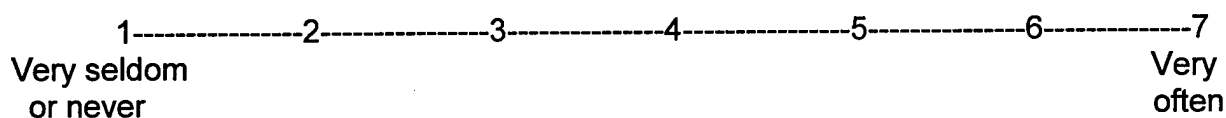
EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

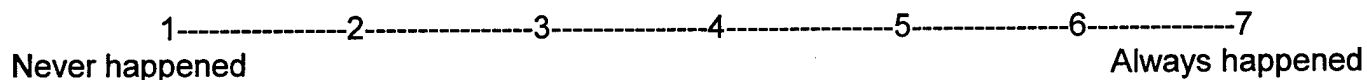
EXAMPLE: Until now, your life has had:



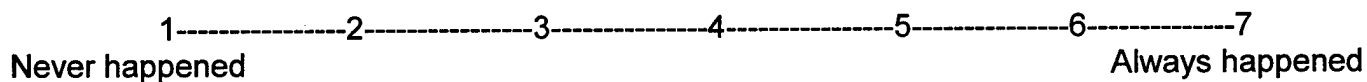
M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.



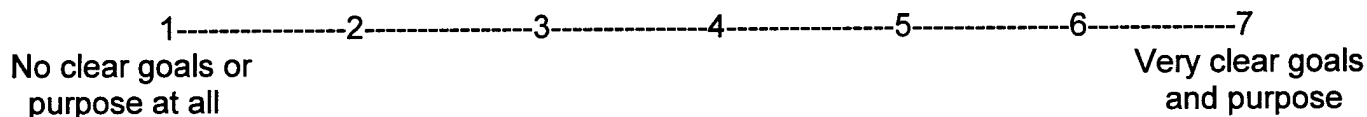
M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.



M3. Has it happened that people whom you counted on disappointed you? Please circle your response.



M4. Until now, your life has had:



M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____

Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the third questionnaire six months from your treatment and/or management initiation date.

Spouse One-Month Follow-up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your husband, and views of your husband's illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____



The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.
Please circle the statement that best describes your thoughts and feelings.
Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment for my husband is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my husband's illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my husband's incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my husband's condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment for my husband is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	I do not know when to expect things will be done to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	My husband's symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C11	I can predict how long my husband's illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C12	My husband's treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	It is difficult to know if the treatments or medications my husband is getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	Because of the unpredictability of my husband's illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	The course of my husband's illness keeps changing. He has good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	It's vague to me how I will manage my husband's care now that he's left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is not clear what is going to happen to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I usually know if my husband is going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	The results of my husband's tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	The effectiveness of my husband's treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	It is difficult to determine how long it will be before I can care for my husband by myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C23	I can generally predict the course of my husband's illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C24	Because of the treatment's side effects, what my husband can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I am certain they will not find anything else wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	They have not given my husband a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	My husband's incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	My husband's diagnosis is definite and will not change.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	The seriousness of my husband's illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

Please continue to the next page of the questionnaire.

The following statements are about your sense of control over your life **during the past month**. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our marriage has been strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our marriage has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u>. Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			



In the space below, please answer the following questions.

F1. During the past month, what has your husband said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way?

F2. During the past month, what have you wished that your husband had done or said to help you cope with his recovery from cancer that he did not do?

The statements below are possible reactions that you may have had towards your husband. Please tell us how often you have responded this way during the past month.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with him when he needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made him wait a long time for help when he needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for him to share with you how he was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around him when he was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given him the idea you really did not want to talk about a problem he was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with him when you thought he was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect his feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems he might have, or about helping him with a task he found difficult to do by himself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to him about how he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way he was coping with his disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with him when you thought he needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of him when he expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your husband **during the past month**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my husband for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my husband to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my husband for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my husband has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my husband's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my husband respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my husband would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my husband that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my husband has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H9	During the past month, my husband has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree
H10	During the past month, my husband has not really relied on me for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my husband has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my husband.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT O PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS.** or each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks ...**

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of the time Most of the time Some of the time A little of the time None of the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

Please answer the following questions related to your husband's prostate cancer diagnosis.

K1. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5 None
A little A moderate A lot A great deal

K2. Did a doctor ever talk to you about your husband's PSA level after surgery? Please mark your response.

1. ____ Yes (Go to K3a)

K3a. How satisfied were you with the discussion that you had with your husband's doctor about his PSA level after surgery? Please circle your response; then go to question K4.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a lot Completely
satisfied satisfied satisfied satisfied satisfied

2. ____ No (Go to K3b)

K3b. Do you wish you'd had the opportunity to talk to your doctor about your husband's PSA level after surgery? _____ YES _____ No

3. ___ Don't know

K4. Do you know your husband's last PSA value?

1. YES. If Yes, please write it here: _____ PSA: _____

2. ____ NO If No, please mark one of the following options:

2a. _____ I don't remember my husband's last PSA value.

2b. _____ I have never been told my husband's PSA value.

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K5. Do you know what different PSA levels mean? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Unsure

K6. Has a doctor ever talked to you about how your husband's PSA level will be used to follow his treatment of prostate cancer? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Don't know.

K7. What do you think is the chance that your husband will have a recurrence of prostate cancer after his treatment? Please circle your response.

1-----	2-----	3-----	4-----	5-----	6-----	7-----
No chance	Very unlikely	Unlikely	Moderate chance	Likely	Very likely	Certain to happen

K8. How worried are you that your husband will have a recurrence of prostate cancer? Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all worried	Slightly worried	Moderately worried	Very worried	Extremely worried

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____
Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the third questionnaire six months from your husband's treatment and/or management initiation date.

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Isaac M. Lipkus
Principal Investigator

Appendix C:

Six-Month Questionnaires

Patient with a Partner Six-Month Follow-Up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your partner, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your partner. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

Alternate Phone Number: (____) _____ - _____

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each Treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have impotence, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care now that I've left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment's side effects, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I am certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life **during the past month**. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about relationship attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our relationship has been strong.		Strongly Disagree	1-----2-----3-----4----- 5 -----6-----7 Strongly Agree
E1	During the past month, we have had a good relationship.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our relationship has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your relationship <u>during the past month</u> . Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			



In the space below, please answer the following questions.

F1. During the past month, what has your partner said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way in regards to how you are coping with your prostate cancer?

F2. During the past month, what have you wished that your partner had done or said to help you cope with cancer that your partner did not do?

The statements below are possible reactions that you may have had towards your partner. Please tell us how often you have responded this way **during the past month.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with your partner when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way your partner was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made your partner wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for your partner to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around your partner when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given your partner, the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

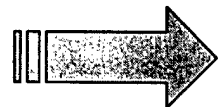
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with your partner when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect your partner's feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems your partner might have, or about helping your partner with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to your partner about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way your partner was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with your partner when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of your partner when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your partner **during the past month**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my partner for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my partner to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my partner for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my partner has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my partner's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my partner respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my partner would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my partner that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my partner has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my partner has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H10	During the past month, my partner has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my partner has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my partner.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please
 circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of the time Most of the time Some of the time A little of the time None of the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

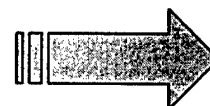
1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30F. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago, how would you rate your health in general now? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.

J2. Which of the following best describes your urinary control **during the last 4 weeks**? Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.

J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.

How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem
J5. Urine leakage interfering with your sexual activity.	No problem	Very small problem	Small problem	Moderate problem	Big problem

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Please circle your response.

1	2	3	4	5
No problem	Very small problem	Small problem	Moderate problem	Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS.**

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than About once Rarely
once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
distress distress distress distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.

J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.

J17. How often have you awakened in the morning or night with an erection?
Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)

J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response.

No	Yes, once	Yes, more than once

J19. Overall, how would you rate your ability to function sexually during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
 Very poor Poor Fair Good Very good

J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
No Very Small Moderate Big
problem small problem problem problem problem

J21. Overall, how satisfied are you with the treatment you received for your prostate cancer?
Please circle your response.

1-----2-----3-----4-----5
Extremely Dissatisfied Uncertain Satisfied Extremely
dissatisfied satisfied

J22a. Have you had erections since your treatment for prostate cancer?

1. _____ No If no please go to question K1.
2. _____ Yes If yes, please go to question J22b.

J22b. Do your erections require assistance? Please mark your response.

1. _____ No If no, please go to question K1.
2. _____ Yes If yes, please indicate which method you use.

- ☐ Viagra
☐ Vasomax
☐ Penile Injections
☐ Urethral Suppositories (MUSE)
☐ Vacuum Device
☐ Constriction Ring
☐ Other Please specify: _____

Please answer the following questions related to your prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

K1. Do you know why the PSA level is measured after surgery?

1 _____ NO (if no, please go to K2)

2 _____ YES (If yes, please answer K1a)

K1a. In the space below please explain briefly why you think the PSA is Measured after surgery.

K2. Do you know what it means to have a detectable PSA level after surgery?

1 _____ NO (if no, please go to K3)

2 _____ YES (if yes, please answer K2a)

K2a. Please explain briefly what you think it means to have a detectable PSA Level after surgery.

K3. Do you think having a detectable PSA level after surgery means that prostate cancer is still present?

1 _____ NO

2 _____ YES

3 _____ Don't know

K4. How many PSA tests have you had since surgery? _____ (Number of tests)

K5. When was your last PSA test? ____/____/____ (Date)

K6. Do you know your last PSA value?

1 ____ NO (if no, please mark one of the following options and go to K7.)

A. ____ I don't remember my last PSA value.

B. ____ I have never been told my PSA value.

2 ____ YES (if yes, please write it here: _____ PSA value (ng/ml) **and go to K6a.**)

K6a. How reassured were you by the results of your last PSA test? Please circle your response

1-----	2-----	3-----	4-----	5-----
Not at all reassured	Slightly reassured	Moderately reassured	Very reassured	Extremely reassured

K7. Was the value of your last PSA test "not detectable" (sometimes called "zero" or "less than zero")?

1 ____ NO (if no, please go to K8)

2 ____ Don't know (please go to K8)

3 ____ I have not had a PSA test since I had my surgery for prostate cancer. (go to K8)

4 ____ YES (if yes, please go to K7a.)

K7a. How reassuring is it to you that your last PSA value was "not detectable" (sometimes called "zero" or "less than zero")? Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all reassuring	Slightly reassuring	Moderately reassuring	Very reassuring	Extremely reassuring

K8. Do you wish you'd had the opportunity to talk more to your doctor about what the results of your last PSA test mean?

1 ____ YES

2 ____ NO

3 ____ Don't know

K9. Please circle your response. How worried are you about the results of your most recent PSA test(s)? Are you...

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K10. How worried are you about the actual number of PSA tests you've had since surgery? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K11. Do you feel you've had the right amount of PSA tests since your surgery?

- 1 ____ Should have had fewer (please go to K12)
2 ____ Number of tests is about right (please go to K12)
3 ____ Should have had more (if more, please go to K11a.)

K11a. How many more tests do you think you should have had? _____.

K12. How long after surgery (months or years) would you want to continue having your PSA level measured? Please enter your response in the appropriate space below.

_____ Months OR _____ Years

K13. Has a doctor ever talked with you about how the PSA test will be used to help monitor your prostate cancer?

- 1 ____ NO (If no, go to K14)
2 ____ YES (If yes, go to K13a.)

K13a. How satisfied have you been with your doctor's explanations about why the PSA test is used to help follow you after your surgery for prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Completely
satisfied satisfied satisfied satisfied satisfied

K14. What do you think is the chance that you will have a recurrence of prostate cancer after your surgery? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance likely to happen

K15. How worried are you that you will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K16. **Before your surgery**, did you join a prostate cancer support group?

1 _____ NO (if no, please go to K17.)

2 _____ YES (if yes, please go to K16a.)

K16a. About how often did you attend prostate cancer support group meetings prior to surgery?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month

K17. **After your surgery**, did you join a prostate cancer support group?

1 _____ NO

2 _____ YES (if yes, please go to K17a)

K17a. About how often did you attend prostate cancer support group meetings?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
 No clear goals or Purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
 Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
 Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
 Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
 No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____
Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the fourth questionnaire twelve months from your treatment and/or management initiation date.

\\CANCERLAN\ccontrl_pro\DODPROST\FORMS\MATERIAL\6 month fu\6 m followup patient partner.final.081099.doc 08/10/1999

Spouse Six-Month Follow-up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your husband, and views of your husband's illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____
Street Apt. #

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

Alternate Phone Number: (____) _____ - _____



The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.
Please circle the statement that best describes your thoughts and feelings.
Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment for my husband is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my husband's illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my husband's incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my husband's condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment for my husband is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	I do not know when to expect things will be done to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	My husband's symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C11	I can predict how long my husband's illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C12	My husband's treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	It is difficult to know if the treatments or medications my husband is getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	Because of the unpredictability of my husband's illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	The course of my husband's illness keeps changing. He has good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	It's vague to me how I will manage my husband's care now that he's left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is not clear what is going to happen to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I usually know if my husband is going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	The results of my husband's tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	The effectiveness of my husband's treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	It is difficult to determine how long it will be before I can care for my husband by myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C23	I can generally predict the course of my husband's illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C24	Because of the treatment's side effects, what my husband can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I am certain they will not find anything else wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	They have not given my husband a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	My husband's incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	My husband's diagnosis is definite and will not change.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	The seriousness of my husband's illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

Please continue to the next page of the questionnaire.

The following statements are about your sense of control over your life during the past month. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our marriage has been strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our marriage has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u> . Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			

In the space below, please answer the following questions.

F1. During the past month, what has your husband said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way in regards to how you are coping with your spouse's prostate cancer?

F2. During the past month, what have you wished that your husband had done or said to help you cope with his recovery from cancer that he did not do?

The statements below are possible reactions that you may have had towards your husband. Please tell us how often you have responded this way **during the past month.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with him when he needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made him wait a long time for help when he needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for him to share with you how he was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around him when he was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G8	During the past month, you've given him the idea you really did not want to talk about a problem he was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G9	During the past month, you've shouted or yelled at him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with him when you thought he was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect his feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems he might have, or about helping him with a task he found difficult to do by himself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to him about how he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way he was coping with his disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with him when you thought he needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of him when he expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your husband **during the past month**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my husband for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my husband to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my husband for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my husband has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my husband's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my husband respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my husband would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H7	During the past month, I have had a close relationship with my husband that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my husband has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my husband has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree
H10	During the past month, my husband has not really relied on me for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my husband has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my husband.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT O PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. or each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
The time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago, how would you rate your health in general now? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

Please answer the following questions related to your spouse's prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

K1. Do you know why the PSA level is measured after surgery?

1 _____ NO (if no, please go to K2)

2 _____ YES (If yes, please answer K1a)

K1a. In the space below please explain briefly why you think the PSA is measured after surgery.

K2. Do you know what it means to have a detectable PSA level after surgery?

1 _____ NO (if no, please go to K3)

2 _____ YES (if yes, please answer K2a)

K2a. Please explain briefly what you think it means to have a detectable PSA level after surgery.

K3. Do you think having a detectable PSA level after surgery means that prostate cancer is still present?

1 _____ NO

2 _____ YES

3 _____ Don't know

K4. How many PSA tests has your spouse had since surgery? _____ (Number of tests)

K5. When was your spouse's last PSA test? ____/____/____ (Date)

K6. Do you know your spouse's last PSA value?

1 ____ NO (if no, please mark one of the following options and go to K7.)

a. ____ I don't remember my spouse's last PSA value.

b. ____ I have never been told my spouse's PSA value.

2 ____ YES (if yes, please write it here: _____ PSA value (ng/ml) **and go to K6a.**)

K6a. How reassured were you by the results of your spouse's last PSA test?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
reassured reassured reassured reassured reassured

K7. Was the value of your spouse's last PSA test "not detectable" (sometimes called "zero" or "less than zero")?

1 ____ NO (If no, please go to K8)

2 ____ Don't know (please go to K8)

3 ____ My spouse has not had a PSA test since he had his surgery for prostate cancer.
(go to K8)

4 ____ YES (If yes, please go to K7a.)

K7a. How reassuring is it to you that your spouse's last PSA value was "not detectable" (sometimes called "zero" or "less than zero")? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
reassuring reassuring reassuring reassuring reassuring

K8. Do you wish you'd had the opportunity to talk more to your doctor about what the results of your spouse's last PSA test mean?

1 ____ YES

2 ____ NO

3 ____ Don't know

K9. How worried are you about the results of your spouse's most recent PSA test(s)?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K10. How worried are you about the actual number of PSA tests your spouse has had since surgery? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K11. Do you feel your spouse has had the right amount of PSA tests since his surgery?

- 1 ____ Should have had fewer (please go to K12)
2 ____ Number of tests is about right (please go to K12)
3 ____ Should have had more (if more, please go to K11a.)

K11a. How many more tests do you think he should have had? ____.

K12. How long after surgery (months or years) would you want your spouse to continue having his PSA level measured? Please enter your response in the appropriate space below.

____ Months OR ____ Years

K13. Has a doctor ever talked with you about how the PSA test will be used to help monitor your spouse's prostate cancer?

- 1 ____ NO (If no, go to K14)
2 ____ YES (If yes, go to K13a.)

K13a. How satisfied have you been with your doctor's explanations about why the PSA test is used to help follow your spouse after his surgery for prostate cancer?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Completely
satisfied satisfied satisfied satisfied satisfied

K14. What do you think is the chance that your spouse will have a recurrence of prostate cancer after his surgery? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance chance likely likely to happen

K15. How worried are you that your spouse will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K16. **Before your spouse's surgery**, did you join a prostate cancer support group?

- 1 _____ NO (if no, please go to K17.)
2 _____ YES (if yes, please go to K16a.)

K16a. About how often did you attend prostate cancer support group meetings prior to your spouse's surgery?

- 1 _____ Several times a week
2 _____ About once a week
3 _____ About twice a month
4 _____ About once a month

K17. **After your spouse's surgery**, did you join a prostate cancer support group?

- 1 _____ NO
2 _____ YES (if yes, please go to K17a)

K17a. About how often did you attend prostate cancer support group meetings?

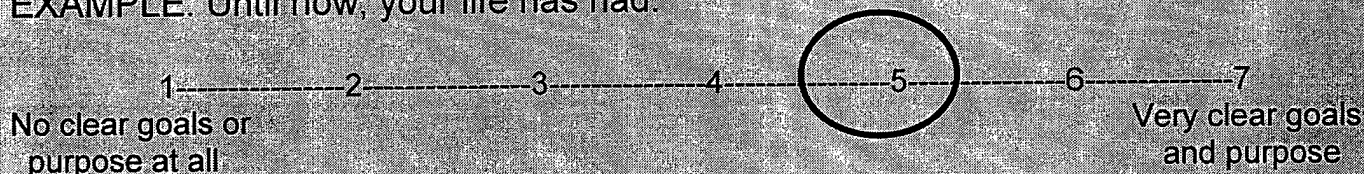
- 1 _____ Several times a week
2 _____ About once a week
3 _____ About twice a month
4 _____ About once a month

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

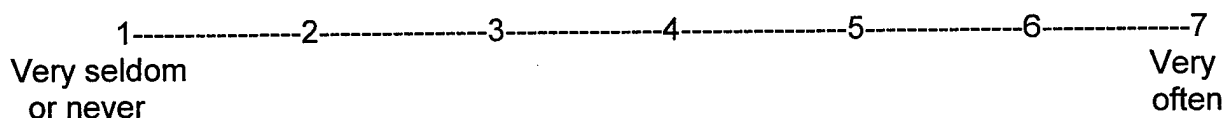
EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

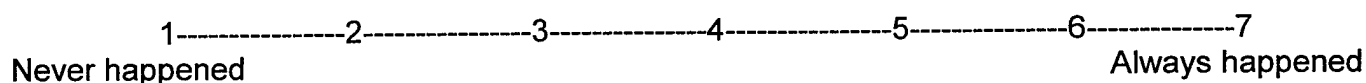
EXAMPLE: Until now, your life has had:



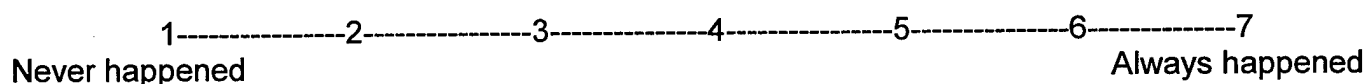
M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.



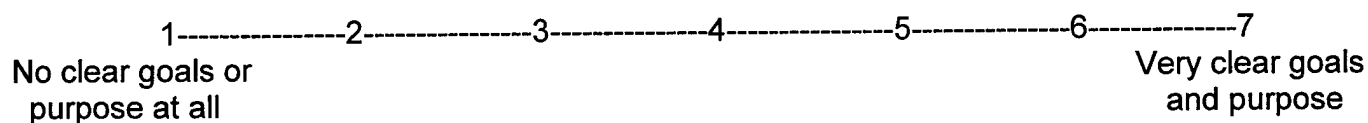
M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.



M3. Has it happened that people whom you counted on disappointed you? Please circle your response.



M4. Until now, your life has had:



M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____
Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the fourth questionnaire twelve months from your husband's treatment and/or management initiation date.

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Isaac M. Lipkus
Principal Investigator

Appendix D:
Twelve-Month Questionnaires

Patient with a Partner Twelve-Month Follow-Up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your partner, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your partner. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____
Street Apt. #

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

Alternate Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / _____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. ☐ Living with spouse or partner
2. ☐ In a significant relationship, but not living together
3. ☐ Not in a significant relationship

A9. What is your current marital status?

1. ☐ Never married
2. ☐ Married
3. ☐ Separated
4. ☐ Divorced
5. ☐ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. ☐ Your husband/wife
2. ☐ Your mother
3. ☐ Your father
4. ☐ Your children 18 or under → How many? _____
5. ☐ Your children over 18 → How many? _____
6. ☐ Sister(s) → How many? _____
7. ☐ Brother(s) → How many? _____
8. ☐ Grandchildren → How many? _____
9. ☐ Grandparent(s) → How many? _____
10. ☐ Other relatives → How many? _____
11. ☐ Other non-relatives → How many? _____
12. ☐ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. ☐ 0 - \$4,000
2. ☐ \$4,001 - \$9,000
3. ☐ \$9,001 - \$18,000
4. ☐ \$18,001 - \$30,000
5. ☐ \$30,001 - \$40,000
6. ☐ \$40,001 - \$50,000
7. ☐ \$50,001 - \$60,000
8. ☐ Above \$60,000

A13. Altogether, how many people live on this income?

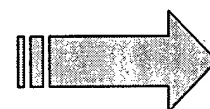
_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
Example: Asthma		No	Yes	Not At All	A Little	A Great Deal	
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal	
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal	
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal	
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal	
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal	
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal	
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal	
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal	
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal	
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal	
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal	
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal	
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal	
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal	
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal	
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal	
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal	

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.** Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each Treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have impotence, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care now that I've left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment's side effects, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I am certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life **during the past month**. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about relationship attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our relationship has been strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good relationship.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our relationship has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your relationship <u>during the past month</u>. Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			

In the space below, please answer the following questions.

F1. During the past month, what has your partner said or done that you experienced as most annoying Or that upset you, made you angry, or just somehow rubbed you the wrong way in regards to how You are coping with your prostate cancer?

F2. During the past month, what have you wished that your partner had done or said to help you cope with cancer that your partner did not do?

The statements below are possible reactions that you may have had towards your partner. Please tell us how often you have responded this way during the past month.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with your partner when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way your partner was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made your partner wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for your partner to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around your partner when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given your partner, the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

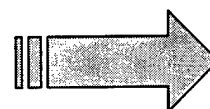
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with your partner when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect your partner's feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems your partner might have, or about helping your partner with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to your partner about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way your partner was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with your partner when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of your partner.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of your partner when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your partner **during the past month**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my partner for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my partner to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my partner for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my partner has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my partner's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my partner respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my partner would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my partner that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my partner has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my partner has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H10	During the past month, my partner has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my partner has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my partner.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
the time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.

J2. Which of the following best describes your urinary control **during the last 4 weeks**? Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.

J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.

How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem
J5. Urine leakage interfering with your sexual activity.	No problem	Very small problem	Small problem	Moderate problem	Big problem

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Please circle your response.

1-----2-----3-----4-----5
 No problem Very small problem Small problem Moderate problem Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS**.

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
distress distress distress distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.

J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.

J17. How often have you awakened in the morning or night with an erection?
Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)

J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response.

No

Yes, once

Yes, more than once

J19. Overall, how would you rate your ability to function sexually during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks?
Please circle your response.

1-----2-----3-----4-----5

No Very Small Moderate Big
problem small problem problem problem problem

J21. Overall, how satisfied are you with the treatment you received for your prostate cancer?
Please circle your response.

1-----2-----3-----4-----5
Extremely Dissatisfied Uncertain Satisfied Extremely
dissatisfied satisfied

J22a. Have you had erections since your treatment for prostate cancer?

1. _____ No If no please go to question K1.
2. _____ Yes If yes, please go to question J22b.

J22b. Do your erections require assistance? Please mark your response.

1. _____ No If no, please go to question K1.
2. _____ Yes If yes, please indicate which method you use.

☐ Viagra
☐ Vasomax
☐ Penile Injections
☐ Urethral Suppositories (MUSE)
☐ Vacuum Device
☐ Constriction Ring
☐ Other Please specify: _____

Please answer the following questions related to your prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

K1. Do you know why the PSA level is measured after surgery?

1 _____ NO (if no, please go to K2)

2 _____ YES (If yes, please answer K1a)

K1a. In the space below please explain briefly why you think the PSA is Measured after surgery.

K2. Do you know what it means to have a detectable PSA level after surgery?

1 _____ NO (if no, please go to K3)

2 _____ YES (if yes, please answer K2a)

K2a. Please explain briefly what you think it means to have a detectable PSA Level after surgery.

K3. Do you think having a detectable PSA level after surgery means that prostate cancer is still present?

1 _____ NO

2 _____ YES

3 _____ Don't know

K4. How many PSA tests have you had since surgery? _____ (Number of tests)

K5. When was your last PSA test? ____/____/____ (Date)

K6. Do you know your last PSA value?

1 ____ NO (if no, please mark one of the following options and go to K7.)

A. ____ I don't remember my last PSA value.

B. ____ I have never been told my PSA value.

2 ____ YES (if yes, please write it here: _____ PSA value (ng/ml) **and go to K6a.**)

K6a. How reassured were you by the results of your last PSA test? Please circle your response

1-----	2-----	3-----	4-----	5-----
Not at all reassured	Slightly reassured	Moderately reassured	Very reassured	Extremely reassured

K7. Was the value of your last PSA test "not detectable" (sometimes called "zero" or "less than zero")?

1 ____ NO (if no, please go to K8)

2 ____ Don't know (please go to K8)

3 ____ I have not had a PSA test since I had my surgery for prostate cancer. (go to K8)

4 ____ YES (if yes, please go to K7a.)

K7a. How reassuring is it to you that your last PSA value was "not detectable" (sometimes called "zero" or "less than zero")? Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all reassuring	Slightly reassuring	Moderately reassuring	Very reassuring	Extremely reassuring

K8. Do you wish you'd had the opportunity to talk more to your doctor about what the results of your last PSA test mean?

1 ____ YES

2 ____ NO

3 ____ Don't know

K9. Please circle your response. How worried are you about the results of your most recent PSA test(s)? Are you...

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K10. How worried are you about the actual number of PSA tests you've had since surgery?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K11. Do you feel you've had the right amount of PSA tests since your surgery?

- 1 _____ Should have had fewer (please go to K12)
2 _____ Number of tests is about right (please go to K12)
3 _____ Should have had more (if more, please go to K11a.)

K11a. How many more tests do you think you should have had? _____.

K12. How long after surgery (months or years) would you want to continue having your PSA level measured? Please enter your response in the appropriate space below.

_____ Months OR _____ Years

K13. Has a doctor ever talked with you about how the PSA test will be used to help monitor your prostate cancer?

- 1 _____ NO (If no, go to K14)
2 _____ YES (If yes, go to K13a.)

K13a. How satisfied have you been with your doctor's explanations about why the PSA test is used to help follow you after your surgery for prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Completely
satisfied satisfied satisfied satisfied satisfied

K14. What do you think is the chance that you will have a recurrence of prostate cancer after your surgery? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance chance likely likely to happen

K15. How worried are you that you will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at Slightly Moderately Very Extremely
Worried worried worried worried worried

K16. Out of 100 men diagnosed with early stage prostate cancer, how many do you think will have a recurrence of prostate cancer in their lifetime after having surgery.
(Please place your response in the form of a whole number from 0 to 100 in the space below)

K17. On a scale where 0% equals no chance and 100% equals certain to happen, what do you think is the likelihood that you will have a recurrence of prostate cancer in your lifetime?
(Please place your response in the form of a whole number from 0% to 100% in the space below)

_____ %

K18. If you were to have a recurrence of prostate cancer after surgery, when do you think that would happen?
(Please place your response in the space below indicating the number of years after surgery that you think you would have a recurrence)

_____ Year(s) after surgery

K19. **Before your surgery**, did you join a prostate cancer support group?

1 _____ NO (if no, please go to K20.)

2 _____ YES (if yes, please go to K19a.)

K19a. About how often did you attend prostate cancer support group meetings prior to surgery?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month

K20. **After your surgery**, did you join a prostate cancer support group?

1 _____ NO

2 _____ YES (if yes, please go to K20a)

K20a. About how often did you attend prostate cancer support group meetings?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month



Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or Purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____
Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! This is the final questionnaire of the SSECaP Project. Thank you for your participation

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Spouse Twelve-Month Follow-up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your husband, and views of your husband's illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

Alternate Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / ____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. ☐ Living with spouse or partner
2. ☐ In a significant relationship, but not living together
3. ☐ Not in a significant relationship

A9. What is your current marital status?

1. ☐ Never married
2. ☐ Married
3. ☐ Separated
4. ☐ Divorced
5. ☐ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. ☐ Your husband/wife
2. ☐ Your mother
3. ☐ Your father
4. ☐ Your children 18 or under → How many? _____
5. ☐ Your children over 18 → How many? _____
6. ☐ Sister(s) → How many? _____
7. ☐ Brother(s) → How many? _____
8. ☐ Grandchildren → How many? _____
9. ☐ Grandparent(s) → How many? _____
10. ☐ Other relatives → How many? _____
11. ☐ Other non-relatives → How many? _____
12. ☐ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. ☐ 0 - \$4,000
2. ☐ \$4,001 - \$9,000
3. ☐ \$9,001 - \$18,000
4. ☐ \$18,001 - \$30,000
5. ☐ \$30,001 - \$40,000
6. ☐ \$40,001 - \$50,000
7. ☐ \$50,001 - \$60,000
8. ☐ Above \$60,000

A13. Altogether, how many people live on this income?

_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.		
Example: Asthma		No	☒ Yes	Not At All	☒ A Little	A Great Deal
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment for my husband is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my husband's illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my husband's incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my husband's condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment for my husband is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	I do not know when to expect things will be done to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	My husband's symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C11	I can predict how long my husband's illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C12	My husband's treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	It is difficult to know if the treatments or medications my husband is getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	Because of the unpredictability of my husband's illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	The course of my husband's illness keeps changing. He has good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	It's vague to me how I will manage my husband's care now that he's left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is not clear what is going to happen to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I usually know if my husband is going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	The results of my husband's tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	The effectiveness of my husband's treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	It is difficult to determine how long it will be before I can care for my husband by myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since your husband began his treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C23	I can generally predict the course of my husband's illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C24	Because of the treatment's side effects, what my husband can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I am certain they will not find anything else wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	They have not given my husband a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	My husband's incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	My husband's diagnosis is definite and will not change.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	The seriousness of my husband's illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life **during the past month**. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about relationship attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our relationship has been strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good relationship.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our relationship has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your relationship <u>during the past month</u> . Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			

In the space below, please answer the following questions.

F1. During the past month, what has your husband said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way in regards to how you are coping with your spouse's prostate cancer?

F2. During the past month, what have you wished that your husband had done or said to help you cope with his recovery from cancer that he did not do?

The statements below are possible reactions that you may have had towards your husband. Please tell us how often you have responded this way during the past month.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with him when he needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made him wait a long time for help when he needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for him to share with you how he was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around him when he was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

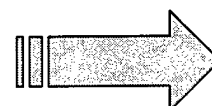
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G8	During the past month, you've given him the idea you really did not want to talk about a problem he was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G9	During the past month, you've shouted or yelled at him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with him when you thought he was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect his feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems he might have, or about helping him with a task he found difficult to do by himself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to him about how he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way he was coping with his disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with him when you thought he needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of him when he expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your husband **during the past month**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my husband for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my husband to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my husband for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my husband has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my husband's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my husband respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my husband would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H7	During the past month, I have had a close relationship with my husband that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my husband has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my husband has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree
H10	During the past month, my husband has not really relied on me for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my husband has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my husband.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT O PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	☒ Yes	☐ No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. or each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
The time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

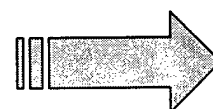
1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

Please answer the following questions related to your spouse's prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

K1. Do you know why the PSA level is measured after surgery?

1 _____ NO (if no, please go to K2)

2 _____ YES (If yes, please answer K1a)

K1a. In the space below please explain briefly why you think the PSA is measured after surgery.

K2. Do you know what it means to have a detectable PSA level after surgery?

1 _____ NO (if no, please go to K3)

2 _____ YES (if yes, please answer K2a)

K2a. Please explain briefly what you think it means to have a detectable PSA level after surgery.

K3. Do you think having a detectable PSA level after surgery means that prostate cancer is still present?

1 _____ NO

2 _____ YES

3 _____ Don't know

K4. How many PSA tests has your spouse had since surgery? _____ (Number of tests)

K5. When was your spouse's last PSA test? ____/____/____ (Date)

K6. Do you know your spouse's last PSA value?

1 ____ NO (if no, please mark one of the following options and go to K7.)

a. ____ I don't remember my spouse's last PSA value.

b. ____ I have never been told my spouse's PSA value.

2 ____ YES (if yes, please write it here: _____ PSA value (ng/ml) **and go to K6a.**)

K6a. How reassured were you by the results of your spouse's last PSA test?
Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all reassured	Slightly reassured	Moderately reassured	Very reassured	Extremely reassured

K7. Was the value of your spouse's last PSA test "not detectable" (sometimes called "zero")?

1 ____ NO (If no, please go to K8)

2 ____ Don't know (please go to K8)

3 ____ My spouse has not had a PSA test since he had his surgery for prostate cancer.
(go to K8)

4 ____ YES (If yes, please go to K7a.)

K7a. How reassuring is it to you that your spouse's last PSA value was "not detectable" (sometimes called "zero")? Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all reassuring	Slightly reassuring	Moderately reassuring	Very reassuring	Extremely reassuring

K8. Do you wish you'd had the opportunity to talk more to your doctor about what the results of your spouse's last PSA test mean?

1 ____ YES

2 ____ NO

3 ____ Don't know

K9. How worried are you about the results of your spouse's most recent PSA test(s)?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K10. How worried are you about the actual number of PSA tests your spouse has had since surgery? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K11. Do you feel your spouse has had the right amount of PSA tests since his surgery?

- 1 _____ Should have had fewer (please go to K12)
2 _____ Number of tests is about right (please go to K12)
3 _____ Should have had more (if more, please go to K11a.)

K11a. How many more tests do you think he should have had? _____.

K12. How long after surgery (months or years) would you want your spouse to continue having his PSA level measured? Please enter your response in the appropriate space below.

_____ Months OR _____ Years

K13. Has a doctor ever talked with you about how the PSA test will be used to help monitor your spouse's prostate cancer?

- 1 _____ NO (If no, go to K14)
2 _____ YES (If yes, go to K13a.)

K13a. How satisfied have you been with your doctor's explanations about why the PSA test is used to help follow your spouse after his surgery for prostate cancer?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Completely
satisfied satisfied satisfied satisfied satisfied

K14. What do you think is the chance that your spouse will have a recurrence of prostate cancer after his surgery? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No chance Very unlikely Unlikely Moderate chance Likely Very likely Certain to happen

K15. How worried are you that your spouse will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all worried Slightly worried Moderately worried Very worried Extremely worried

K16. Out of 100 men diagnosed with early stage prostate cancer, how many do you think will have a recurrence of prostate cancer in their lifetime after having surgery.

(Please place your response in the form of a whole number from 0 to 100 in the space below)

K17. On a scale where 0% equals no chance and 100% equals certain to happen, what do you think is the likelihood that your spouse will have a recurrence of prostate cancer in his lifetime?

(Please place your response in the form of a whole number from 0% to 100% in the space below)

_____ %

K18. If your spouse were to have a recurrence of prostate cancer after surgery, when do you think that would happen?

(Please place your response in the space below indicating the number of years after surgery that you think your spouse would have a recurrence)

_____ Year(s) after surgery

K19. **Before your surgery**, did you join a prostate cancer support group?

1 _____ NO (if no, please go to K20.)

2 _____ YES (if yes, please go to K19a.)

K19a. About how often did you attend prostate cancer support group meetings prior to surgery?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month

K20. **After your surgery**, did you join a prostate cancer support group?

1 _____ NO

2 _____ YES (if yes, please go to K20a)

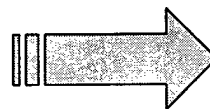
K20a. About how often did you attend prostate cancer support group meetings?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month



Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____
Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! This is the final questionnaire of the SSECaP Project. Thank you for your participation.

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Isaac M. Lipkus
Principal Investigator

Appendix E:
Meeting Abstract

Isaac M. Lipkus*, Elizabeth Clipp, Richard Potthoff , and
Cary Robertson
Duke University Medical Center, Durham, North Carolina, United States
June 1999

There has been little research exploring how prostate cancer patients and their spouses' feelings of disease uncertainty, perceived social support, negative social interactions (i.e., critical and avoidant behaviors), and marital satisfaction affect their own and their partners' quality of life. We explored these influences among 72 early stage prostate cancer patients and their spouses shortly before having surgery (radical prostatectomy).

Patients' emotional and social well-being, as assessed by the SF-36, were most consistently related to perceptions of their disease uncertainty, spousal support, degree to which they viewed their spouses as critical and avoidant, and to marital satisfaction. Spouses' quality of life was related less consistently to their own perceptions of these outcomes. Patients with wives that expressed greater marital satisfaction reported enhanced emotional well-being. However, spouses' quality of life was unrelated to patients' perceptions of their own disease uncertainty, perceived spousal support, spouses' negative and avoidant behaviors and marital satisfaction. Patients reported better emotional well-being, more energy/less fatigue, and less bodily pain than reported by their spouses. These data suggest that in contrast to their spouses, quality of life among men with early stage prostate cancer, prior to surgery, is related strongly to their feelings of disease uncertainty, to the nature of support they feel from their spouses, and to the quality of their spousal relationships. Future studies aimed at assessing quality of life in men with prostate cancer should take accounts from both members of the spousal relationship, focusing especially on the nature of support experienced by men between diagnosis of prostate cancer and surgical intervention.

Isaac M. Lipkus
Principal Investigator

Appendix F:

List of Personnel

List of Personnel

"The Effects of Supportive and Non-Supportive Behaviors on the Quality of Life of Prostate Cancer Patients and Their Spouses."

Isaac Lipkus, Ph.d
Principal Investigator (see attached Bio-Sketch)

Elizabeth C. Clipp (Jody), RN, MS, Ph.D.
Co-Investigator (see attached Bio-Sketch)

Cary Robertson, MD
Co-Investigator (see attached Bio-Sketch)

Dick Potthoff, Ph.D.
Statistician (see attached Bio-Sketch)

Deborah Iden, B.A.
Project Manager

Jill Smith, B.S.
Data Technician/Research Assistant

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel in the order listed on Form Page 2. Photocopy this page or follow this format for each person.

NAME	POSITION TITLE
Isaac M. Lipkus	Associate Research Professor
	Cancer Prevention, Detection & Control Research

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)			
INSTITUTION AND LOCATION	DEGREE (if applicable)	YEAR(s)	FIELD OF STUDY
University of California, San Diego, CA	B.A.	1986	Sociology
University of North Carolina at Chapel Hill, Chapel Hill, NC	M.A.	1988	Social Psychology
University of North Carolina at Chapel Hill, Chapel Hill, NC	Ph.D.	1991	Social Psychology

RESEARCH AND PROFESSIONAL EXPERIENCE: Concluding with present position, list, in chronological order, previous employment, experience, and honors. Include present membership on any Federal Government public advisory committee. List, in chronological order, the titles, all authors, and complete references to all publications during the past three years and to representative earlier publications pertinent to this application. If the list of publications in the last three years exceeds two pages, select the most pertinent publications. DO NOT EXCEED TWO PAGES.

PROFESSIONAL EXPERIENCE:

1991-1993 Postdoctoral Fellow, Duke University Medical Center, Department of Psychiatry, Durham, NC
 1992-1993 Correspondence Course Instructor, University of North Carolina at Chapel Hill, Department of Psychology, Chapel Hill, NC
 1993-1994 Postdoctoral Fellow, Ohio State University, Department of Psychiatry, Columbus, OH
 1994-1995 Visiting Assistant Professor, University of Wisconsin-Whitewater, Department of Psychiatry, Whitewater, WI
 1994-1995 Adjunct Assistant Professor, Southwestern University, Department of Psychology, Kenner, LA
 1995-1999 Assistant Research Professor, Duke University Medical Center, Department of Psychiatry, Program of Cancer Prevention, Detection and Control Research, Durham, NC.
 1999-present Associate Research Professor, Duke University Medical Center, Department of Psychiatry, Program of Cancer Prevention, Detection and Control Research, Durham, NC.

HONORS AND PROFESSIONAL ACTIVITIES (Examples)

1991-1993 Postdoctoral Fellow, Duke University Medical Center
 1992-1993 Evening College Instructor, Wake Technical Community College
 1994-1995 Postdoctoral Fellow, Ohio State University

PUBLICATIONS:

Rusbult C, Verette J, Whitney G, Slovik L, Lipkus I. Accommodation processes in close relationships: Theory and preliminary empirical evidence. *J Pers Soc Psychol* 60(1): 53-78, 1991.
 Lipkus IM. The construction and preliminary validation of a global belief in a just world scale and the exploratory analysis of the multidimensional belief in a just world scale. *Pers Individ Diff* 12: 1171-1178, 1991.
 Lipkus IM. A heuristic model to explain perceptions of unjust events. *Soc Just Research*, 5:359-384, 1992.
 Barefoot JC, Beckham JC, Haney TL, Siegler IC, Lipkus IM. Age differences in hostility among middle-aged and older adults. *Psychol Aging* 1: 3-9, 1993.
 Lipkus IM, Martz JM, Panter A, Drigotas SM, Feaganes, JR. Do optimists distort their predictions of future positive and negative events? *Pers Individ Diff* 15: 577-589, 1993.
 Lipkus IM, Rusbult CE. Reactions to individuals who are consistently positive or negative: The impact of differing interaction goals. *Hum Rel* 46: 481-499, 1993.
 Lipkus IM, Siegler IC. The belief in a just world and perceptions of discrimination. *J Psychol* 127: 465-474, 1993.
 Rusbult CE, Onizuka R, Lipkus IM. What do we really want? Mental models of ideal romantic involvement explored through multidimensional scaling. *J Exper Soc Psychol* 29: 493-527, 1993.
 Lipkus IM, Barefoot JC, Williams RB, Siegler IC. Personality measures as predictors of smoking initiation and cessation. *Health Psychol* 13: 149-155, 1994.

- Lipkus IM, Barefoot JC, Feaganes JR, Siegler IC. A short MMPI scale to identify people who are likely to begin smoking. *J Pers Assess* 63: 213-222, 1994.
- Barefoot JC, Lipkus IM. The assessment of anger and hostility. In A Siegman and T Smith (Eds.), *Anger, hostility, and the heart*. Erlbaum, 1994.
- Lipkus IM, Siegler IC. Do comparative self-appraisals during young adulthood predict adult personality? *Psychol Aging* 10: 229-237, 1995.
- Malarkey WB, Lipkus IM, Cacioppo JT. The dissociation of catecholamine and hypothalamic-pituitary-adrenal responses to daily stressors using Dexamethasone. *J Clinl Endocrinol Metab* 80: 2458-2463, 1995.
- Lipkus IM, Bissonnette V. Belief in a Just World, Willingness to accommodate, and Marital Well-Being. *Pers Soc Psychol Bulletin* 22: 666-677, 1996.
- Lipkus IM, Dalbert C, Siegler IC. The importance of distinguishing the belief in a just world for self versus others: Implications for psychological well-being. *Pers Soc Psychol Bulletin* 22: 1043-1056, 1996.
- Lipkus IM, Rimer BK, Lyna PR et al. Colorectal screening patterns and perceptions of risk among African-Americans users of a Community Health Center. *J Comm Health* 21: 409-427, 1996.
- Lipkus IM, Rimer BK, Strigo T. The relationships among objective risk, subjective risk, and mammography stages of change. *Cancer Epidemiol Biomarkers Prev* 5: 1005-1011, 1996.
- Stoddard AM, Rimer BK, Lane D, Fox SA, Lipkus I, Luckmann R, Avrunin JS, Sprachman S, Costanza M, Urban N. Under-users of mammogram screening: stage of adoption in five U.S. sub-populations. *Prev Med* 27: 478-487, 1998.
- Bloom PN, Lipkus IM, Schwartz-Bloom, McBride CM, Feaganes J. A field experiment using the foot-in-the-door technique to recruit teen smokers to a smoking cessation program. *Soc Mark Quart Summer* 61-63, 1998.
- Lipkus IM, Lyna PR, Rimer BK. Using tailored interventions to enhance smoking cessation among African-Americans at a Community Health Center. *Nic Tobacco Res* 1: 77-85, 1999.
- Lipkus IM, Hollands J. The visual communication of risk. *Mono J Nat Cancer Instit* 25: 149-163, 1999.
- Lipkus IM, Iden D, Terrenoire J, Feaganes J. Relationships Among Breast Cancer Concern, Risk Perceptions, and Interest in Genetic Testing for Breast Cancer Susceptibility Among African-American Women With and Without a Family History of Breast Cancer. *Cancer Epidemiol Biomarkers Prev* 8: 533-540, 1999.
- Lipkus IM, Crawford Y, Fenn K, Biradavolu M, Binder RA, Marcus A, Mason M. Testing different formats for communicating colorectal cancer risks. *J Health Comm* 4: 311-326, 1999.
- Rimer BK, Conaway M, Lyna P, Glassman B, Yarnall K, Lipkus IM, Barber T. The impact of tailored Interventions on a community health center population. *Patient Educ Counsel* 37: 125-140, 1999.
- Demark-Wahnefried W, Peterson B, McBride C, Lipkus I, Clipp J. Current health behaviors and readiness to pursue lifestyle change among men and women diagnosed with early stage prostate and breast cancers. *Cancer*, 88: 674-684, 2000.
- Lipkus IM, Rimer BK, Halabi S, Strigo TS. Can tailored interventions increase mammography use among HMO women? *Am J Prev Med* 18: 1-10, 2000.
- Lipkus IM, Kuchibhatla M, McBride CM, Bosworth, HB, Pollak, KI, Siegler IC, Rimmer BK. Relationships among Breast Cancer Perceived Absolute Risk, Comparative Risk and Worries. *Cancer Epidemiol Biomarkers Prev* 9: 973-975, 2000.
- Lipkus IM, Halabi S, Strigo TS, Rimer BK. The impact of abnormal mammograms on psychosocial outcomes and subsequent screening. *Psycho Oncol*. 9: 402-410, 2000.
- Lipkus IM, Lyna P, Rimer BK. Colorectal cancer risk perceptions and screening intentions in a minority population. *J Natl Med Assoc* 92 (10), 492-500, 2000
- Rimer BK, Halabi S, Strigo TS, Crawford Y, Lipkus IM. Confusion about mammography: Prevalence and consequences. *J Womens Health Gender-based Med* 8: 509-520, 2000.
- McBride CM, Halabi S, Bepler G, Lyna P McIntyre L, Lipkus I, Albright J. Maximizing the motivational impact of feedback of lung cancer susceptibility on smoker's desire to quit. *J Health Comm* 5: 229-241, 2000
- McBride CM, Clipp E, Peterson B, Lipkus IM, Demark-Wahnefried W. Psychosocial impact of diagnosis and risk factor reduction among cancer survivors. *Psycho Oncol*. 9 (5), 418-427, 2000.
- Bastian LR, Lipkus IM, Kuchibhatia MN, Weng HH, Halabi S, Ryan PD, Skinner CS, Rimer BK. Women's interest in taking chemoprevention for breast cancer. *Arch Int Med* 161:1639-1644, 2001.
- Dalbert C, Lipkus IM, Sallay H, Goch I. A just and unjust world: Structure and validity of different world beliefs. *Pers Indiv Diff Personality & Individual Differences*, 30 (4) 561-577, 2001.
- Lipkus IM, Biradavolu M, Fenn K, Keller P, Rimer BK. Informing women about their breast cancer risks: Truth and consequences. *Health Comm* 13, 205-226, 2001.
- Lipkus IM, Green JD, Feaganes JR, Sedikedis C. The relationship between attitudinal ambivalence and desire to quit

- smoking among college smokers. *J Appl Soc Psychol* 31:113-133, 2001.
- Lipkus IM, Samsa G, Rimer BK. General performance of a risk numeracy scale among highly educated samples. *Med Decis Making*. 21, 37-44, 2001.
- Lipkus IM, Klein WM, Rimer BK. Communicating breast cancer risks to women using different formats. *Cancer Epidemiol Biomarkers Prev* 10:895-898, 2001.
- Pollak KI, Arredondo EM, Yarnall KS, Lipkus IM, Myers E, McNeilly M, Costanzo P. How do residents prioritize smoking cessation for "high-risk" women? Factors associated with addressing smoking cessation. *Prev Med* 33:292-299, 2001.
- Rimer BK, Halabi S, Skinner CS, Kaplan EB, Crawford Y, Samsa GP, Strigo TSE, Lipkus, IM. The short-term impact of tailored mammography decision-making interventions. *Patient Educ Couns* 43: 269-285, 2001.
- McBride CM, Pollak KI, Lyna P, Lipkus I, Samsa G, Bepler. Reasons for quitting among low-income African American smokers. *Health Psychol* (In Press).
- McBride CM, Bastian LA, Halabi S, Fish L, Lipkus IM, Bosworth HB, Rimer BK, Siegler IC. Efficacy of a tailored intervention to aid decision-making about hormone replacement therapy. *Am J Pub Health* (In Press).
- Keller P, Lipkus IM., & Rimer BK. Depressive realism and health risk accuracy: The negative consequences of positive mood. *J. Consum. Res.* (In press).

BOOK CHAPTERS:

- Barefoot JC, Lipkus IM. The assessment of anger and hostility. In A. Siegman and T. Smith (Eds.), *Anger, hostility, and the heart*. Erlbaum, 1994.
- Lipkus IM, Bissonette VL. The belief in a just world and willingness to accommodate among married and dating couples. In L. Montada & M.J. Lerner (Eds.), *Belief in a just world: Development of a scientific construct*. New York: Plenum Press, 1998.
- Lipkus IM, Nelson DE. Visual Communication. In DE Nelson, R Brownson, P Remington, & C Parvanta (Eds.). *Communicating Public Health Information Effectively: A Guide for Practitioners*. American Public Health Association: Washington, DC.,(In press)

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel in the order listed on Form Page 2.
Photocopy this page or follow this format for each person.

NAME Richard F. Potthoff		POSITION TITLE Statistician	
EDUCATION (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)			
INSTITUTION AND LOCATION	DEGREE	YEAR CONFERRED	FIELD OF STUDY
Swarthmore College, Swarthmore, PA	B.A.	1953	Mathematics
University of North Carolina, Chapel Hill, NC	Ph.D.	1959	Mathematical Statistics

RESEARCH AND PROFESSIONAL EXPERIENCE: Concluding with present position, list, in chronological order, previous employment, experience, and honors. Include present membership on any Federal Government public advisory committee. List, in chronological order, the titles, all authors, and complete references to all publications during the past three years and to representative earlier publications pertinent to this application. If the list of publications in the last three years exceeds two pages, select the most pertinent publications. **DO NOT EXCEED TWO PAGES.**

Positions

1958-1961	Blue Bell, Inc., Greensboro, NC
1961-1965	Research Associate, Department of Statistics, University of North Carolina, Chapel Hill, NC
1965-1989	Senior Operations Research Analyst, Burlington Industries, Inc., Greensboro, NC
1989-1990	Adjunct Associate Professor, School of Business and Economics, North Carolina Agricultural and Technical State University, Greensboro, NC
1990-Present	Senior Research Scientist, Center for Demographic Studies, Duke University, Durham, NC
1995-Present	Statistician, Cancer Center Biostatistics (1995-present), School of Nursing (1995-1998), and Duke Clinical Research Institute (1996-present), Duke University Medical Center, Durham, NC
1998-Present	Department of Political Science, Duke University, Durham, NC

Other Activities

Member of American Statistical Association, Institute of Mathematical Statistics, and International Biometric Society
Fellow of the American Statistical Association, elected 1995
Chair, Committee on Elections, American Statistical Association, 1984-89
Consultant and research collaborator with Educational Testing Service, Princeton, NJ, 1961-65 and at times during 1978-82

Publications

Tardiff BE, Jennings LK, Harrington RA, Gretler D, Potthoff RF, Vorchheimer DA, Eisenberg PR, Lincoff AM, Labinaz M, Joseph DM, McDougal MF, Kleiman NS; for the PERIGEE investigators: Pharmacodynamics and Pharmacokinetics of Eptifibatide in Patients with Acute Coronary Syndromes: Prospective Analysis from PURSUIT. *Circulation* 104:399-405, 2001.

Potthoff RF, Peterson BL, George SL: Detecting Treatment-by-Centre Interaction in Multi-Centre Clinical Trials. *Statistics in Medicine* 20:193-213, 2001.

Potthoff RF, Manton KG, Woodbury MA: Dirichlet Generalizations of Latent-Class Models. *Journal of Classification* 17:315-353, 2000.

Berger MM, Munger MC, Potthoff RF: The Downsian Model Predicts Divergence. *Journal of Theoretical Politics* 12:228-240, 2000.

Parnes HL, Conaway M, Aisner J, Potthoff RF, Kornblith AB, Cooper MR, Kirshner JJ, Davila E, Sztatowski TP, Ellerton J, Shea TC, Mortimer JE, Maurer LH, Vinciguerra V: Megestrol Acetate for the Treatment of Cachexia in Patients With Advanced Lung or Colorectal Cancers. *Cancer Therapeutics* 2:75-82, 1999.

Potthoff RF: Book review of *On Voting: A Public Choice Approach* by Gordon Tullock (Cheltenham, UK: Edward Elgar, 1998), *Southern Economic Journal* 66:204-208, 1999.

Potthoff RF: Degrees of Freedom, in *Encyclopedia of Biostatistics*, eds. P. Armitage and I. Colton, Chichester, West Sussex, UK: John Wiley & Sons, pp. 1119-1120, 1998.

Potthoff RF, Brams SJ: Proportional Representation: Broadening the Options. *Journal of Theoretical Politics* 10:147-178, 1998.

Potthoff RF: Telephone Sampling in Epidemiologic Research: To Reap the Benefits, Avoid the Pitfalls. *American Journal of Epidemiology* 139:967-978, 1994.

Potthoff RF, Manton KG, Woodbury MA: Correcting for Nonavailability Bias in Surveys by Weighting Based on Number of Callbacks. *Journal of the American Statistical Association* 88:1197-1207, 1993.

Potthoff RF, Woodbury MA, Manton KG: Reply to Kott's Letter (answering letter to the editor from Phillip S. Kott). *Journal of the American Statistical Association* 88:716-717, 1993.

Potthoff RF, Woodbury MA, Manton KG: 'Equivalent Sample Size' and 'Equivalent Degrees of Freedom' Refinements for Inference Using Survey Weights Under Superpopulation Models. *Journal of the American Statistical Association* 87:383-396, 1992.

Potthoff RF: Comment: Use of Integer Programming for Constrained Approval Voting, *Interfaces* 20(5):79-80, 1990.

- Potthoff RF: Run Lengths, Tests of, in *Encyclopedia of Statistical Sciences, Supplement Volume*, eds. Samuel Kotz and Norman L. Johnson, New York: John Wiley & Sons, pp. 141-143, 1989.
- Potthoff RF: Generalizations of the Mitofsky-Waksberg Technique for Random Digit Dialing: Some Added Topics, American Statistical Association, 1987 *Proceedings of the Section on Survey Research Methods*, pp. 615-620, 1987.
- Potthoff RF: Some Generalizations of the Mitofsky-Waksberg Technique for Random Digit Dialing, *Journal of the American Statistical Association* 82:409-418, 1987.
- Potthoff RF: Potthoff-Whittinghill Tests, in *Encyclopedia of Statistical Sciences, Volume 7*, eds. Samuel Kotz and Norman L. Johnson, New York: John Wiley & Sons, pp. 124-128, 1986.
- Potthoff RF: Choice of Weights for the O'Brien-Dyck Runs Test (in Reader Reaction), *Biometrics* 41:1071-1072, 1985.
- Potthoff RF: Johnson-Neyman Technique, in *Encyclopedia of Statistical Sciences, Volume 4*, eds. Samuel Kotz and Norman L. Johnson, New York: John Wiley & Sons, pp. 299-303, 1983.
- Potthoff RF: Matrix Algebra Versus Geometry (letter to the editor), *The American Statistician* 37:251, 1983.
- Potthoff RF: Book review of *Seats, Votes, and the Spatial Organisation of Elections* by G. Gudgin and P.J. Taylor (London: Pion Limited, 1979), *Journal of the American Statistical Association* 78:204-205, 1983.
- Potthoff RF: Some Issues in Test Equating, in *Test Equating*, eds. Paul W. Holland and Donald B. Rubin, New York: Academic Press, pp. 201-242, 1982.
- Bohrer R, Potthoff RF: An Exercise in Analysis of Variance Theory (in The Teacher's Corner), *The American Statistician* 29:166-168, 1975.
- Potthoff RF: A Non-Parametric Test of Whether Two Simple Regression Lines Are Parallel, *The Annals of Statistics* 2:295-310, 1974.
- Potthoff RF: Comment (on article by T.W.F. Stroud), *Journal of the American Statistical Association* 67:412-413, 1972.
- Potthoff RF: Letter to the editor (on school desegregation and linear programming), *The American Statistician* 25(1):59-60, 1971.
- Potthoff RF: The Problem of the Three-Way Election, in *Essays in Probability and Statistics*, eds. R.C. Bose, I.M. Chakravarti, P.C. Mahalanobis, C.R. Rao, and K.J.C. Smith, Chapel Hill, NC: The University of North Carolina Press, pp. 603-620, 1970.
- Potthoff RF: Book review of *The Analysis of Variance* by Alan Huitson (New York: Hafner Publishing Co., 1966), *Technometrics* 9:341-342, 1967.
- Potthoff RF: Equating of Grades or Scores on the Basis of a Common Battery of Measurements, in *Multivariate Analysis, Proceedings of an International Symposium held in Dayton, Ohio, June 14-19, 1965*, ed. Paruchuri R. Krishnaiah, New York: Academic Press, pp. 541-559, 1966.
- Potthoff RF: Statistical Aspects of the Problem of Biases in Psychological Tests (*Institute of Statistics Mimeo Series No. 479*), Chapel Hill, NC: Department of Statistics, University of North Carolina (113 pages), 1966.
- Potthoff RF, Whittinghill M: Testing for Homogeneity II. The Poisson Distribution, *Biometrika* 53:183-190, 1966.
- Potthoff RF, Whittinghill M: Testing for Homogeneity I. The Binomial and Multinomial Distributions, *Biometrika* 53:167-182, 1966.
- Potthoff RF, Whittinghill M: Letter to the editor (replying to letter from A.S. Wiener), *American Journal of Human Genetics* 18:310-311, 1966.
- Potthoff RF, Whittinghill M: Maximum-Likelihood Estimation of the Proportion of Nonpaternity, *American Journal of Human Genetics* 17:480-494, 1965.
- Potthoff RF, Whittinghill M: Letter to the editor (on smoking-and-health research and twins), *The American Statistician* 19(5):41, 1965.
- Potthoff RF: Some Scheffé -Type Tests for Some Behrens-Fisher-Type Regression Problems, *Journal of the American Statistical Association* 60:1163-1190, 1965.
- Potthoff RF, Roy SN: A Generalized Multivariate Analysis of Variance Model Useful Especially for Growth Curve Problems, *Biometrika* 51:313-326, 1964.
- Potthoff RF: On the Johnson-Neyman Technique and Some Extensions Thereof, *Psychometrika* 29:241-256, 1964.
- Potthoff RF: Use of the Wilcoxon Statistic for a Generalized Behrens-Fisher Problem, *The Annals of Mathematical Statistics* 34:1596-1599, 1963.
- Potthoff RF: Three-Dimensional Incomplete Block Designs for Interaction Models, *Biometrics* 19:229-263, 1963.
- Potthoff RF: Some Illustrations of 4DIB Design Constructions, *Calcutta Statistical Association Bulletin* 12:19-30, 1963.
- Potthoff RF: Four-Factor Additive Designs More General Than the Greco-Latin Square, *Technometrics* 4:361-366, 1962.
- Potthoff RF: Three-Factor Additive Designs More General Than the Latin Square, *Technometrics* 4:187-208, 1962.
- Roy SN, Potthoff RF: Confidence Bounds on Vector Analogues of the 'Ratio of Means' and the 'Ratio of Variances' for Two Correlated Normal Variates and Some Associated Tests, *The Annals of Mathematical Statistics* 29:829-841, 1958.

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel in the order listed for Form Page 2.
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME	POSITION TITLE		
Elizabeth C. Clipp, RN, MS, PhD	Professor of Nursing and Research Associate Professor of Medicine Duke University Medical Center and Associate Director for Research, Durham VA GRECC		
EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)			
INSTITUTION AND LOCATION	DEGREE (if applicable)	YEAR(s)	FIELD OF STUDY
University of Maryland, College Park, MD	RN, BS	1972	Nursing
University of Maryland, College Park, MD	MS	1980	Psychiatric Nursing
Cornell University, Ithaca, NY	PhD	1984	Developmental Psychology
Duke University Center for Aging, Durham, NC	Fellowship	1984-85	Aging Research

A. Positions and Honors.

1972-80 **Nurse Clinician**, University of Maryland Hospital, Department of Emergency Medicine, Masters Degree Candidate (1978-79)

1980-1984 **Doctoral Candidate**, Cornell University (1980-1984)

1981 **Predoctoral Intern**, Nat. Inst. on Aging (NIA), Gerontological Research Center

1984-1985 **Postdoctoral Fellow**, Duke University, Center for the Study of Aging and Human Development; Preceptor: Linda K. George

1985-1996 **Research Assistant Professor**, Department of Medicine, Division of Geriatrics, Duke University Medical Center, Durham, NC

1985-1998 **Nurse Scientist**, Geriatric Research Education and Clinical Center, (GRECC), VA Medical Center, Durham, NC

1985-present **Senior Fellow**, Center for the Study of Aging and Human Development, Duke University Medical Center, Durham, NC

1991-1999 **Clinical Assistant Professor of Nursing**, School of Nursing, Duke University

1993-present **Psycho-Oncology Division Leader**, Duke University Comprehensive Cancer Center

1995-present **Senior Research Fellow**, Durham VA Health Services Research Field Program

1996-present **Research Associate Professor**, Department of Medicine, Division of Geriatrics, Duke University Medical Center, Durham, NC

1998-present **Associate Director for Research**, Geriatric Research Education and Clinical Center, (GRECC), VA Medical Center, Durham, NC

2001-present **Professor with tenure**, Duke University School of Nursing

2001-present **Core Faculty**, Duke Institute for Care at the End of Life

HONORS Phi Kappa Phi, 1980; Sigma Theta Tau, 1980; The University of Maryland Faculty Award for Excellence in Clinical Practice, 1980; NIMH predoctoral fellowships, 1978-1983; Sigma Xi, 1983; NY State Human Ecology Research Award, 1983; Junior Scholar, XIIIth International Congress of Gerontology, NY City, 1985; Scientific Presentation Award, American Geriatrics Society Annual Meeting, May 1987. Veterans Administration Special Performance Award, 1989. Richard Kalish Innovative Publication Award, sponsored by the Gerontological Society of America, 1991. Who's Who in American Nursing 1992; Special Contribution Award, Dept. of Veteran Affairs, 1993; Fellow, Gerontological Society of America, 1994. Nominee, Women in Science and Engineering (WISE) Award Program, 1996. Nurse Scientist, Oncology Nursing Core, Cancer and Leukemia Group B (CALGB), 2001.

B. Selected peer-reviewed publications (in chronological order).

- Clipp, E.C.** and Moore, M.J. Impact of Therapy on Caregiving Time and Costs. Progress in Alzheimer's Disease, Vol.2, No.1, p. 6-7, 1995.
- White, H., **Clipp, E.C.**, Schmader, K. and Hanlon, J. The Role of the Caregiver in the Drug Treatment of Patients with Dementia. CNS Drugs, Vol. 4, No. 5, p. 58-67, 1995.
- Clipp, E.C.**, Moore, M.J., George, L.K. The Content and Properties of the Caregiver Activities Time Survey (CATS): An Outcome Measure for Use in Clinical Trial Research on Alzheimer's Disease. The American Journal of Alzheimer's Disease, Vol. 11, No. 6, p 3-9, 1996.
- Clipp, E.** and Elder, G.H., Jr. The Aging Veteran of World War II. In: Aging and Posttraumatic Stress Disorder. Edited by Paul E. Ruskin and John A. Talbott. American Psychiatric Press, Inc., 1996.
- Siebert, L., **Clipp, E.**, Mulhausen, P. & Kochesberger, G. Low Impact of Advance Directive Video on Patient Comprehension and Treatment Preferences. Archives of Family Medicine, Vol. 5, April 1996, 207-212.
- Clipp E.C.**, Elder, G.H., George, L.K. and Pieper, C. Trajectories of Health in Aging Populations. Approaches to Rural Health and Aging Research. W.Gesler, D.Rabiner (Eds.), Baywood, 1997.
- Sutton, L., **Clipp, E.C.** and Winer, E. Managing Terminal Illness in the Elderly. In Cancer in the Elderly. C.P. Hunter, K.A. Johnson and H.B. Muss (Eds.), New York: Marcel Dekker, 2000.
- McBride, C.M., **Clipp, E.**, Peterson, B., Lipkus, I. and Demark-Wahnefried, W. Cancer Diagnosis as a Teachable Moment for Risk Factor Reduction. Psycho-Oncology, 9(5): 418-427, 2000.
- Steinhauser, K.E., **Clipp, E.C.**, McNeilly, M. D., Christakis, N.A., McIntyre, L.M. and Tulsy, J.A. In Search of a Good Death: Observations from Patients, Families, and Providers. Annals of Internal Medicine, 132:825-832, 2000.
- Demark-Wahnefried W, Peterson B, McBride C, Lipkus I, **Clipp J.** Health behaviors and readiness to pursue lifestyle change among men and women with early stage prostate and breast cancers. Cancer 88: 674-684, 2000.
- George, L.K. and **Clipp, E.C.** Quality of Life: Conceptual Issues and Clinical Implications. In Review, Neurological Report, 2000.
- Clipp, E.C.** Quality of Life. In press, The Encyclopedia of Aging, 3rd Edition, G. Maddox (Chief Ed.), New York: Springer, 2000.
- Steinhauser, K.E., Christakis, N.A., **Clipp, E.C.**, Maya McNeilly, M.D., McIntyre, L. and Tulsy, J.A. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Health Care Providers. JAMA, Vol. 284:19, p 2476-2482, Nov. 2000.
- Moore, M.J., Zhu, C.W., **Clipp, E.C.** Informal Costs of Dementia Care: Estimates from the National Longitudinal Caregiver Study. Journal of Gerontology: Social Sciences, 56B, S219-S228, 2001.
- Clipp, E. C.**, Hollis, D., and Cohen, H.J. Considerations of Psychosocial Illness Phase in Cancer Survival. Psycho-Oncology, 10, 166-178, 2001.
- Steinhauser KE, Christakis NA, **Clipp EC**, McNeilly M, McIntyre LM, Tulsy JA, Preparing for the end of life: preferences of patients, families, physicians and other care providers. Journal of Pain and Symptom Management, 2001;22(3):727-737.
- White, H., McConnell, E., **Clipp, E.**, Branch, L., Sloane, R., Pieper, C., Box, T. A Randomized Controlled Trial of the Psychosocial Impact of Providing Internet Training and Access to Older Adults. In press, J Aging and Health, 2001.
- Fonda, S.J., **Clipp, E.C.** and Maddox, G.L. Patterns in Functioning Among Residents of an Affordable Assisted Living Housing Facility. In press, The Gerontologist, 2001.
- Zhu, C., **Clipp, EC**, Moore, MJ Informal Care Costs of Dementia. In Research and Practice in Alzheimer's Disease and Other Dementias (special Issue on Caregiving). B. Vellas, Editor-in-Chief, European Alzheimer's Disease Consortium (EADC), In press, 2002.
- Howell J, Frederick J, Olinger B, Strickland R., Leftridge D, Fryar M, Wade B, Hess R, **Clipp, E.C.** Can Nurses Govern in a Government Agency? Journal of Nursing Administration, 31, 4: 187-196, 2001.
- Ingram, S., Seo, P., Martell, R., **Clipp, E.C.**, Doyle, M.E. and Cohen, H.J. Comprehensive Assessment of the Elderly Cancer Patient: The Feasibility of Self-Report Methodology. In press, Journal of Clinical Oncology, 2001.
- Steinhauser, K., **Clipp, E.C.**, and Tulsy, J. Evolution in Measuring the Quality of Dying. In press, Journal of Palliative Medicine, 2001.

C. Research Support.

IRR-98-162-1

9/1/99-8/31/02

VA HSR&D AWARD (Tulsky, PI; Clipp, Co-I))**Measuring the Quality of Dying**

The purpose of this study is to measure quality of dying in an in-patient VA population.

NINR NR-01-001 (1 P20 NR07795-01; Clipp, PI)

8/1/01-7/31/04

Trajectories of Aging and Care in Nursing Science

The overall goal of the TRAC Center is to enhance the capacity for nurse investigators to examine patterns of health, illness, and care among the elderly over time and across diverse settings, including home and institution, including care at the end of life.

VA Contract #NRI #95-218 (Clipp, PI)

10/1/97-9/30/01

VA Merit Review Award

Informal Caregivers of Veterans with Dementia

The overall goal of this project is to conduct a national, prospective, longitudinal study of informal caregivers of elderly veterans with Alzheimer's disease or related disorders to: determine the impact of dementia on veterans' families in terms of caregiver cost (informal disease cost) and quality of life; and to identify the correlates of service use and the predictors of institutionalization.

NCI (Demark-Wahnefried, PI; Clipp, Co-I))

12/01/00-11/30/05

Promoting Health in Prostate & Breast Cancer Survivors

The purpose of this study is to determine: 1) the relative short (1 year) & long term (2 years) efficacy of a personalized, computer-generated diet and exercise intervention; 2) the effects of the intervention on other endpoints, e.g., quality of life, perceived health, etc. and 3) factors such as race and gender that may interact with the intervention predicting program efficacy.

Dept. of Defense (Lipkus, PI; Clipp Co-I)

8/1/98-1/31/01

The Effects of Supportive and Nonsupportive Behaviors on the QOL of Prostate Cancer Patients and their Spouses

The aim of this 30-month longitudinal study is to explore how prostate cancer patients' and spouses' supportive and nonsupportive behaviors during the diagnostic and early treatment phases affect and are affected by disease-related stress and feeling of uncertainty, and personal QOL and well-being.

Dana-Farber Cancer Institute (Emmons, PI; Clipp, Co-I)

9/30/98-7/31/02

RO1 CA74000-01A1 (Clipp, Co-Investigator)

Multi-Risk Factor Intervention for Colon Polyp PatientsMulti-Risk Factor Intervention for Colon Polyp PatientsMulti-Risk Factor Intervention for Colon Polyp Patients

The aim of this 4-year, two-site (Dana-Farber Cancer Institute and Duke University Comprehensive Cancer Center) intervention study is to evaluate the effectiveness of a comprehensive multiple risk factor intervention in changing risk behaviors of patients diagnosed with colon polyps.

NIA Renewal of 5P60 AG11268 (Cohen PI; Clipp Co-I)

7/1/99-6/30/04 NIA Renewal of 5P60 AG11268

(Cohen)

7/1/99-6/30/04 15%NIA Renewal of 5P60 AG11268 (Cohen)

7/1/99-6/30/04 15%NIA

Renewal of 5P60 AG11268 (Cohen)

7/1/99-6/30/04 15%

Phoning for Function: Promoting Health after Cancer

The aim of this project is to determine the efficacy of a diet-physical activity telephone counseling program in improving physical function among elderly men and women newly diagnosed with early stage breast or prostate cancer.

AARP Andrus Foundation (Gwyther PI; Clipp, Co-I)

11/1/99-10/31/2000

Home Care for Persons with Alzheimer's Disease and Other Dementias

This study aims to identify the personal, patient, and social characteristics associated with caregiving-related health problems and to examine the predictors of service use, both community-based and institutional. In addition,

telephone interviews of a sub- sample of NCS caregivers will be conducted to examine the decision processes by which caregivers adopt or discontinue formal service use.

BIOGRAPHICAL SKETCH

Give the following information for the key personnel and consultants listed on page 2. Begin with the Principal Investigator/Program Director. Photocopy this page for each person.

NAME	POSITION TITLE	BIRTHDATE (Mo., Day, Yr.)	
Cary N. Robertson, M.D.	Assistant Professor	11/28/51	
EDUCATION (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)			
INSTITUTION AND LOCATION	DEGREE	YEAR CONFERRED	FIELD OF STUDY
Southern Methodist University, Dallas, TX	B.A.	1973	Biology
Tulane Medical School, New Orleans, LA	M.D.	1977	Medicine

RESEARCH AND PROFESSIONAL EXPERIENCE: Concluding with present position, list, in chronological order, previous employment, experience, and honors. Include present membership on any Federal Government public advisory committee. List, in chronological order, the titles and complete references to all publications during the past three years and to representative earlier publications pertinent to this application. DO NOT EXCEED TWO PAGES.

PREVIOUS EMPLOYMENT AND EXPERIENCE

- 1977-78 Intern in Surgery, Univ. of Oregon Health Sciences Center, Portland, Oregon.
- 1978-80 Senior Assistant Surgeon, USPHS, National Health Service Corps Alleghany Family Practice Center, Sparta, North Carolina.
- 1980-81 Junior Assistant Resident in Surgery, Duke University Medical Center, Durham, North Carolina.
- 1981-84 Assistant Resident in Urology, Duke University Medical Center, Durham, North Carolina.
- 1984-85 Chief Resident in Urology, Duke University Medical Center, Durham, North Carolina.
- 1985-87 Cancer Expert, Urologic Oncology Section, Surgery Branch NCI/NIH, Bethesda, Maryland.
- 1987-88 Senior Investigator, Urologic Oncology Section, Surgery Branch, NCI/NIH, Bethesda, Maryland.
- Oct. 1988- Assistant Professor, Division of Urology, Department of Surgery, Duke University Medical Center, Durham, North Carolina.

PUBLICATIONS

- Walther PJ, Robertson CN, Paulson DF: Lethal Complications Of Standard Self-Retaining Ureteral Stents In Patients With Ileal Conduit Urinary Diversion. *J Urol* 133:851-853, 1985.
- Robertson CN, Santora A, Liang G, Linehan WM: Human Recombinant TNF Mediates Bone Resorption In Vitro. *Surgical Forum* 37:669-670, 1986.
- Belldgrun A, Linehan WM, Robertson CN, Rosenberg SA: Isolation And Characterization Of Lymphocytes Infiltrating Human Renal Cell Cancer: Possible Application For Therapeutic Adoptive Immunotherapy. *Surgical Forum* 37:671-673, 1986.
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- Topalian SL, Solomon D, Avis FP, Chang AE, Linehan WM, Lotze MT, Robertson CN, Seipp CA, Simon P, Simpson CG, Rosenberg SA: Immunotherapy Of Patients With Advanced Cancer Using Tumor Infiltrating Lymphocytes And Recombinant Interleukin-2: A Pilot Study. *J Clin Oncol* 6:839, 1988.
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