

**Université de Montréal**

**Predictors of Adaptation in Wives  
During the Initial Psychosocial Phase of Prostate Cancer**

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**Thèse présentée à la Faculté des études supérieures  
en vue de l'obtention du grade de Philosophiae Doctor (PhD)  
en sciences infirmières**

**avril, 2003**

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Université de Montréal  
Faculté des études supérieures

Cette thèse intitulée :

**Predictors of Adaptation in Wives  
During the Initial Psychosocial Phase of Prostate Cancer**

présentée par :  
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## Summary

The phase of diagnosis and initial treatment for prostate cancer is an anxious time not only for patients but also for their spouses who are directly affected by the illness experience. For them, the threats to life that the prostate cancer represents are compounded by changes in sexuality and by urinary problems that accompany their partners' treatment. A prospective study of the factors associated with wives' adaptation was undertaken to provide an empirical basis to guide nursing interventions for women at this phase of the illness.

The McGill Model of Nursing provided the nursing perspective for the study. Family stress and adaptation theory directed the choice of variables, and indicated the nature of the relationships between predictor variables and adaptation. The model-testing study examined the contribution of symptom distress, personal resources, marital resources and situational appraisal to global adaptation (Psychosocial Adjustment to Illness Scale), and to the psychological dimension of adaptation (Profile of Mood States). The study also examined the role of situational appraisal as a mediator between the set of independent variables and each measure of adaptation separately.

Seventy wives completed data collection at the onset of the initial phase, prior to treatment (Time 1), and three months into the initial phase, at the end of treatment (Time 2). Following the procedure outlined by Baron and Kenny (1985), the theoretical model was verified at time 1 and the confirmation of the model was examined at time 2. Two sets of projective tests were also carried out in order to evaluate the contributions of change in the predictors in explaining adaptation at time 2, and change in adaptation between time 1 and 2.

Across the model tests, between 30% - 62.7% of the variance in global adaptation and emotional adaptation was explained by variables in the retained models. Each of the variables contributed to explaining adaptation in at least one of the model tests, with the personal resource variable of sense of coherence

emerging as a very strong and consistent predictor across tests. The model was not entirely stable between time 1 and 2. Illness appraisal acted as a mediator only at time 2, mediating the effect of symptom distress only on global adaptation. The projective tests indicated that change in sense of coherence and change in family resources acted as predictors of global and psychological adaptation at time 2, and as predictors of change in adaptation between the two data collection periods for both PAIS and POMS. The models explained consistently more of the variance in wives' psychological adaptation than in their global adaptation.

The study provides support for interventions that mobilize and build wives' sense of coherence (the manageability, meaningfulness and comprehensibility of life events), and foster the cohesion and flexibility within the marital relationship. Interventions that mitigate the impact of urinary symptoms, and the appraisal of threat in the illness event are also indicated. The results also provide avenues for continued research using family stress and adaptation theory and for the further development of nursing knowledge.

**Key words:** adaptation; cancer; prostate; family; spouse; caregivers

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## Résumé

La période entourant le diagnostic du cancer de la prostate et son traitement est anxiogène non seulement pour les patients mais également pour les conjointes. Pour ces dernières, la menace à la vie que représente le cancer de la prostate est majorée par les problèmes d'ordre sexuel et urinaire qui accompagnent les traitements contre le cancer. Une étude prospective des facteurs reliés à l'adaptation de conjointes de patients atteints de cancer de la prostate a été réalisée afin de fournir une base empirique pour des interventions infirmières dans cette période.

Le Modèle Infirmier de McGill a servi de conception globale des sciences infirmières à cette recherche. Le modèle théorique du stress et d'adaptation familiale a guidé le choix des variables et indiqué la nature de la relation entre les variables prédictives et l'adaptation. Ce modèle théorique a été testé en examinant la proportion de la variance de la variable adaptation expliquée par la détresse reliée aux symptômes, les ressources personnelles et familiales et l'appréciation situationnelle. L'adaptation était mesurée globalement (Psychosocial Adjustment to Illness Scale) et dans une perspective psychologique (Profile of Mood States). La présente recherche a aussi examiné le rôle médiateur de la variable appréciation situationnelle entre l'ensemble des variables indépendantes et chacune des mesures de l'adaptation.

Soixante-dix conjointes ont complété les questionnaires à deux reprises dans la phase initiale: avant le traitement, et trois mois plus tard, à la fin du traitement. Selon la procédure décrite par Baron et Kenny (1985), le modèle théorique a été testé au temps 1 et la confirmation du modèle examinée au temps 2. Deux séries de régressions ont également été effectuées afin d'évaluer les contributions apportées par le changement dans les variables indépendantes à expliquer l'adaptation au temps 2, et à expliquer le changement dans l'adaptation entre les temps 1 et 2.

Dans l'ensemble, entre 30% et 62.7% de la variance de l'adaptation globale et de l'adaptation psychologique a été expliquée par les variables indépendantes. Chacune des variables a contribué à l'explication de l'adaptation dans au moins un des tests du modèle. La ressource personnelle, sens de cohérence, s'est avérée être la variable prédictive la plus importante. Le modèle théorique ne s'est pas comporté de façon complètement stable entre les temps 1 et 2. L'appréciation situationnelle de la maladie a joué un rôle médiateur qu'au temps 2, et seulement pour l'adaptation globale. Les analyses projectives ont indiqué que les changements dans le sens de cohérence et dans les ressources familiales expliquaient l'adaptation globale et psychologique au temps 2, ainsi que le changement entre les temps 1 et 2 dans les deux mesures.

Ces données offrent des pistes pour des interventions infirmières qui favorisent le sens de cohérence (la signification, la compréhensibilité, et la perception que les événements de la vie sont maniables) et qui renforcent la cohésion et la flexibilité dans la relation du couple. Les interventions qui diminuent l'importance des symptômes urinaires et la menace perçue chez les conjointes sont également indiquées. Les résultats ouvrent la voie à des recherches utilisant la théorie du stress et d'adaptation familiale afin de bâtir les connaissances en sciences infirmières.

Mots-clé: adaptation; cancer; prostate; famille; conjointes; soignants naturels



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This work is dedicated to my family,  
my husband Edward,  
and my daughters Nadine, Nicole and Joanne.

## Acknowledgements

I wish to express my sincere thanks to Dr. Nicole Ricard, my thesis advisor, for extending her research and clinical interests and agreeing to work with me. Her input, availability, clarity of thought, precision, and her knowledge of nursing research have been both comforting and inspiring. I would also like to thank Louise Bouchard, my co-director, who directed me towards this population of cancer patients and consistently provided support, encouragement and critical feedback throughout the project. I am deeply appreciative to both of them for their warmth and their friendship.

I would also like to express thanks to my graduate students Julie Gross, Cindy Dalton and Muriel Mac-Seing who helped in preparing the questionnaires and in the initial data collection, and to Adam Sherrard who entered mountains of data using EpiInfo. Special expressions of gratitude to Marie Durand, my research assistant, for her tenacity and meticulousness in data collection, and for the sensitivity and understanding she showed to each family member who participated. I am also grateful to Dr. Luis Souhami, Dr Fred Saad, Dr. Armen Aprikian, Dr. Yosh Taguchi, Ellen Kucharski and Raquel de Léon for their involvement in the recruitment of subjects for the study, and to Rhonda Amsel and Jocelyn Bisson who provided statistical consultation.

I am deeply indebted to my colleagues and friends, Nancy Feeley, Margaret Purden, Laurie Gottlieb, and Ariella Lang, who answered every question, listened to every worry, willingly shared their knowledge and ideas and asked nothing in return. My family deserves special thanks. I have been encouraged by the unfailing support of my husband, Edward Ezer. My daughters Nadine, Nicole and Joanne, helped out in so many ways and made the many adjustments that facilitated the completion of this study. To Daniel Herrera, who generously stepped in every time the



computer crashed, my eternal thanks. Without each of you, I would never have been able to make this journey.

I would also like to acknowledge the financial support I received from the Faculté des sciences infirmières (Université de Montréal), the Faculté des études supérieures (Université de Montréal), the Ordre des infirmiers et infirmières du Québec (OIIQ), McGill University School of Nursing, and McGill University Faculty of Graduate Studies (operating grant funding through the Social Sciences and Humanities Research Council).

Most importantly, this study would not have been possible without the participation of the 81 men and their wives who gave many hours of their time and so willingly shared their experiences with this illness. It was a privilege and a pleasure to know them.

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**Chapter 1**  
**Introduction**

Cancer is not a disease of just one family member. For others in the family, cancer creates new demands, evokes fears of loss, and strains resources at the personal and collective level. It challenges the way in which individuals relate to the world and calls into question the meanings they ascribe to life events. It is this sense of the meaning of the situation that sets the context within which the dynamic processes of adaptation to newly diagnosed cancer will occur for each member of the family. In order to assist spouses who are the family members most closely involved with the adult cancer patient, clinicians must understand the factors that contribute to the nature of their adaptation to this disruptive event.

The impact of cancer on the family has been well documented (Blanchard, Albrecht, & Ruckdeschel, 1997; Cassileth et al., 1985; Laizner, Yost, Barg, & McCorkle, 1993; Lewis, 1986; Manne, 1998; Sales, Schulz, & Biegel, 1992). Studies have highlighted the implications of the illness not only on emotional well-being, but also in such areas as family roles (Vess, Moreland, & Schwebel, 1985a; Vess, Moreland, & Schwebel, 1985b), family relationships (Hilton, 1993; Carlson, Bultz, Speca, & St.Pierre, 2000), sexual adjustment (Baider & Kaplan De-Nour, 1984; Lavery & Clarke, 1999), and relationships with others in the social network (Bloom, 1996; Lavery et al., 1999; Peters-Golden, 1982; Stommel & Kingry, 1991).

Spouses of patients with cancer are profoundly affected by the diagnosis and are the first to respond to the demands related to their partner's illness and its treatment. Not only do they assume the responsibility for meeting the emotional and physical needs of their mates (Biegel, Sales, & Schulz, 1991; Blanchard et al., 1997; Laizner et al., 1993; Manne, Pape, Taylor, & Dougherty, 1999), they also make their own personal adjustments in the face of the illness and set the stage for the adaptation

of other family members. In fact, there is a significant body of research that suggests that the experience of the illness can be as distressing or more distressing for them as it is for the person with the disease and that the distress may continue well beyond the initial period of diagnosis (Baider, Koch, Esacson, & Kaplan De-Nour, 1998; Baider, Perez, & Kaplan De-Nour, 1989; Carlson et al., 2000; Cook Gotay, 1984; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000b; Given & Given, 1992; Morse & Fife, 1998; Northouse, 1990; Oberst & James, 1985).

Descriptions of family reactions to cancer suggest that the experience evolves over time as the illness moves through initial, chronic and late phases, with the periods of greatest distress coming at times of diagnosis, recurrence and at the end stages of the disease (Biegel et al., 1991; Rolland, 1987). The initial psychosocial phase of the illness has also been described as the “existential plight of the first 100 days” (Weisman & Worden, 1976-77) and is characterized by uncertainty, predominance of life/death concerns, symptom distress, interpersonal strains and the demands of new treatment protocols. It often begins prior to the actual diagnosis when symptoms appear or abnormalities are suspected, and continues until the treatment is over or has become stable and predictable. At this phase of the illness, health services are focused on the acutely ill patient. Spouses take on the role of mediator, gatekeeper and protector, and are frequently unwilling to add to the patient's burden by expressing their own needs (Carey, Oberst, McCubbin, & Hughes, 1991). In fact, some studies have indicated that spouses report little support from health professionals at this time (Northouse, 1988; Oberst et al., 1985), and suggest that these important players may often be left on their own to manage as best they can with the demands of the illness.

The majority of studies on adaptation to cancer have focused on the person with the disease, with relatively few studies of the adaptation of other family members. While some understanding of the spouses' experiences can be extrapolated from the cancer caregiving literature, the subjects in these studies often include individuals with different relationships to the patient, including members of the nuclear family, from the

extended family, or from the broader social network. This makes it difficult to get a clear understanding of the impact of the illness on spouses. In addition, the caregiver studies generally include subjects dealing with cancer across the psychosocial stages, and this tends to mask whatever differences exist between stages. Finally, most of the spouse studies have focused on male spouses of women with breast cancer (Hoskins et al., 1996; Northouse, 1990; Northouse, Templin, & Mood, 2001). Recently, studies that have addressed both male and female spouses' experiences with other types of cancer suggest that there are important gender differences in their experiences of illness, with women at least as distressed and at times more distressed than their husbands with the disease (Harrison, Maguire, & Pitceathly, 1995; Northouse, Mood, Templin, Mellon, & George, 2000; Peleg-Oren & Sherer, 2001; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000a). To date there has been little systematic examination of women's personal experiences with cancer in their partners during the initial psychosocial phase of the illness.

The absence of studies on wives of male cancer patients is all the more remarkable given the prevalence of prostate cancer in men and the repercussions of the treatment options of this particular disease. Prostate cancer is the most frequently diagnosed cancer in men (excluding skin cancer) and accounted for 26% of the 69,800 estimated new cases of cancer in Canadian men for the year 2002. It is also the second leading cause of cancer mortality in men in Canada after lung cancer (National Cancer Institute of Canada, 2002a). Although rare in men under the age of 40, the risk of prostate cancer increases with age, with the peak incidence in men between 60-70 years of age. Usually the disease has a slow rate of spread, but if untreated ultimately leads to metastases and death. Overall 5 year survival rates are 87% for men of all ages, and relative 5-year survival rates are 81% for men less than 55 years of age and 67% for men over 85 years of age (NCIC, 2002b). There are three major treatment options – radical prostatectomy, radiotherapy (with or without adjuvant hormone treatment), or less frequently, a close observation approach<sup>1</sup>. Because survival is favourable

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<sup>1</sup> Older men who or those who have lost sexual function may be managed with hormonal ablation therapy.

regardless of the type of treatment, treatment decisions depend on a variety of factors including: therapy-specific outcomes, age, ability to undergo the treatments, the Gleason rating (cancer cell count of biopsy tissue), tumour stage (degree of spread), and the men's personal preferences.

Both surgery and radiotherapy will likely bring problems related to urinary continence as well as problems in sexual functioning (Schover, 1996). These difficulties continue to resolve over the first year following treatment (Litwin, McGuigan, Shpall, & Dhanani, 1999; Litwin, Melmed, & Nakazon, 2001) but not infrequently become chronic (Shrader-Bogen, Kjellberg, McPherson, & Murray, 1997). For men who undergo radical prostatectomy, 15-20% will experience some degree of stress incontinence after surgery with 2-3% experiencing continuous dribbling (Smith & Middleton, 1996). Impotence is an almost universal early consequence of this surgery and persists beyond the initial recovery period in 20-50% of men, even in those receiving nerve-sparing surgical procedures (Litwin et al., 2001; Perez, Fair, & Ihde, 1989; Shrader-Bogen et al., 1997). For those who choose radiation therapy, impotence remains the primary complication of radiation, with 50% of men impotent by 7 years after the completion of treatment because of vascular scarring (Bagshaw, Cox, & Gay, 1988). Urinary continence and varying degrees of bowel problems are also concerns in the short term and occasionally persist over time.

Clearly, these issues are important not only for the men but also for their wives, who must deal with the psychological impact of the diagnosis, are frequently involved in making the decisions about treatment, and will be affected by the physical symptoms that their husbands experience. In the existing studies of prostate cancer where wives have been included, the focus has been on their perceptions of their husbands' illness (Carlson, Ottenbreit, St Pierre, & Bultz, 2001; Ptacek, Pierce, Ptacek, & Nogel, 1999) and their involvement with treatment decisions (Davison et al., 2002; Gray, Fitch, Phillips, Labrecque, & Klotz, 1999; Gray et al., 2000a; O'Rourke & Germino, 2000). The earliest of these (Kornblith, Herr, Ofman, Scher, & Holland, 1994) suggested that

wives were experiencing significantly greater psychological distress than their husbands. More recent studies of prostate cancer undertaken from a qualitative perspective have noted similarities in the perceptions of men and their wives regarding the illness over the long term, but also important differences in their perceptions of stress and in their coping patterns in the first year following diagnosis (Boehmer & Clark, 2001; Gray et al., 2000a; Heyman & Rosner, 1996; Lavery et al., 1999; Peleg-Oren et al., 2001; Ptacek et al., 1999). However, these studies of the couples' experience have been retrospective and cross-sectional, and have included wives in the chronic as well as the late stages of the disease. There has been only one prospective qualitative examination of the couples' experience of prostate cancer that has focused on the initial psychosocial stage of the illness (Gray et al., 2000a). The qualitative studies suggest that the symptoms associated with treatment are a source of distress for wives, but no studies, either qualitative or quantitative, have addressed the factors that influenced the adaptation of wives to prostate cancer during the initial psychosocial phase of prostate cancer. No studies have explored how available resources might influence their adaptation during this period. Theory driven, longitudinal studies are needed to systematically build knowledge about wives' adaptation to this illness.

Nurses working with families with cancer know that the initial psychosocial phase of illness is an opportune time to get to know family members and begin a helping relationship. In the case of prostate cancer, which brings specific challenges to sexuality, sense of self, and the marital relationship, understanding the impact of the illness on wives early in the experience is particularly important. Knowledge of the factors associated with their adaptation will help nurses to identify and provide additional support to women at risk who have few resources on which they can call. It would also help nurses to work with other women to identify and mobilize the personal and family resources that they already have in place. Such knowledge would also provide an empirical basis for early interventions that enhance the processes of learning and development within the family. Such nursing actions will result not only in a better experience for the wives, but ultimately for the larger family unit. Finally, the



knowledge gained about factors that influence adaptation in spouses of prostate cancer patients are likely to be applicable to spouses and families dealing with other types of cancer, and indeed, in other serious illness situations.

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**Chapter 2**  
**Theoretical Perspectives and Literature Review**

This chapter will first present the nursing perspective and the middle-range theory that provided the theoretical basis for the study. It will then identify the major variables derived from theoretical constructs in family stress and coping theory that were included in an explanatory model of wives' adaptation to prostate cancer at the initial stage of the illness. This is followed by a review of the studies on the constructs in the model, and by a review of the literature related to the adaptation of wives to prostate cancer. The chapter will conclude with a statement of the hypotheses that were tested and with a description of the expected contributions of the study.

### **Nursing Perspective**

The McGill Model of Nursing served as the broad conceptual orientation of the study (Gottlieb & Rowat, 1987; Gottlieb & Ezer, 1997). In this framework the central construct of health is viewed as a dynamic process - co-existing with but separate from illness - that subsumes the sub-concepts of coping and development. Coping is seen as a process of problem-solving that includes dealing with the emotional responses to events as well as achieving a degree of mastery over the illness experience. Development includes acts of recognizing, mobilizing and maintaining the potential and resources that reside within the individual, family or larger social context. The family system is the context in which individuals learn about health, and is seen as the unit of nursing intervention. The act of nursing is to engage the individual, the family or group in a learning process, and to assist them to mobilize, sustain and build their resources, strengths and potentials in order to reach their goals. This is achieved in the context of a collaborative nursing process in which consideration of individual and family feelings and perceptions of events serves as the starting point for the nurse and clients' work in making decisions, taking action, and evaluating outcomes. In summary, a broad

definition of health and processes of coping and development, an emphasis on understanding and working with family members' perspectives in a collaborative nurse-client relationship, and a focus on building and using resources are central features of the nursing framework on which this study was based.

### **Family Stress and Adaptation Theory**

The second theoretical source for the study, family stress and adaptation theory (McCubbin & McCubbin, 1993; Patterson, 1989; Patterson & McCubbin, 1983) is based on the assumption that an individual's perceptions will shape his or her own beliefs, values and behaviours as well as those of others in the family. It includes a set of theoretical constructs that are particularly relevant to the nursing perspective of the study. This middle-range theory suggests that demands created by normative and non-normative events, personal, family, and community resources, and different levels of meaning interact to determine how individuals and families will cope and adapt to crises such as newly diagnosed cancer. The theory can be used to build knowledge about families through its application to the study of the family unit or to the study of individual family members' experiences, and it provided the theoretical basis for the selection of the constructs that were included in the study.

According to theory (Patterson, 1989), there are four broad categories of demands facing the family – individual survival needs and developmental tasks, family tasks of maintenance and development, changing social conditions, and acute and chronic illness and handicapping conditions. The latter are of particular interest to nursing. In cancer research, demands have frequently been described as the distress felt in response to the physical and emotional symptoms created by the illness and its associated treatment regimens (Fawzy, 1995; Given et al., 1993). Symptoms of most concern to cancer patients identified across diagnostic categories were: intensity and frequency of pain, intensity and frequency of nausea, mood, appetite, insomnia, concentration, fatigue, bowel pattern changes, appearance, coughing, and respiration (McCorkle & Young, 1978). The demands created by the illness interact with the

normative events of family life to create a “pile-up” of demands that call for change in the family system. In order to handle this overload of demands, the family calls upon two potential sources of capability: its resources - what it has, and coping behaviours - what it does.

Resources, the first source of capability, are the characteristics, traits, and competencies that exist at the personal, family, or the community level. Personal resources include such things as innate intelligence, knowledge and skills, physical and emotional health, self-esteem, as well as a range of personality attributes (Patterson, 1989). Some of these personal resources are presumed to be relatively stable; others are acquired through positive experiences and interactions or depleted over time with repeated stresses and negative life experiences. Studies of the relationships between personal characteristics and health are numerous and have been summarized in a number of reviews (Rodin & Salovey, 1989; Carson, 1989; Taylor, 1990). While some studies have suggested that negative emotional states such as hostility make an individual more vulnerable to disease (Taylor, 1990), increasingly researchers are also emphasizing the protective function of positive emotional states.

Examples of personal qualities that serve as important personal resources and have been found to enhance health are hardiness (Kobasa, Maddi, & Kahn, 1982), optimism (Scheier & Carver, 1987) and sense of coherence (Antonovsky, 1987). Hardiness, a specific set of attitudes of challenge, commitment, and control that mediate the stress response was first studied in utility company executives and has since been examined in illness as new measures of the construct have been developed (Pollock & Duffy, 1990). Optimism, defined as the relatively stable tendency to believe that one will generally experience good versus bad outcomes in life (Scheier & Carver, 1985) is also emerging as a predictor of health outcomes in prospective studies of cancer (Carver et al., 1994, Kurtz, Kurtz, Given, & Given, 1995) and in other illness situations (Scheier et al., 1989).

The construct of sense of coherence (SOC) was also originally concerned with

understanding why people do well. It is seen as a global orientation to the world and to life events which is determined by three inextricably intertwined components - comprehensibility, manageability, and meaningfulness (Antonovsky, 1987).

Comprehensibility reflects the feeling that the stimuli derived from one's internal and external environments in the course of living are structured, predictable, and explicable; manageability reflects the feeling that the resources are available to meet the demands posed by these stimuli; and meaningfulness refers to the sense that these demands are challenges worthy of investment and engagement. Antonovsky (1985) describes the SOC as a resistance resource that provides individuals with life experiences that have three characteristics – consistency, a balance between demands and the capacity to meet them, and the possibility of participation in decision-making. He suggests that the SOC develops through childhood and becomes relatively stable by the age of 30, but adds that movement on the SOC continuum can occur even after early adulthood, and that even minor modifications in both directions can make considerable differences in the health of people.

The construct of family resources is one of the most intensely studied domains in family literature, with many of the prominent theoretical models of the family focusing on variables that could be considered as family resources (Patterson, 1988; Olson, 1989). In fact, there are a number of different terms used in the literature to reflect family characteristics that may be associated with better functioning and better health. In a review of the definitions of over 50 concepts, Olson and his colleagues (Olson, Russell, & Sprenkle, 1993) found that the terms used were conceptually similar and dealt with closely related family processes. They identified three distinct processes of family functioning. The first, called cohesion, focuses on the degree to which an individual was separated from or connected to his or her family system and reflects the emotional bonding that family members have toward one another. The second, called adaptability, focuses on the degree to which the family system is flexible and able to change. The third was communication between various members and was described as the process of transmitting feelings, attitudes, facts, beliefs, and ideas, through verbal

and nonverbal means. It was viewed as a facilitative process that permits the family to achieve optimum levels of cohesion and flexibility (Olson, 1989). Patterson (1988) and McCubbin & McCubbin (1987) have described these constructs as consistent with family resources in family adaptation theory.

Community resources are all the characteristics, competencies and means of persons, groups and institutions outside the family including medical and health services, schools, community groups, churches or other organizations upon which the family may call to meet its demands. Resources at the community level have most frequently been examined in the cancer population under the rubric of social support (Bloom, 1996; Fink, 1995; Morse et al., 1998). While there are many conceptual and methodological issues in the measurement of social support, the concept has been related to better outcomes for patients and for family members dealing with cancer.

Coping behaviours, the second source of capability, are the attempts of the family and its members to maintain or restore the balance between demands and resources by 1) reducing the number of demands, 2) acquiring additional resources, 3) maintaining existing resources so they can be reallocated to new demands, 4) managing the tension associated with ongoing strains, and 5) changing the meaning of demands.

According to the family stress models, these two sources of capability - resources and coping behaviours - interact with the meanings that the family ascribes to what is happening to them, and will determine the nature of the adaptation that the family and its members make to crisis events. Patterson & Garwick (1994) suggest that families construct and share meanings on three levels: 1) around specific stressful situations, 2) their identity as a family and 3) their view of the world.

The first level, called situational meaning, is essentially an incorporation of the concept of cognitive appraisal (Lazarus & Folkman, 1984) which refers to two appraisal processes that occur simultaneously. Primary appraisal reflects an individual's

subjective definitions of the demands to be faced, and secondary appraisal refers to the perception of the capabilities or resources available to meet them. In primary appraisal, encounters or transactions with the environment are assessed as irrelevant to one's well being, as benign-positive, or as stressful. Three stress appraisals have been proposed: harm/loss, threat, and challenge. These appraisals are not mutually exclusive, and could occur simultaneously in the face of multifaceted situations. Secondary appraisal is concerned with the evaluation of one's coping options in an attempt to overcome them or improve the situation or to prevent harm. Appraisal, or situational meaning, is viewed as a dynamic and continuous process, changing as the stressor changes and as coping resources are acquired or depleted (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Situational meanings are the most concrete of the three levels of meaning in family adaptation theory, are more immediately available to individual consciousness, and are the most responsive to changing circumstances (Richer & Ezer, 2000).

The second level of meaning, the family identity, is described as the shared values, beliefs and expectations that determine how the family sees itself (McCubbin, Thompson, Thompson, & McCubbin, 1993; Patterson, 1993). In contrast to situational meaning, it develops gradually and changes more slowly. The third level, or the family's worldview, is the most abstract, implicit, and stable level of meaning. It is often something the family is not conscious of, nor readily able to articulate. It provides the framework for both individuals' ways of defining the stressful situations and for the development of family identity. However, despite their importance in family coping theory, little empirical work has been done to explore or measure the constructs of family identity and family worldviews.

The phenomena of interest in family stress and adaptation theory are the processes of adjustment and adaptation of the family unit and of family members. In the literature, the terms adjustment and adaptation are used interchangeably, but in family adaptation theory a distinction is generally made between the terms (Patterson, 1989)



with adjustment used to refer to the ongoing accommodations to be made in response to relatively minor strains, while adaptation refers to major second-order changes (Watzlawick, Weakland, & Frisch, 1974). Adaptation is seen as a continuous process that evolves as circumstances change. It ranges from maladaptation to bonadaptation (McCubbin & Figley, 1983), with both types of responses being of importance. At the negative end of the continuum, maladaptation is defined as the continued imbalance between demands and capabilities, and may be characterized by deterioration in family unit integrity or in individual family members' sense of well-being, physical and/or psychological health. At the positive end of the continuum, bonadaptation is seen as a minimal discrepancy between demands and capabilities, and is characterized by maintenance or strengthening of the integrity of the family unit and by maintenance or improvement of individual family members' sense of well-being. In order to remain consistent with the theoretical framework, the term "adaptation" is used to refer to the phenomenon of interest in this study.

Family stress and adaptation theory includes a broad range of constructs to be considered in building knowledge about how individuals and families adapt in the face of stressful events. The constructs that were selected in this study were symptom distress, personal resources, family resources, and situational appraisal. Because the theory incorporates dynamic processes of appraisal and adaptation, it called for a prospective view that would capture how these processes evolved over time. This study incorporated a prospective approach in a test of a model derived from this theory in an attempt to build knowledge about wives' adaptation to prostate cancer over the course of the initial psychosocial phase of illness.

### **Literature Review**

The review that follows begins with an overview of cancer studies related to the individual variables that were selected as predictors of adaptation in the theoretical model of wives' adaptation to prostate cancer. These were: symptom distress as an illness demand; the sense of coherence as a personal resource; the family resources of

cohesion, adaptability and communication; and primary and secondary cognitive appraisals as of illness. The review will then address the research literature on spouses' adaptation to cancer, the phenomenon of interest in this study. This section will include: studies of spouses' adaptation to prostate cancer, studies of spouses' adaptation to other types of cancers, and model-testing studies of spouse adaptation.

It should be noted that many of the studies are relevant to more than one section of the literature review. In the case of quantitative studies, if a study addressed the phenomenon of adaptation broadly defined, it was included in that section of the review. If a study was relevant to the predictor variables but was not concerned with adaptation, it was included in the review related to the study variables. This decision ensured that a study would be described only once. In the case of qualitative studies, all studies were described in the section on adaptation to prostate cancer. However, the portion of qualitative data relevant to symptom distress in prostate cancer was described in the section on study variables.

### *Study Variables*

Four variables related to the demands of the situation, personal and family resources and situational appraisal were considered in the theoretical model. These were: symptom distress, the sense of coherence as a personal resource, the family resources of cohesion, adaptability and communication and cognitive appraisals of illness.

*Symptom distress.* An overview of studies of symptom distress suggests that illness-related symptoms are associated with disturbances in patients' mood, functional status and the meaning of illness. The literature on caregivers of cancer patients, while more limited, suggests that the symptom experience is also an important feature of the spouses' experience of illness.

In the case of prostate cancer, the problems of urinary continence and sexual

functioning are the most common and enduring symptoms. These problems not only constitute a major threat to the men's sexual identity, but also highlight their inability to exercise control over a basic of human function. However, only recently has the subjective experience of those symptoms been described. In a study of men's experiences (Bertero, 2001), "altered sexual patterns" was reported as the major theme and included more than a disruption of intercourse and other physical sexual activities. This disruption of sexual patterns was influenced by the men's view of their manliness, by their role as a partner in sexual and intimate relationships, by concerns coming from their wives/partners, and by their age and social situation.

Other studies suggest that the husbands' symptoms affect the women as well, but not necessarily in the same way. In their analysis of the couples' experiences with prostatectomy during the first year following treatment, Gray and his colleagues (2000a) noted that an important aspect of managing the illness for both husbands and wives was dealing with the practical issues related to symptoms. These included managing incontinence, post-operative urinary blockages, and experimentation with drug injections, vacuum pumps or other technologies that were available to deal with impotence. They suggested that wives were particularly prone to distress as they attempted to help their husbands deal with both the physical and emotional consequences of treatment.

In another study of 12 couples' experiences with prostate cancer (Lavery et al., 1999), all of the couples who had been sexually active prior to diagnosis reported negative changes arising from the patients' impotence brought about by their treatment for prostate cancer, citing disturbed body image, loss of spontaneity and sexual emotions as causing the most difficulty. While some of the women admitted this had been difficult for them, they had adopted a philosophical stance and were generally less disturbed than their partners.

In a study of couples' perceptions of the experience of prostate cancer on their

lives (N = 20), Heyman and Rosner (1996) suggested that particularly for the women, the incontinence had an even greater impact than the impotence because it influenced the routine of daily living. The women indicated that intercourse and intimacy were not synonymous and many were satisfied with loving feelings expressed in other ways, while the men grieved over their loss, and found redefining intimacy in new terms a very difficult adjustment. Both men and their wives were left with a diffuse sense of anger, as the continuing symptoms were not only something to deal with every day but served as a constant reminder of the possibility that the disease might recur.

Butler, Downe-Wambolt, Marsh, Bell & Jarvi (2000) described the experience of 21 women whose husbands had undergone radical prostatectomy during the previous 24 months. With respect to the symptoms their husbands experienced, nine women described the need for more information that would enable them to manage at home. Most women reported that sexual activity was altered after surgery, but almost all reported that lack of intercourse was not a personal problem for them. Several did see it as a problem area for their husbands. Eleven of the women stated there was no effect of the illness and its treatment on their relationship with their spouse, while others reported there was some conflict within the marriage and four felt isolated by the experience.

In summary, the qualitative literature suggests that the urinary and sexual problems that accompany treatment have an impact on the wives of men with prostate cancer. Some studies in the cancer literature on spouse and caregiver adaptation that are described in the sections that follow also suggest that symptom distress affects family caregivers at all psychosocial phases of cancer, but particularly during recurrence and in the late phases of the experience (Goldberg, Wool, Glicksman, & Tull, 1985; Northouse, 1990; Northouse, Laten, & Reddy, 1995b). Collectively, this body of literature suggested that the inclusion of symptom distress in the explanatory model would enable a further exploration of the role that symptom distress plays in the adaptation of wives to prostate cancer.

*Sense of coherence as a personal resource.* The relevance of the construct of sense of coherence to family stress and adaptation theory has been noted in the literature (Patterson, 1989) (McCubbin, Thompson, Thompson, Elver, & McCubbin, 1994). The construct can be seen as a personal resource when examining the adaptation of individual family members; it may also be seen as an antecedent for family identity and the family schema or world-view, which are the family members' shared perceptions of the world and their place in it. Sense of coherence as a personal resource has been examined as a predictor for patient outcomes in cancer as well as other illness states. It has also been associated with outcomes for both patients and for family members.

Post-White (1994) carried out a longitudinal, experimental study that tested the effects of mental imagery/support group intervention on hope, on the SOC, on cellular immune function, disease state, and quality of life in a group of individuals receiving chemotherapy for cancer ( $n = 22$ ) and a time-matched control group ( $n = 16$ ). They also explored the concept of sense of coherence as a dynamic versus a stable disposition. Seventy-seven percent of the variance in QOL was explained by the SOC, time since chemotherapy, disease state, and  $\beta$ -endorphin levels. This finding provided strong support for the importance of SOC in explaining quality of life outcomes. With respect to the intervention, there was no difference in the SOC scores between the experimental and control groups. However, although the *mean* SOC scores for the control and experimental group remained stable over time, scores within some individuals fluctuated over the four months, with both increases and decreases measured. The authors were not able to identify which factors resulted in the change of the SOC over the four months, but felt that the factors appeared to be individualized to the participant, suggesting that stability or change in the SOC may not always be captured by group analysis. Certain demographic factors - less advanced disease, age in the 50-61 year range, and more than 14 years of education - corresponded with higher SOC scores.

Because of the population from which their respondents were drawn, Nesbitt and Heidrich' study (2000) of SOC in 137 community dwelling older women (mean age, 76yrs) were of interest in this review. They examined the relationships among physical health limitations, the sense of coherence, illness appraisal and quality of life in their subjects. They found that regardless of the level of difficulty with functional health, women with a higher sense of coherence and more positive appraisals had higher levels of quality of life. They also found that higher SOC and more positive appraisals mediated the negative effect of physical health limitation, notably symptom bother and functional health, on the women's quality of life.

In a qualitative study of patients with brain tumours (n = 20) and their next of kin (n = 16), Strang and Strang (2001) explored whether the themes of manageability, comprehensibility and meaningfulness of the SOC were related to how subjects coped with the situation. They found that manageability was achieved by active information-seeking strategies, by social support, by coping and by a positive re-interpretation of the situation. Comprehensibility was constructed by the patients' own thoughts and theories, and meaningfulness was created by close relations, faith as well as by work. The researchers felt that SOC was an important concept in an "intermediate position", bringing together the coping model and spiritual/existential issues.

In summary, the literature suggested that the construct of sense of coherence has been associated with better outcomes for both patients and family caregivers. It provides general directions for the development of nursing interventions and can be considered a potentially strong predictor of adaptation in wives dealing with prostate cancer in their mates.

*Family resources.* The studies in cancer research that have included family resource variables have been carried out with patients, and have focused primarily on the impact of the cancer on the marital relationship (see Manne, 1998). More recently,

the importance of family and marital resources for spouses has also been described.

Vess and his colleagues (Vess et al., 1985a; Vess et al., 1985b) studied 54 married cancer patients and their spouses on admission to an oncology service and five months later. They found that the couples' marital communication scores were significantly related to the husbands' role competence ( $r = .48$ ), family cohesion ( $r = .46$ ), family conflict ( $r = -.52$ ) and role conflict ( $r = -.51$ ) at time 1. Five months later at time 2, they found that spouses' communication patterns measured at time 1 were significantly associated with family cohesion ( $r = .25$ ), role conflict ( $r = -.32$ ) and husbands role competence ( $r = .34$ ) at time 2. Although there was a substantial decrease in the response rate at time 2 which suggested that the subset of respondents may not have been representative of the original sample, the importance of open communication to reducing role conflict and to enhancing role performance was raised as an important consideration. While no conclusions were drawn related to the change in the level of correlation over time, the findings did suggest that there were shifts in marital processes over the five month period following diagnosis.

In a qualitative study carried out over a period of 1 year (Hilton, 1993), the verbal communication patterns of 43 couples dealing with newly diagnosed, non-metastatic breast cancer were examined. Three patterns of communication were identified based on whether couples shared similar or different views about the importance of talking. The patterns included: couples with open communication, couples with no communication between themselves, and couples with divergent views on communicating. The most facilitative communication pattern was open, but with selective disclosure, whereas couples with divergent communication needs had the greatest difficulties. Major reasons for talking /not talking were related to prior beliefs, and to uncertainty about whether to talk, and how and when the talking should happen.

In a qualitative analysis of the responses of 30 men interviewed at 16-20 months following their partners' diagnosis of breast cancer (Zahlis & Shands, 1993), 27% of

the men continued to describe negative feelings and effects of the illness on their daily lives. Fear of recurrence continued in the forefront of their thoughts, and they worried about their ability to handle their partner's emotional response to it. The men also reported that breast cancer often added to other stressors already present in the family, and described marital and communication problems related to the illness that had continued to persist since the very early stage after diagnosis.

In a longitudinal study Hoskins (1995) examined the differences in fulfilment of emotional and interactional needs of breast cancer patients ( $n = 128$ ) and their partners ( $n = 121$ ) at 6 points in time during the first year following diagnosis. At the initial 7 to 10 day post-surgical phase, partners reported more dissatisfaction with the extent to which the patients agreed with their thinking, were open to communicating feelings and perceptions, were sensitive, insightful, were considerate of their feelings and shared in their needs for companionship. At each of the remaining 5 time periods in which couples responded during the first year, the position on dissatisfaction was reversed for patients and partners - partners were less dissatisfied while the patients were more dissatisfied. A similar pattern emerged for emotional needs, with partners less satisfied at 7-10 days with the expression of affection, the emotional security and stability of the relationship, and the recognition and appreciation they received, and more satisfied in the later phases. These findings suggest that patients and partners alternated in the extent to which they perceived that their needs were met by their mates. The author suggested that in this sample, the effects of cancer accentuated the dynamics of a complementary pattern of interaction as a means of coping.

In a study of mutual spousal support and psychological health in 73 cancer patients (37 women, 36 men) and their partners who had been living with cancer for varying lengths of time (Douglass, 1997), spouses perceived less interpersonal support than did patients. Spouses also experienced more self-esteem and less depression when levels of reciprocal support and interpersonal support were balanced and high in the marital relationship than when they were unbalanced, or balanced but low. Finally,



conflict in the marital relationship was negatively related to marital reciprocal and interpersonal support and positively related to depression.

The importance of family functioning in cancer, described in the studies above, is supported by the findings in the qualitative work on prostate cancer (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2000; Gray et al., 2000a; Heyman et al., 1996) which suggested that while some men were communicating less openly about their feelings, their spouses wanted to share in a mutual expression of emotion related to the illness and treatment. These studies are described in the review on spouses' adaptation to prostate cancer that follows. Together this body of work provided strong empirical support for the inclusion of family variables – notably closeness and communication – in the explanatory model of spouses' adaptation to prostate cancer.

*Situational appraisal.* Despite the importance of the construct for both individual and family adaptation theories, there have been a number of limitations in the study of cognitive appraisal. One difficulty has been addressing the problem of confounding between appraisal and coping that occurs when both constructs are measured in the same study. Another has been the conceptual blurring that has occurred as a variety of terms including beliefs, purpose in life, spirituality and meaning in illness, meaning of illness, illness appraisal and cognitive appraisal have been used interchangeably when in fact they deal with different although related concepts (Richer et al., 2000). While instruments that measure cognitive or situational appraisal are available, measurement issues remain. The issues identified in the past (Peacock & Wong, 1990) related to 1) the use of single item measures which carry a likelihood of high measurement error, 2) the availability of instruments that measure dimensions of both primary and secondary appraisal and 3) the meagre information available regarding the psychometric properties of the measures, are still of concern at present.

Researchers interested in the concept of appraisal in spouses or family caregivers have generally examined the mediating effects of appraisal on adaptation,

and those studies are included in the review section related to caregiver adaptation that follows. However, the studies of appraisal in cancer patients also add to our understanding of the construct and are summarized here. In the empirical literature in cancer, no prospective studies of appraisal were found.

In a study of the appraisal of stress among family caregivers of cancer patients receiving radiotherapy (N = 47, 77% women), Oberst, Thomas, Gass, & Ward (1989) explored the relationships between the caregiver, situational characteristics, appraisal of caregiving, and caregiver demands. The authors reported that despite the fact that ambulatory radiation treatments usually are not thought of as requiring extensive care at home, the family participants suggested that considerable time and effort were involved. Their findings showed that appraisal was related to caregiver characteristics and resources. Higher perceptions of caregiver load were strongly correlated with harm/loss ( $r = .48$ ) and threat ( $r = .41$ ) appraisals. Caregiver's health, social class, and education level all correlated negatively with one or both of the negative appraisals, suggesting that persons with the fewest personal and material resources were most likely to perceive the caregiving situation as harmful and threatening. Caregivers in the poorest health, those with less education and those of lower socioeconomic status had higher scores on the appraisals of harm/loss and threat. No relationship was found between age and the negative appraisals. Rather, age was related to positive appraisal as older caregivers saw their situation as significantly more benign ( $r = .50$ ) and challenging ( $r = .25$ ) than did younger caregivers.

Appraisals of cancer, heart disease and surgery were examined in a prospective study of 49 breast cancer patients and a comparison group of 57 healthy women (Orr & Meyer, 1990). In an analysis of variance for group, disease and appraisal items (2x3x7), the researchers found that breast cancer patients appraised cancer, heart disease and surgery significantly more optimistically than did healthy respondents. Healthy respondents appraised cancer as significantly more negative than heart disease. The patients' appraisals were more optimistic at the beginning of the post-mastectomy

year than at the end. Also, patients who regarded cancer as less negative than heart disease adjusted better than patients whose appraisals were more negative. Finally, more positive appraisals were prospectively related to better social adjustment for patients. While initial appraisal did not explain concurrent adjustment, appraisal at time 1 and 2 accounted for 44% of the variance in adjustment at time 3, and 34% of the variance at time 4.

Jenkins and Pargament (1988) examined primary and secondary appraisal and its relationship to adjustment in 62 cancer patients receiving chemotherapy. Predictor variables included the patient's ratings of life-threat (primary appraisal), their perceived control over cancer, and their perceived control over emotional reactions (secondary appraisal). With respect to primary appraisal, they found that higher levels of perceived threat were associated with higher levels of observed behavioural upset and lower levels of observed adjustment to illness. With respect to secondary appraisal, perceived control over cancer emerged as only a weak correlate of adjustment, while two external sources of control (God and chance) also emerged as correlates of adjustment. Overall, appraisal variables, along with other independent variables, acted as rather modest predictors of adjustment as reflected by self-esteem ( $R^2 = .21$ ) and behavioural upset ( $R^2 = .28$ ).

In a study of 216 chronically ill subjects from oncology, rheumatology and gastroenterology clinics (Arpin, Fitch, Browne, & Corey, 1990), severity or type of disease was not related to adjustment nor to the observed level of disability. Rather, the meaning variables of "the illness as a harm, loss, threat associated with disability, deterioration, and disfigurement" and "illness adversely affecting daily living", followed by poor family function and disability variables explained 57% of the variance in adjustment outcomes for the patients in this study.

Padilla, Mishel and Grant (1992) evaluated the influence of factors that had an impact on several dimensions of health-related quality of life in 100 women with newly

diagnosed gynaecological cancer. In the first of a series of separate analyses, the predictor variables of positive mood state, danger-focused appraisal, ambiguity about illness state and an appraisal of mastery, accounted for 57% of variance in the total score on the quality of life scale. The contribution of the same four variables accounted for 56% of the variance in the psychosocial well-being dimension of the quality of life measure. In a third analysis, negative mood state and ambiguity about illness accounted for 25% of the treatment distress dimension of quality of life. Finally danger-focused appraisals explained 23.5% of the variance in the physical well-being subscale. In addition to significant contributions made by appraisal, the findings suggest that demographic variables (age, time since diagnosis) and illness variables (metastasis and stage of cancer) had almost no impact on psychosocial well being, and a minor impact on treatment distress and total quality of life of patients with gynaecological cancer.

Oberst, Hughes, Chang and McCubbin (1991) explored the extent to which selected illness factors including symptom distress, personal factors, and family resource factors contributed to patients' (N = 72) self-care burden, and then tested a model of the effects of self-care burden and appraisal of illness on patients' mood. Self-care burden and family hardiness were the best predictors of appraisal scores, explaining 42% of the variance, with symptom distress accounting for an additional 5%. Four variables - appraisal of illness, symptom distress, family hardiness, and the health deviation component of self-care burden explained 55% of the variance in mood dysfunction, with appraisal accounting for most of the variance. Their findings suggested that appraisal mediated the effects of self-care burden on mood and partly mediated or reduced the effects of symptom distress on patients' mood.

Together these studies suggest that for patients, there is consistent evidence that more positive appraisals are associated with better adaptation. However, despite the centrality of appraisal in both individual and family adaptation theories, and the frequent calls for longitudinal studies of the concept (Aldwin, 1994; Lazarus, 1993), the data on cognitive (situational) appraisals of spouses and other caregivers during

cancer remain limited and the longitudinal studies are absent. The evidence from existing patient studies cited here, and from the caregiver studies cited in the sections that follow provided support for examining the contribution of situational appraisal in a study of wives' adaptation to prostate cancer.

### *Adaptation*

The terms adaptation, adjustment, functional status, psychological well-being, quality of life, and life satisfaction are often used interchangeably to refer to an individual's general health and overall adjustment (McDowell & Newell, 1987). Despite the range of terms currently in use, there is general consensus that psychosocial adaptation is both a subjective and multidimensional construct (Aaronson et al., 1991). The subjective component suggests measurement from the person's perspective. The multidimensional component is more problematic as there is no agreement on which dimensions of the person's life should be assessed. Recurrent themes that have been measured include physical status or functional ability, emotional well-being and the fulfilment of social roles (Goodinson & Singleton, 1989; Jenkins, 1992).

*Spouse adaptation to prostate cancer.* The overview of studies of wives' experiences during prostate cancer revealed a focus on wives' views of their husbands' experiences, or on their involvement in making decisions about treatment. There are, however, a few qualitative studies that have reported on selected aspects of their own experiences with the illness.

In their study of the psychological impact of prostate cancer on patients and their wives, Heyman & Rosner (1996) found that both men and women described two phases in the illness experience as having subjective significance. The early phase was at the time of diagnosis and treatment choice when both partners expressed fear of death as the dominant issue, felt intense pressure to be actively involved in treatment decisions, and experienced feelings of anxiety and sometimes anger. At this phase, women felt that they played an essential role in the decision making process and had a

great deal at stake. They were involved in the early phase coping strategies that included searching for information and seeking professionals who showed they cared. They attempted to help their husbands emotionally, acted as agents for their partners by raising questions and clarifying treatment options, and felt angry when they thought that professionals were being insensitive to their husbands' needs. One unexpected theme that emerged for both husbands and wives was the importance of their relationship with the care-provider, with the differing needs and behaviours of husbands and wives making the encounter more complex for treating physicians, particularly in the early phase. The late phase was marked by the realization that cancer was something they had to live with, and the issues at that time were related to managing the symptoms and side effects of treatment, and the fear of recurrence. The wives' late phase coping strategies included maintaining a positive outlook, redefining intimacy, and expanding their knowledge base.

In another descriptive study (Harden et al., 2002), 22 men and 20 spouse-caregivers in the early stages of treatment for prostate cancer, in the chronic phase, or in late stages of the disease, participated in separate focus group discussions. The analysis of the discussions did not attempt to distinguish the experiences for each phase but indicated that intense emotional responses, a need for information about treatment effects and ways to handle them, as well as the need to voice concerns were important themes for both the men and their spouses. The importance of the role of the wives in managing the illness and the importance of including them in programs of care also emerged as a recurrent theme.

In a qualitative study that examined both coping and adaptation in 12 men and their wives who had been dealing with prostate cancer for a period between 5 and 24 months (Lavery et al., 1999), the researchers found that in contrast to their husbands, relatively few spouses reacted to the diagnosis with stoic acceptance. They were more actively engaged in meeting the demands of illness than were patients and, as in the previous study, were actively involved in seeking information. The wives in this study

were less likely than their husbands to use more protective buffering strategies such as avoiding discussions about their cancer or denying anxieties and concerns. The majority of partners reported that their marital relationships had remained intact, with a few reporting improvement. However, as reported in the preceding review of the role of symptoms, there were negative changes to many couples' sexual relationships as a result of the impotence caused by the men's prostate cancer treatment.

In the first report of a longitudinal qualitative study of couples awaiting prostatectomy (Gray et al., 1999), Gray and his colleagues found that the diagnosis was a shock for both partners. At this phase of the illness, couples found themselves readdressing the marital relationship, searching for information, seeking to maintain normality in their lives, while at the same time experiencing feelings of anxiety. The second report on the experiences of this cohort (Gray et al., 2000a) followed with the analysis of data collected at 10 weeks post surgery and 1 year after surgery. These data were grouped under a core category described as "managing the illness" which included five major domains: dealing with the practicalities; stopping illness from interfering with everyday life; keeping relationships working; managing feelings; and making sense of it all. As in Lavery and Clark's (1999) study, the authors also reported that there were indications of tension and conflict within many couples. Most of the women in this study, while agreeing with their husbands' need to avoid excessive preoccupation with the illness, nevertheless wanted more discussion of issues and feelings than they were able to achieve. They minimized their own expression of feeling in order to support their partners. The authors suggested that while it may have been important to manage illness by downplaying the importance of prostate cancer as a health crisis, the overall impact of prostate cancer was greater than openly acknowledged by most couples in this study. In a third report based on the data from the same study (Fergus, Gray, Fitch, Labrecque, & Phillips, 2002) the participants' responses pertaining specifically to supportive interactions within the marital dyad were described. A core category of "active consideration" referred to the nature of the support that patients gave to their spouses. Four domains of patient- provided support

were part of this category. These were: easing spousal burden; keeping us “up”; maintaining connection; and considering my spouse. A fifth domain labelled no help referred to a small proportion of men who were classified either by themselves or by their wives as not being supportive in any way.

The available studies of prostate cancer offer a description of wives’ lived experiences with the illness. However, questions remain about the factors associated with better outcomes for wives and how the experience evolves over time.

*Spouse adaptation to other cancers.* Additional insight into the nature of the wives’ experiences is available from literature that addresses spouse and caregiver adaptation in other types of cancer. In this literature, the term “spouses” refers to both men and women when the studies deal with mixed types of cancer. When the disease is breast cancer, spouses are exclusively male. No studies were found that dealt exclusively with female spouses.

In an early study of factors associated with mood (Goldberg et al., 1985), the contributions of measures of physical status and social involvement to depression were described in 20 lung cancer patients and 18 spouses at 3 intervals between time of diagnosis and 6 months into the illness. For patients, physical status was an important determinant of depression at 6 months, while social interests and involvement were not significantly associated with their depression scores across the 6-month period. For spouses, patients’ physical status was not associated with their depressive symptoms but was consistently related to their levels of social interest and involvement over the six month period. One of the reasons offered for the differences between the spouse and patient group was the fact that the spouses were predominantly women for whom social interests may have been more important predictors.

In a study of the health of 65 spouse caregivers (mean age 66.4 yrs, 68% female) caring for patients with advanced cancer in the home (Stetz, 1987), the role of



existential meaning (purpose in life) and of other dimensions of the caregiving experience that might buffer or prevent negative health outcomes were examined. Contrary to expectations, difficulty with performing physical tasks and role alterations were not related to sense of purpose in life. The author suggested that the absence of a relationship may have been related to constrained variability in the measures. However, the study did show that age and gender of the caregiver, a higher sense of purpose in life and lower levels of perceived uncertainty about the patients' illness were able to explain 33% of the variance in caregivers' health.

In a cross-sectional correlational study (Ell, Nishimoto, Mantell, & Hamovitch, 1988), researchers examined whether illness related factors and psychosocial coping factors were related to psychological adaptation in patients (n = 230) and their significant others. The significant other group consisted of spouse (n = 152) and non-spouse (n = 78) subgroups. For the significant others group, the psychosocial coping factors of personal control and of perceived adequacy of attachment, followed by less advanced stage of cancer and higher age were the most important predictors, accounting for 45.3% of the variance in their mental health. Differences in the nature and relative importance of the variables that influenced psychological adaptation emerged between patients and significant others with age less important and cancer stage more important for the group of significant others than for patients.

In a longitudinal descriptive study of adjustment in 41 mastectomy patients and their husbands at 3 days, 30 days and 18 months after surgery (Northouse, 1990), three components of psychosocial adjustment – mood, symptom distress, and role functioning were assessed. Patients' and spouses' levels of mood did not differ from one another, and mood showed a significant improvement in both patients and spouses over time. Most of the change in subjects' scores occurred between time 1 and 2 with a levelling off of their mood scores between time 2 and time 3. Spouses reported as much symptom distress as patients across the 3 data collection periods, and their distress scores did not change significantly across time. Distress levels were significantly above

the level reported for the normal population over the course of the study, with approximately one-third of patients and one-fourth of spouses continuing to experience moderate levels of distress a year and a half after surgery. Spouses reported significantly more role functioning problems than did the patients with breast cancer, with significant decreases in the number of problems reported by both patients and spouses across time.

Carey, Oberst, McCubbin and Hughes (1991) explored the extent to which selected personal, family and illness factors predicted type of appraisal and mood in 49 family caregivers (mean age 56 yrs, 50% female) of patients receiving chemotherapy. Caregiving burden, family hardiness, and caregiver health predicted 50% of the variance in negative appraisal of caregiving. Generally caregivers had low negative appraisal scores, with those who reported high family hardiness less likely to view the situation negatively. Caregivers who viewed the situation negatively were more likely to experience mood disturbances. The regressions showed that caregiving burden, family hardiness and caregiver health predicted 50% of the variance in negative appraisal of caregiving; negative appraisal and age of the caregiver explained 49% of the variance in mood disturbance.

In a study of 22 women with breast cancer and their spouses, measures of psychological distress, marital cohesion, marital satisfaction, coping and marital history were examined in 22 breast cancer patients and their spouses one year after the diagnosis (Hannum, Giese-Davis, Harding, & Hatfield, 1991). For the female patients, psychological distress was related much more to their husbands' behaviour, marital adjustment, and reported cohesiveness than to their own behaviour and marital adjustment and their own reports of marital cohesiveness. For the male spouses, the wife's behaviour and perception of the cohesiveness of their relationship were almost as important as their own individual variables in predicting their psychological adjustment. These findings suggest that interpersonal variables, not individual factors alone, influence the process of coping and adaptation to cancer. As the authors suggest, the

differences in the findings between patient and spouse may be related to being in the patient versus caregiver role, or they may be gender related because women are typically more interpersonally oriented than men.

Northouse, Laten and Reddy (1995b) compared the reports of women with recurrent breast cancer ( $n = 81$ ) and their husbands ( $n = 74$ ) to determine whether their reports of adjustment, support, symptom distress, hopelessness, and uncertainty were different. Women reported more emotional distress than their spouses, but both had a similar number of role adjustment problems. Women and husbands differed in the amount of support and uncertainty they reported but their reports of symptom distress were not significantly different. Women in this study found the recurrent phase of illness more distressing. In contrast, 56% of their spouses reported that the initial phase was more distressing, 39% found the recurrence phase more distressing and 4.2% found both periods equally stressful. Patients and spouses did not differ in the level of symptom distress they perceived. In a further analysis (Northouse, Dorris, & Charron-Moore, 1995a), the data from the women and their husbands were combined ( $N=155$ ) in order to examine the relationships between the four predictor variables (support, uncertainty, symptom distress, hopelessness) on the women's and husbands' adjustment and emotional distress. For the spouses, 57% of the variance in their role adjustment problems was explained by their own health problems (entered first as a control variable) and by their wives' levels of distress, their perceived support and their levels of hopelessness. Also for the spouses, 32% of their emotional distress was accounted for by whether or not their wives were receiving treatment and their perceptions of their own health (entered first), and by their perceptions of their wives symptom distress. The findings suggested that multiple factors, some shared and some not, influenced patients' and spouses' adjustment and needed to be considered when planning for care.

In a study of adjustment among husbands of women with breast cancer (Hoskins et al., 1996), the researchers reported that the husbands' ( $N = 121$ ) emotional

adjustment could be predicted by their satisfaction with the patients' response to their interactional and emotional needs and by support from other adults. The relationships were significant at concurrent times, across contiguous times, and predictive from the 7-10 day post surgical period to both the 6-month and one year end points. The authors also reported that 21% of the variation in emotional and physical adjustment of spouses at 12 months could be explained by the canonical variable of marital support. In this study, support provided by the marital relationship as well as support provided by others outside the marriage were important factors in adaptation.

In a prospective study of the impact of coping and family relations on psychological distress in cancer patients ( $n = 133$ ) and their spouses ( $n = 133$ ) at 1 month following diagnosis and on follow-up one and a half years later ( $n = 67$ ) (Baider et al., 1998), the authors noted that on the whole, patients and spouses were moderately distressed. The psychological distress of male patients was higher than for female patients, and the distress scores of their wives approached the cut-off for psychiatric "caseness". At one month, 41% of variance in spouses' distress was explained by intrusive coping, female gender, and to some extent by the patients' distress. On follow-up one and a half years later, 35% of variance in spouses' distress was explained by the same variables. Interestingly, while cohesion was related to patients' distress at the time of diagnosis, cohesion did not have significant protective effects for spouses either at the onset of the illness nor at the end of their study. Despite the attrition in the respondents between the initial and final phase of data collection, the authors thought that certain findings were clear. Spouses were as distressed as patients, and different factors related to patients' and spouses' distress at different points in time.

Morse et al. (1998) examined the contributions of sources of social support, dyadic adjustment, coping strategies, emotional response, and cognitive response (measured by the significance of the illness on one's life in the present and in the future) in explaining adjustment in spouses ( $N=175$ , mean age, 49 years, 56% female) dealing with a variety of cancers at four stages in the illness trajectory. An analysis for gender

differences indicated that female partners experienced greater psychological distress than male partners. Analysis of variance was undertaken to determine whether significant differences existed across the illness trajectory for variables considered important to the adaptation of partners. These analyses showed that the most important differences were found in the global measure of adaptation, in psychological distress, and in the partners' cognitive responses to the illness. Spouses experiencing the first recurrence had the greatest difficulty adapting and were the most distressed. Along with spouses who were dealing with metastatic cancer, they had the most negative cognitive response to the illness. No differences were found in spouses' perceptions of social support, satisfaction with the marital relationship, expression of affection, and cohesiveness within the partner relationship across the illness trajectory. In contrast to other studies, gender differences in subjects' scores on the study variables were statistically significant. In hierarchical regression analysis that combined the spouses across the four illness stages, 55.5% of the variance in spouses' adjustment was explained by partner cohesion, family support, depression and cognitive response.

*Model-testing studies of spouse adaptation.* There are relatively few model-testing studies in the cancer literature. Most of those have been based on individual coping theory and focused on coping and adaptation of breast cancer patients. In some cases (notably in the work of Northouse and her colleagues) those studies have also included an analysis of adaptation of their spouses.

In a study based on cognitive appraisal models of stress and coping carried out with cancer patients (Munkres, Oberst & Hughes, 1992), the relationships between symptom distress, appraisal and mood in 60 patients undergoing chemotherapy for initial ( $n = 28$ ) and recurrent ( $n = 32$ ) cancer were explored. The researchers examined the relationships between symptom distress, self-care burden, appraisal of illness and mood disturbance in both patient groups. Mood disturbance scores were low and did not differ between the initial and recurrent groups. The recurrence group had higher symptom distress scores and burden scores and more stressful appraisals. The data from both groups were combined for the model tests. Symptom distress was best

predicted by recurrence and by symptom control (an illness related variable). Economic status, symptom distress, and recurrence status predicted 49% of appraisal variance. Appraisal, symptom distress and perceived seriousness of illness predicted 36 % of the variance in mood with appraisal partially mediating the effects of symptom distress.

In a study of independent groups of cancer patients ( $N = 42$ , 57% female, mean age 57 years) and spouses of cancer patients ( $N = 32$ , 66% female, mean age 59 years), (Mullen, Smith, & Hill, 1993), psychological stress was regressed on the demands of illness, sense of coherence, family strengths, and spiritual resources. Accumulated demands was not a direct predictor of stress for either patients or spouses, but path analysis showed that for patients, sense of coherence was the only significant direct predictor of psychological stress ( $R^2 = .555$ ), with spiritual resources and family strengths showing significant indirect paths through sense of coherence as the mediator. For spouses, sense of coherence was also the only significant predictor ( $R^2 = .291$ ) but only family strengths had an indirect path, strengthening the effect of the sense of coherence.

Given (1993) examined the relationships between patients' physical and mental health and the reactions and mental health of their family caregivers ( $N = 196$ , mean age 55.5 years) in 196 cancer patient-caregiver dyads in a community treatment centre. Two thirds of the caregivers were women, and 80% of the caregivers were spouses of the patients. While they did not test a model that had been determined a priori, they did generate model that had a good fit with the data and that explained between 24% and 44% of the variance in the caregiver reactions. They found that patients' dependencies in activities of daily living (ADL), symptom distress and immobility were directly related to the impact of caring on family members' daily schedules. However, symptom distress and patients' immobility were related to caregivers' health and caregivers' depression only indirectly through patients' depression. Patients' depression played an important intervening role between symptom distress or patients' immobility and all of the caregivers' reactions. The authors felt that the most significant finding was that

caregivers' level of optimism emerged as an important and independent predictor in caregivers' depression, on the perceived impact of caregiving on health, and on the caregivers' daily schedule.

In a model testing study of caregivers (Schumacher, Dodd, & Paul, 1993) the predictors of strain and depression at the onset of chemotherapy in 75 caregivers (mean age, 43.8 years, 51% female) of persons with different types of cancer were examined. The question of whether coping and social support operated as mediators or as moderators in their model was also examined. Single-order correlations showed that caregivers of male patients, and caregivers with less social support and coping efficacy were more depressed. The first set of regressions indicated that the antecedent variables of caregiver gender, patient age and gender, patient functional status, disease recurrence and perceived efficacy of coping strategies explained 44% of the variance in strain. In the second set of analyses when caregiver strain was added to the model, only coping efficacy and perceived social support emerged as predictors and together explained 40% of the variance in depression. The subsequent analyses that addressed the question of moderation and mediation showed that social support mediated the relationship between functional status and depression. The perceived efficacy of coping strategies mediated the relationship between strain and depression. Although limited by the heterogeneity of the sample where familial relationships and living arrangements of the caregivers were not considered, this study highlighted factors that explained a relatively large proportion of caregivers' psychological state. It also provided evidence for the mediating effect of coping on depression among the caregivers in the study.

Northouse, Mood, Templin, Mellon, and George (2000) examined the influence of person factors (demographics, role, concurrent stress), social factors (marital satisfaction, family functioning, social support), illness related factors (severity of illness), appraisal (uncertainty, hopelessness) on overall role adjustment and on emotional distress of 56 patients and their spouse caregivers at 1 week, 2 months and 1 year following the diagnosis of colon cancer. One of the important findings from the

descriptive portion of the study was that *patterns* of adjustment appeared to be influenced by a person's role (patient or spouse caregiver) and by gender. Spouses reported significantly more emotional distress, lower levels of family functioning and less support than did patients during the first year. Both patients and spouses reported a decrease in their perceived levels of family functioning, with women reporting more fluctuations than men. There was no significant decrease in couples' marital satisfaction over time, no significant change in the appraisal variables of hopelessness and uncertainty, and no differences according to either gender or role in those variables. The variables in the final model accounted for 64% of the variance in spouses' overall role adjustment. Spouses' own baseline role adjustment problems emerged as the best predictors of their role adjustment at 1 year, while spouses' increasing age and concurrent stress had indirect effects on adjustment that were mediated by the appraisal of uncertainty. Uncertainty had a small but significant effect, but the hopelessness appraisal did not emerge as a significant predictor of overall adjustment. Marital satisfaction had only a direct effect on spouses' overall adjustment. The variables in the model that predicted spouses' emotional distress were similar to those in the model that explained their overall adjustment, and accounted for 54% of the variance in the emotional distress measure.

Northouse, Templin and Mood (2001) followed up on the colon cancer study with a study of couples' adjustment to breast disease, and examined the direct or indirect effects of the same factors as in the previous study on role adjustment and emotional distress at 1 week, 2 months and 1 year after diagnosis. The sample consisted of 131 couples, 58 of those had received a breast cancer diagnosis and 73 had received a benign diagnosis. The strongest predictor of the spouse caregivers' (husbands) role adjustment at 1 year was their own baseline level of adjustment reported at 1 week after diagnosis. Education and marital satisfaction had indirect effects on adjustment that were mediated by an appraisal of uncertainty. Together these factors explained 59% of the variance in spouses' adjustment at 1 year. The strongest predictor of their emotional distress at 1 year was their own baseline level of distress



reported just after diagnosis. An appraisal of hopelessness and their wives emotional distress were the other factors that had significant direct effects on husbands' stress and together these factors explained 70% of the variance in husbands' adjustment. Appraisals of hopelessness and uncertainty did not act as mediators in the model for emotional distress at 1 year.

In a recent study (Banthia, Malcarne, Varni, Ko, Sadler & Greenbergs, 2003), researchers examined the relationship between coping and psychological distress in 154 couples with prostate cancer 5 months after the diagnosis. The contribution of dyadic functioning was considered as a third variable that could potentially moderate or mediate the relationship. Several simple regressions were significant for spouses. The couples dyadic functioning predicted the spouses' psychological distress, and the spouses' coping strategies of avoidance, intrusiveness and hyperarousal. These same coping strategies each predicted distress in spouses. However, neither the mediational nor moderational models were supported for spouses' psychological adaptation. The authors noted the differences in findings for patients and spouses on most response variables, and suggested that they may be responding differently to the demands associated with cancer. The authors did not report whether or not the couples had begun treatment at the time the data were collected, making it difficult to know whether phase of illness played a role in their findings.

### *Summary of the Literature Review*

The studies on the adaptation of spouses to prostate cancer are of recent vintage and have been primarily qualitative in nature. Spouses' and partners' data are frequently combined and presented as couples' experience of illness. The data presented describe the respondents' emotional reactions and attempts to handle the illness. The findings suggest that wives are clearly participants in the couples' experience of the disease, and that they have a personal experience of the illness that differs from that of their partners. They are affected by their husbands' distress over the changes in their sexual relationships and the problems related to continence. They more

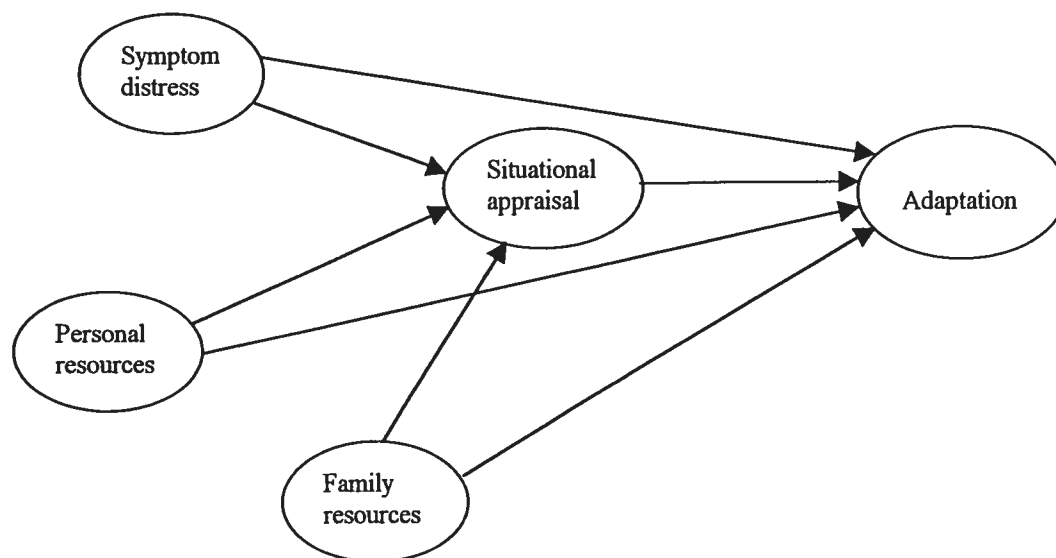
often wish to express their worries and concerns, while partners choose to minimize their worries and avoid discussing feelings. Little is known about how the prostate cancer experience evolves over time because the studies are primarily cross-sectional in design.

The studies of spouses' experiences with other types of cancer in the initial psychosocial phase suggest that they too experience considerable emotional strain, feelings of uncertainty about their own ability to manage, and anxiety related to anticipated losses. Although role functioning improves over time, the distress persists well into the first year. Studies showed differences between the types of concerns identified by patients and spouses, but considerable similarity in the intensity of their response. While there are correlations between patient and spouse adaptation to cancer, different factors are at play in predicting adaptation for spouses and for partners at initial and subsequent phases of illness. Factors associated with spouses' adaptation include illness-related factors (stage of illness, patient's symptoms, caregiving demands) personal characteristics and resources (age, gender, nature of the partner relationship, and social support) as well as meaning of illness and methods of coping. With one recent exception, the few theory-based model-testing studies that are available have dealt with cancers other than prostate cancer. They suggest that age, gender, appraisals of illness and quality of marital relationship are important predictors of spouses' adaptation. Some have found that illness appraisals of threat, and of uncertainty acted as mediators in the relationships between other predictor variables and adaptation. Studies of spouse adaptation are limited by the predominance of cross-sectional designs, samples selected across the phases of illness, and a respondent mix which includes include spouses, other family members as well as other non-kin helpers.

### **Explanatory Model of Adaptation**

Family stress and adaptation theory, supported by clinical knowledge and available empirical data, provided support for the inclusion of a number of variables in a model to explain the adaptation of wives to prostate cancer in the period immediately

after diagnosis and at the onset of treatment. These were: demands of the illness, personal resources, family resources, situational appraisal and adaptation. Other theoretical constructs from family stress and adaptation theory were not included in the model for specific reasons. A measure of coping was not included because of the conceptual overlap between situational appraisals - which refer to the assigning of meaning - and coping which refers to changing those meanings. This results in a possible confounding between measures of coping and adaptation that could result in methodological problems for the analysis. The problems associated with the measurement of coping that have been described in the literature ( McHaffie, 1992) were also an important consideration in the decision not to include this variable in the model. With the idea of theoretical parsimony and to avoid redundancy, the decision was made to focus on family resources and not to include a measure of community resources because of the importance of the marital partner as a primary source of support for couples dealing with cancer. Finally, the decision was made to focus on situational meaning because of its importance during the early period of cancer treatment. The other two levels of meaning were not included because of concerns about measurement and conceptual overlap between variables. The nature of the relationships between the constructs in the final theoretical model that was tested in this study is illustrated in Figure 1 below.



**Figure 1.** *Relationships between symptom distress, personal resources, family resources, situational appraisal and adaptation*

The purpose of the study was to test this model of adaptation in wives at two points in time during the initial psychosocial phase of non-metastatic prostate cancer. These two periods corresponded to the beginning of the initial phase - prior to surgery or radiotherapy treatment (T1), and the end of the initial phase - three months later (T2). The model verification tests would determine the relative contributions of treatment-related symptom distress, personal resources, family resources and situational appraisal to psychosocial adaptation at the onset of the initial phase of the illness and identify the mediating effect of situational appraisal in the relationship between symptom distress, resources and adaptation. The model tests would also determine the stability of the model by re-examining the relationships between variables at the end of the initial phase (T2). Finally the study would determine whether the change measured in the predictor variables between the two periods in the initial phase would explain adaptation at T2, and the change in adaptation between T1 and T2.

### Study Hypotheses

In this model-testing study of adaptation, the hypotheses were formulated and are presented in a sequence that is consistent with the procedure for testing for mediation laid out by Baron and Kenny (1986). The hypotheses are repeated for each set of model tests in order that the reader can readily follow the process of analysis.

The first set of hypotheses was used to verify the contributions of the independent variables and the mediator to adaptation, and were carried out with data from the onset of the initial phase of illness (Time 1). The hypotheses for these analyses were:

- 1) Lower levels of symptom distress and higher levels of personal and family resources will be associated with more positive appraisal.
- 2) Lower levels of symptom distress, higher personal and family resources and more positive appraisal will be associated with better adaptation.
- 3) Appraisal will mediate the effect of symptom distress, personal and family resources on adaptation.

In order to test the relevance of the model over the course of the initial phase of the illness, the same hypotheses were re-examined with the second set of data collected three months later, at the end of the initial phase of the illness (Time 2). According to the theoretical basis and the available empirical evidence, it was expected that the personal and family resources would remain relatively stable while symptom distress and appraisal might vary depending on the response to treatment. Despite possible changes in the scores on the variables, it was expected that the relationships between the variables in the model would remain the same. Therefore, at time 2, hypotheses 1, 2 and 3 were re-examined and an additional hypothesis related to the stability of the model was formulated:

- 4) The relationships observed between variables at Time 1 would be observed again at Time 2.

As part of the prospective nature of the study, a second set of hypotheses

examined how the independent variables and the change in those variables influenced *adaptation at time 2*. The second set of hypotheses for the first projective test of the model was:

- 5) Lower levels of symptom distress, higher levels of personal and family resources at time 1, a reduction in symptom distress and an increase in personal and family resources between time 1 and 2 will be associated with more positive appraisal at time 2.
- 6) Lower levels of symptom distress, higher levels of personal and family resources at time 1, a reduction in symptom distress and an increase in personal and family resources between time 1 and 2 and more positive appraisal at time 2, will be associated with better adaptation at time 2.
- 7) Appraisal at time 2 will mediate the effect of symptom distress, personal and family resources at time 1, the reduction in symptom distress and the increase in personal and family resources between time 1 and 2 on adaptation at time 2.

Similar hypotheses were applied in a second projective test to examine how the independent variables at time 1 and change in those variables between time 1 and 2 influenced *change in adaptation* over time. The third set of hypotheses for the second projective model was:

- 8) Lower levels of symptom distress, higher levels of personal and family resources at time 1, a reduction in symptom distress and an increase in personal and family resources between time 1 and 2 will be associated with more positive appraisal at time 2.
- 9) Lower levels of symptom distress, higher levels of personal and family resources at time 1, a reduction in symptom distress and an increase in personal and family resources between time 1 and 2 and more positive appraisal at time 2, will be associated with an improvement in adaptation over time.
- 10) Appraisal at time 2 will mediate the effect of symptom distress, personal and

family resources at time 1, the reduction in symptom distress and the increase in personal and family resources between time 1 and 2 on the improvement in adaptation over time.

In the interpretation of the results, when all the relationships described in a hypothesis were observed, the hypothesis was confirmed. When at least one, but not all, of the relationships described in the hypothesis was observed, the hypothesis was considered partially confirmed.

### **Contributions of the Study**

While there is a significant body of literature on the impact of cancer on patients and on family members, much of the development of knowledge in this field has developed in an atheoretical fashion. This has made it difficult to bring together the findings and to evaluate the weight of the evidence that might support specific interventions. Family stress and adaptation theory provides a comprehensive set of theoretical constructs that can be used to build knowledge in areas not yet explored, and to suggest interventions as the weight of the evidence accumulates. Nurses who assist patients and families to make an effective adaptation to cancer are concerned that a strong body of evidence drives their interventions. This study is concerned with building the evidence that would direct and support their practice. Specifically, it was anticipated that the study would provide support for the hypothesized relationships between demands of illness, personal and family resources, cognitive appraisals of illness and the adaptation of wives to prostate cancer during the initial psychosocial phase. These findings would then provide nurses with a basis for identifying women with limited resources who would benefit from early intervention and additional support. It would also be helpful to nurses in planning interventions that would mobilize and sustain women's existing personal and interpersonal resources. The findings could also be applied to planning group interventions that would address the needs of families who have just received a prostate cancer diagnosis. It was hoped that the findings would increase our understanding of spouses' adaptation to other types of

cancers and to other stressful situations. Finally, from a research perspective, the conceptual basis and the methodological approach in this study could be extended to research with patients or other family members, as well as provide the basis for continuing research in other phases of the prostate cancer experience.



**Chapter 3**  
**Methods**

This chapter describes the operationalisation of the study. It includes a description of the design, the instruments selected to measure the variables in the model, the study procedures related to sample determination, recruitment of subjects, data collection and ethical reviews, the characteristics of the final sample and the procedures for data analysis.

### **Design**

A prospective design was used to test a model of the relationships between symptom distress, personal resources, family resources, situational appraisal and psychosocial adaptation in wives of men diagnosed with non-metastatic prostate cancer. Data were collected twice during the initial psychosocial stage of their husbands' illness. Time 1 data were collected following diagnosis and prior to treatment, and time 2 data were collected three months after the onset of treatment.

### **Constructs and Measures**

The following section describes the instruments that were selected as operational measures of the constructs in the model (see Appendix 1). For psychosocial adaptation, two measures were selected: the spouse version of the Psychosocial Adjustment to Adjustment to Illness Scale (PAIS) (Derogatis, 1986), a global, multidimensional measure of adjustment, and the Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1992) a measure of psychological adaptation which focuses specifically on feelings, affect and mood. In order to measure wives' distress related to their husbands' symptoms, the urinary and sexual function subscales of the the UCLA/Rand Prostate Cancer Index (Litwin et al., 1998) were adapted in a wives' version of these scales for this study called the Prostate Specific Symptom Evaluation

(PSSE). The construct of sense of coherence, a reflection of personal resources, was measured by the Orientation to Life Questionnaire (commonly referred to as the SOC scale) (Antonovsky, 1987). Cohesion and adaptability, concepts that reflect family resources, were measured by the couples' version of the Family Adaptability and Cohesion Evaluation Scale – Version II (FACES-II) (Olson, Bell, & Portner, 1982). Situational appraisal, reflected by primary and secondary cognitive appraisal, were measured by the Subjective Appraisal Rating Scale (SARS) (Biron, 1992).

French and English language versions of each of the measures were used in this study. With the exception of the OLQ, a French version of each of the measures was available from the test developers, but no information was available on the how the translated versions had been developed. In the case of the OLQ, the back translation technique was used in the development of the French version of the measure (Thomas & Duquette, 1995). The internal consistency measures of reliability reported in this study are based on the combined French and English responses.

#### *Psychosocial Adjustment to Illness Scale - Self Report*

The PAIS-Self-Report (spouse version) was selected as the primary measure because it captures the overall multidimensional nature of the phenomenon of adaptation. It has previously been used with spouses of cancer patients and has sound, well-documented psychometric properties. This 46 item self-report measure includes seven domains of psychosocial adjustment: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress (Derogatis, 1986). Health care orientation (8 items) is concerned with the wives' current attitude toward health care and whether it will promote a positive adjustment to the illness and its management. Vocational environment (6 items) assesses whether the present illness has led to disruptions in the wives' performance, satisfaction, and adjustment in the work setting, school, or at home. Domestic environment (8 items) is oriented toward illness-induced problems that arise mainly in the home. Sexual relationship (6 items) refers to any shifts in the quality of sexual functioning or relationships that may have occurred as a result

of the illness. Extended family relationships (5 items) reflects difficulties in relationships with the extended family caused by the illness. Social environment (6 items) measures the interference in the wives' social and leisure activities caused by the illness. Psychological distress (7 items) represents the degree to which wives experience psychological problems as a result of the disease. Items are anchored on 4-point likert scales, with weights of zero to three for each response choice. Respondents are asked to refer to the previous 30 days when selecting their answers. Scores are totalled to obtain a total for each domain, and domain scores are totalled for a total PAIS score. The total adjustment score may range from zero to 138, with lower scores indicating better adjustment and higher scores indicating worse adjustment. The instrument takes approximately 20 minutes to complete.

*Validity.* In a structure-confirming factor analysis based on results obtained from lung cancer patients, Derogatis (1986) reported on the item loadings in a 7 factor solution. Items from the vocational environment domain, the sexual relations domain and the social environment domain loaded well and exclusively on their respective factors. Most of the items in the other domains loaded on a single factor, however 3 of the domestic environment items loaded on other factors, and 3 of the psychological distress items had factor loadings over .35 on two factors. In addition the average of the correlation coefficients between domain scores were low ( $r = .33$ ), while the average correlation between domain scores and the total score was high ( $r = .65$ ) in a study of 120 lung cancer patients. Derogatis suggests that "these scales tend to reduce measurement redundancy while reflecting multiple dimensions of adjustment" (p.24-25). He also reports on the correlations between PAIS and other measures of adjustment in addressing the question of convergent and discriminative validity. These are: a correlation of .81 with the Global Adjustment to Illness Scale (GAIS); a correlation of .83 with the SCL-90-R (Symptom Check List) which measures psychological symptoms; a correlation of .77 for psychological distress domain of the PAIS with the Affect Balance Scale (ABS) which measures mood; and finally, correlation of .69 for the total PAIS and the ABS. The PAIS has been used in a variety

of other studies since Derogatis' first published report on its psychometric properties, and the research seems to confirm the instrument's ability to measure both global adjustment and specific aspects of adjustment. While the bulk of the data on the PAIS is derived from the use of the original patient self-report version, the spouse version has been used extensively with spouses of cancer patients (Baider et al., 1984; Northouse, 1990; Northouse et al., 1995b; Northouse et al., 1995a). In this study, principal components analysis of the wives' responses on PAIS showed that 7 factors explained 54.8% of the variance in wives' adjustment at time 2 (N = 70).

*Reliability.* Derogatis (1986) reports estimates of internal consistency for each of the domains of PAIS for renal dialysis, lung cancer and cardiac patients. The range of the alphas reported for these three population groups were as follows: health care orientation domain (.47-.83), vocational environment (.76-.87), domestic environment (.67-.77), sexual relationship (.80-.93), extended family domain (.62-.66), social environment (.78-.93) and psychological distress (.80-.85). Baider and Kaplan De-Nour (1984) who first used PAIS to examine adjustment of both patients and spouses to mastectomy, reported a very strong correlation ( $r = .65$ ) between the couples on the total score of PAIS. Northouse, Laten & Reddy (1995b) in a study of adjustment of women and their spouses to breast cancer recurrence reported alphas of .90 on the total score of the PAIS-SR (Spouse version) and .90 for breast cancer patients. In this study, Cronbach's alpha for the total score it was .84 at both time 1 and time 2, suggesting that the measure had a strong degree of internal consistency.

For the seven subscales at time 1 and 2, the alphas in this study were as follows: health care orientation (.44 and .41), vocational environment (.49 and .61), domestic environment (.46 and .59), sexual relationship (.78 and .75), extended family relationships (.26 and .52), social environment (.88 and .80), psychological distress (.71 and .79). It should be noted that the variance for health care orientation, domestic environment, and the extended family relationship subscales were low, an observation that may be explained by the limited variance in the scores obtained in this study (see

Table 2. Other studies have reported low alphas (0.12) for both the extended family relationships and health care orientation domains, with alphas for the total score remaining at higher levels (Peleg-Oren et al., 2001).

### *Profile of Mood States*

The POMS was included as a secondary measure because it reflects fluctuations in mood that might occur over the course of an illness, and because it offered a specific and more comprehensive focus on the psychological dimension of adjustment than does the PAIS. It was felt that this emotional dimension was a particularly important part of the wives' experiences of the illness.

POMS consists of 65 adjectives which represent six mood factors - tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and 5 point likert scales, with weights of 0 to 4 for each response choice. Respondents are asked to rate their feelings over the past week. The purpose of the one-week rating is to focus on a period long enough to depict the person's typical and persistent mood reactions to his current life situations and sufficiently short to capture responses to changes related to treatments (McNair et al., 1992). The possible ranges of scores for each of the factors are: tension, -4-36; depression 0-60; anger 0-48; vigor 0-32; fatigue 0-28; and confusion -4-28. A total mood disturbance score (TMD) is obtained by summing the scores across all six factors (weighting the vigor score negatively), with higher scores reflecting greater mood disturbance. The TMD score may range from -40-200. (The negative score at the lower range is explained by the negative weighting of items on the tension, confusion and vigor subscales). The measure requires a grade seven reading level, takes approximately 5 minutes to administer, and has low to moderate correlations with social desirability (McNair et al., 1992). It continues to be frequently used with cancer patients, particularly in intervention studies (Cunningham, Edmonds, Jenkins, & Lockwood, 1995; Miaskowski & Dibble, 1995; Braslis, Santa-Cruz, Brickman, & Soloway, 1995; Fawzy, 1995; Schumacher et al., 1993). Norms on POMS for cancer patients and their next-of-kin have been reported in the literature

(Cassileth, Lusk, Brown, & Cross, 1986).

*Validity.* Factor analyses of the POMS have repeatedly provided support for a six factor structure of the scale. In their reviews of studies using the POMS, McNair, Lorr & Droppleman (1992) report evidence to support the predictive and construct validity of the measure from a number of areas of research, including brief psychotherapy studies, controlled drug trials, cancer research and studies of response to emotion-inducing conditions. Numerous studies using the POMS with cancer patients suggest that cancer affects mood states, with cancer patients' POMS profiles often indicating higher levels of depression, tension-anxiety, fatigue, confusion-bewilderment, and total mood disturbance (McNair et al., 1992). In this study, principal components analysis for POMS using a 6 factor solution explained 59.3% of the variance of mood disturbance in wives at time 2.

*Reliability.* McNair, Lorr, and Droppleman (1992) report reliability coefficients for the six POMS factor scores ranging from .84 to .95. They do not report reliabilities for the total POMS score (TMD) given the different mood states that are being measured, but they suggest that the TMD score makes clinical sense and can be presumed to be highly reliable because of the correlations among the six primary factors. The correlations between factors reported for 3 samples of male and female psychiatric patients and male undergraduate students range from -.12 (anxiety with vigor) to .77 (tension with depression). The test-retest stability coefficients reported for the six factors in 100 patients completing POMS during an intake interview and 6 weeks later (prior to treatment) ranged from .65 to .74. A comparison of the correlations between the scores at the intake interview and at six weeks after treatment began ranged from .43 to .52. Since the second set of correlations reflected a longer time period and the influence of treatment, they would be expected to be lower. These test-retest correlations are considerably lower than the .80 to .90 levels expected of measures of stable personality characteristics (McNair et al., 1992), and support the contention that POMS is reflecting mood changes in response situational events rather

than capturing a stable personality dimension. In this study, the alpha coefficients for the six POMS factor scores were generally high and were consistent with previous reports of internal consistency for the subscales in other populations. They were as follows for the 70 wives at time 1 and 2 respectively: depression-dejection, .88 and .90; tension-anxiety, .85 and .89; anger-hostility, .82 and .87; vigor-activity, .80 and .79; fatigue-inertia, .81 and .86; confusion-bewilderment, .71 and .84.

### *Prostate Specific Symptom Evaluation*

Although clinical practice, available empirical data and family adaptation theory suggested that the symptom distress related to the illness and its treatment should be considered, there were no measures available to reflect the wives perceptions of the urinary and sexual problems that accompanied their husbands' illness. A measure to reflect the wives perceptions of their husbands' urinary and sexual symptoms was adapted from the UCLA/RAND Prostate Cancer Index (Litwin et al., 1995; Litwin et al., 1998). The Index includes six disease-targeted domains that measure function and bother in the urinary, sexual and bowel domains. It includes 5 questions related to urinary function which constitute a urinary function scale, and 8 items related to sexual function which constitute the sexual function scale. Some items are anchored on 4 point and some on 5 point scales, with scoring on each item ranging from 0 to 100. The scores on items are summed and the raw total scores are then converted by a simple linear transformation to yield the reported scores that range from 0 to 100 for each scale. Higher scores indicate better urinary and sexual function. There are 2 additional items that reflect the degree to which men were bothered by their urinary or sexual symptoms. These single item measures constitute a urinary bother and a sexual bother scale.

In the wives' version of the scale, the items from the urinary and sexual function scales were reworded to capture wives' perception of their husbands' urinary and sexual function. As in the original measure, raw scores on the scales were summed and then converted by simple linear transformation to yield a score on urinary and sexual



function that ranged from 0 to 100. The original single item bother scales were also included and reflected the degree to which the wives themselves were bothered by their husbands' urinary and sexual symptoms.

*Validity.* The UCLA/RAND Prostate Cancer Index was developed with the direct and ongoing involvement of patients and spouses who had first hand experience with cancer and descriptive statistics and psychometric properties of the original scales used with men with prostate cancer ( $n = 321$ ) and matched groups of patients without prostate cancer ( $n = 598$ ) have been reported (Litwin et al., 1998). As with the original measure, the items in the wives' Urinary and Sexual Function Scales have high face validity. In this study, the single dimension of each of the scales for wives ( $N = 70$ ) was confirmed in a principal components analysis in which one factor explained 67.7% of variance in the urinary function, and one factor explained 77.6% of the variance in sexual function.

*Reliability.* Litwin (Litwin et al., 1995; Litwin et al., 1998) reports internal consistency reliabilities of .87 for the urinary function scale, and .93 for sexual function in 214 men with prostate cancer and in their age-matched comparison group of 273 patients without cancer. The test-retest correlation, measured at a 4-week interval was .93 for sexual function and .92 for urinary function. In this study using the wives' version, assessment of the internal consistency of the sexual and urinary function scales were calculated in cases where all items on the scales had been answered. There was a high proportion of cases in which one or more items were not answered, or where wives reported that they could not rate/did not know about their husband symptoms. These cases were dropped from the calculation of alpha for the scale. The alphas for urinary function for the 70 wives were .88 at time 1 (50/70 wives reporting on all items) and .93 at time 2 (37/70 wives). For sexual function, alphas were .96 at time 1 (26/70 wives reporting on all items) and .90 at time 2 (32/70 wives). While this suggests a high degree of internal consistency on the two scales based on those who did respond, the alphas were calculated on a relatively small number of subjects and

questions remain regarding the general efficacy of these scales as measures of wives' perceptions of their husbands' urinary and sexual function.

Internal consistency is not applicable as a measure of reliability for the single item scales of wives sexual bother and wives urinary bother. However one would expect to find some correlation between the degree to which wives were disturbed by their husbands' urinary and sexual function and the corresponding function scale. Significant correlations were found between wives' urinary bother scores and the urinary function scores at time 1 ( $r = .705, p \leq .000,$ ) and at time 2 ( $r = .667, p \leq .000$ ). No significant correlations were found between wives' sexual bother and sexual function scores at either time 1 or time 2.

### *Sense of Coherence Scale*

The Orientation to Life, more commonly referred to as the SOC scale, was developed as measure of the sense of coherence by Antonovsky (1993). This is a 29-item scale that includes 11 comprehensibility, 10 manageability and 8 meaningfulness items. Items are anchored on a 7-point scale, with each item scored from 1 to 7. Selected items are reverse scored and a total score is obtained. Higher scores on the SOC indicate a stronger sense of coherence. The measure can be administered during interview or self-completed and takes approximately minutes to complete. The strong psychometric properties of the measure, its consistent emergence as a predictor of psychosocial and physiologic outcome measures (Coe, Miller, & Flaherty, 1992; Post-White, 1994) and its use in previous studies with both cancer patients and their spouses (Mullen et al., 1993; Mullen et al., 1993), were factors that were considered in the selection of this measure.

*Validity.* Antonovsky (1993) cites the theoretical work that preceded the scale's construction, the methodological approach taken in the construction of the scale, and the widespread use of the scale in its original form as beginning evidence for the content, face and consensual validity of the measure. He suggests there is no ideal score for the SOC, but that criterion validity can be evaluated by examining the

relationship between the SOC and measures for which there are theoretical grounds to expect a correlation. He reports significant correlations ranging from .19 to .76 with a variety of measures in 25 published studies of health and well-being. He adds that no data are currently available regarding the question of discriminant validity, and suggests that other methods of measuring the construct of sense of coherence (e.g. structured interviews, ethnographic methods) would supply some additional evidence for its construct validity. With respect to the factor structure of the scale, he notes that the facet-theoretical design used in constructing the measure, the principal components analysis carried out on the original data, and additional evidence from other researchers together suggest a single factor measure (Antonovsky, 1987).

*Reliability.* Antonovsky reports on the internal consistency of the scale based on 26 studies using the 29-item version. The average alpha, unweighted for sample size ranges from .82 to .95. Test-retest reports of reliability include correlations of 0.52 and 0.56 between a first interview and the second conducted one year later among Israeli retirees and kibbutz residents. Correlations of 0.54 and 0.55 were obtained after two years with these two groups. The six-month test-retest correlations in veterans in a US medical clinic age 55 and over were .80. In reports of studies done with Dutch psychology students with a 6 week interval between testing, the correlation between scores was higher ( $r = .80$ ) (Antonovsky, 1993). In this study, the alphas calculated as a measure of the internal consistency of the SOC for the 70 wives were .89 at time 1 and .91 at time 2, and were consistent with Antonovsky's reports.

#### *Family Adaptability & Cohesion Evaluation Scale - II*

Following a review of concepts in the literature related to effective family functioning, Olson and his colleagues (Olson, 1989, Olson, Russel & Sprenkle, 1993) developed the Family Adaptability and Cohesion Evaluation Scales (FACES) to measure the concepts of family cohesion, flexibility and communication. The scale measures the first two concepts directly and provides a cohesion and an adaptability score. Communication, considered a facilitating dimension that enables families to be

close and flexible, is measured indirectly in the total FACES scores. A number of versions of the scale (FACES II-IV) exist. FACES II, the version recommended for research use, consists of a 30-item scale with a 5-point response format in which individual family members describe how they perceive their family. The scale contains 16 cohesion items and 14 adaptability items. FACES II yields two independent scores of cohesion and adaptability as well as a total score that is a global reflection of the family's resources. The couples' version that focuses on the marital relationship was used in this study. This well established measure is relatively short, is easy to for respondents to read, and for researchers to administer and score. Olson & Tiesel (1991) suggest that FACES II be considered a linear measure with higher scores representing well-functioning families, and lower scores representing poor functioning. The total score for FACES II was used in this study as a measure of family resources.

*Validity.* In a review of family resource measures in psychosocial cancer research, Fobair & Zabora (1995) highlight the frequent use of FACES-II and its relevance as both an independent and dependent measure. In studies using different versions of FACES, Olson (1991) reports that the measure was able to discriminate between families with an alcoholic parent and non alcohol dependent families, between high risk and low risk families, and between delinquent and non-delinquent families. In other empirical studies with cancer patients, higher levels of cohesion and adaptability seem to be associated with better family functioning (Friedman et al., 1988). Concurrent validity reflected by the correlation of .93 between the cohesion scale of FACES II and the Dallas Self-Report Family Inventory (SFI), a global measure of family health, and of .79 between the adaptability subscale of FACES and the SFI (Hampson, Hulgus, & Beavers, 1991). Principal components analysis in this study confirmed the 2-factor solution explaining 44.3% of the wives' scores on FACES-II at time 2.

*Reliability.* The alpha coefficient of internal consistency for the adaptability subscale is .78, for the cohesion subscale is .87 and for the total measure is .90; test-retest reliability reported for a 4-5 week interval on FACES II is .83 for cohesion and

.80 for adaptability (McCubbin & McCubbin, 1987; Olson & Tiesel, 1991). The high internal consistency reliabilities reported for this measure were also evident in this study, with alpha coefficients for the total score of .93 at time 1 and .94 at time 2.

### *Stress Appraisal Rating Scale*

The Subjective Appraisal Rating Scale (SARS) is a 10-item scale developed to evaluate situational appraisal (Biron, 1992; Biron, 1992; Lemyre, 1986). This measure provides a score for impact of the situation and a score for mastery over the situation. The 5-item Impact Scale reflects an appraisal of the event as having negative consequences, and bringing on perceptions of loss, fear, uncertainty, threat or failure. The 5-item Mastery scale measures the importance of the event, and the extent to which it constitutes a challenge, can be controlled, coped with or influenced. Items are rated on a scale of 1 to 8. High scores on Impact correspond to a negative appraisal of the situation. High scores on Mastery correspond to a positive appraisal of one's ability to handle it. The theoretical spread of scores on Impact and Mastery is from 5 to 40.

*Validity.* The measure was originally developed to reflect 2 principal factors: primary appraisal reflecting the nature and degree of risk associated with the stressor, and secondary appraisal, reflecting the perception of resources or abilities to cope with an event. Fillion and her colleagues (1996a) evaluated the psychometric properties of the English version of SARS in a sample of 65 HIV sero-negative and 90 sero-positive subjects. They reported a 2 factor structure corresponding to primary and secondary appraisals that were named Impact and Mastery. A correlation of .51 with the Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979) demonstrated convergent validity. Impact and Mastery appraisals predicted a significant part of the variance in total mood disturbance measured by POMS in the HIV positive subjects. In a study of cognitive appraisal, stress state, and cellular immunity responses in women before and after diagnosis of a breast tumour (Fillion, Lemyre, Mandeville, & Piche, 1996b), Mastery increased and Impact decreased after notification of diagnosis in both the cancer group as well as the matched control group. A decrease in stress state correlated

with decreases in women's perception of Impact. In this study, a principal components analysis of the Impact subscale showed a one factor solution explaining 61.7% of variance at time 2, and a two factor solution explained 58.5% of the variance in Mastery scores at time 2. These results are consistent with the three factor solution for the total SARS named Impact, Mastery and Uncertainty by the authors, that was based on data from breast cancer patients (Fillion, 1996b). These results suggest that the construct validity of the Mastery scale as a single dimensional scale may be problematic.

*Reliability.* Fillion (1996b) reported alphas of .81 for Impact and .75 for Mastery in their study of HIV positive and negative subjects. Their 2-week test-retest reliabilities for Impact were  $r = .60$ ,  $p \leq .001$  and for Mastery were  $r = .50$ ,  $p \leq .001$ . For the 70 wives in this study, Cronbach's alpha for the Impact Scale at time 1 was .82, and .84 at time 2. In this study, the reliability for the Mastery Scale at time 1 was .48, and at time 2 was .45. Item analysis with a selected item dropped resulted in only a small increase of the alpha to .51 and .47. Therefore, the mastery subscale was used in the subsequent analyses with all original items.

#### *Background Data Questionnaire*

For purposes of sample description, background data concerning the wives' age, years married, number of children, attempts to seek professional support, religious importance, education, place of birth, maternal language, work status, income, major events experienced in the previous two years, serious illness in previous ten years, type of prostate cancer treatment, and satisfaction with their health were collected (see Appendix 2). The demographic variables were included because they frequently emerge as correlates of outcome in studies with a variety of different populations; type of treatment was selected as a possible confounding variable because it could be considered as a possible predictor of outcome.

## Study Procedures

Although it had been decided at the outset that this study would focus exclusively on spouses, a decision was made to include both husbands and wives in the data collection process. This decision was based on practical, ethical, and theoretical concerns. First, it was felt that it would be difficult and inappropriate to request access to wives at this early period in the couples' experiences without the knowledge and agreement of their partners who were themselves just coming to grips with the illness. Second, in the event that the men did agree that their wives be contacted, proceeding without their participation did not fit with the nursing perspective of this study that places importance on working with the family unit. Finally, the availability of husbands' data would be important in the development of family stress and adaptation theory. Therefore, a non-probability convenience sampling approach was used to recruit consecutive eligible couples. The sample in this study consisted of the wives who responded, and only the wives data were used in the analyses.

### *Selection Criteria*

Inclusion criteria were: both wives and their partners were aware of the diagnosis; had been cohabiting for at least one year prior to the onset of the study; lived within a 1 hour radius (by car) of downtown Montreal; and were able to read and understand either French or English. The exclusion criteria were selected to control for variables that would confound the model being examined. They were: metastatic prostate cancer (Stage D); other imminently life-threatening illness in wives or their husbands; apparent, unmanaged psychiatric illness; couples with children under the age of 16. It was felt that wives who were dealing with the issues of imminent death were in a different situation with different factors affecting their adaptation. Similarly families with young children likely face different stressors, suggesting that their experiences might be significantly different from the rest of the group, so they too were excluded during sample selection.

### *Sample Size Justification*

Several approaches are commonly used to determine sample size requirements for multiple regression analysis. One of these is to consider the number of independent variables included in the regression model, with most authors recommending between 5 to 10 subjects per independent variable. (Tabachnik & Fidell, 1989; Dawson-Saunders & Trapp, 1990). The model to be tested included 6 independent variables related to the theoretical constructs being examined in the study and 4 demographic variables (age, education, income, type of treatment). Therefore, following the conventional ratio of 10 subjects per variable, a sample size of 100 would be required to capture significant correlations between the variables in the study.

Another approach to sample size estimation is based on power and effect size. (Cohen, 1992; Cohen, 1988). Using this approach to determine sample size and accounting for a significance level of .05, a moderate effect size of .15 using the F- test in multiple regression, a power of .80, and 10 study parameters, the goal was to recruit 105 couples.

### *Subject Recruitment*

The rationale and plan for the study, the information letters and response cards, and the consent forms were submitted to the scientific and ethical review committees at Notre Dame Hospital and at the McGill University Health Centre. Scientific and ethical review and approval was obtained for the duration of the study at both sites (see Appendix 3). Subjects were recruited at two large university teaching hospitals -the McGill University Health Centre - Royal Victoria and Montreal General Hospital sites, and the Centre hospitalier de l'Université de Montréal - Hopital Notre Dame site. The agreement of physicians in the Departments of Urology and Radiation Oncology to refer patients to the study was obtained. Ethical review committees required that the physicians, or their delegates (the office secretaries, or nurses and secretaries in the Urology Clinic) give the letter of information (see Appendix 4) describing the study to men who met the selection criteria. The men were asked to share this information with their wives and return the attached response card indicating their decision regarding



participation. After two weeks, couples who did not return response cards were telephoned by the principal researcher to confirm that they had received the information letter and to answer any questions they may have had. Those who agreed to participate were contacted and an arrangement was made to visit them in their home prior to the onset of treatment. At the time of the first visit in the home, any additional questions were answered, and a nurse researcher familiar with prostate cancer and its treatment obtained written consent. Recruitment of subjects continued until preliminary analysis revealed significant correlations between predictors and outcome variables, indicating that there was no Type II error.

#### *Accrual and Attrition*

At the onset of the study, there were no prospective studies in the area of prostate cancer where both husbands and wives were required to participate on which to predict how quickly subjects could be recruited or what attrition rates might be. Retrospective, survey-based studies of quality of life in men with prostate cancer reported response rates ranging from 80-92% (Fowler, Jr. et al., 1995; Litwin et al., 1995; Helgason, Fredrikson, Adolfsson, & Steineck, 1995). The accrual rate of 43 % (81 subjects entered/188 referred) in this study should be considered an approximation because the recruitment process required by the ethical review committees made it difficult to know whether all patients who were eligible actually received an information letter about the study. This low accrual rate is also related to the prospective nature of the study and to the fact that it required the participation of both partners, factors which have already been identified in a review of studies of cancer in the marital context (Manne, 1998). The issues accrual and retention were not dissimilar to another prospective study with cancer patients and their spouses (Baider et al., 1998), where only 67 of the 204 couples (36%) recruited prior to treatment completed the final phase of data collection one and a half years later. In a recent study of couples with prostate cancer (Gray et al., 2000a), the accrual of 38.5% was comparable to this study.

Recruitment of subjects began in November 1997. Time 2 data collection was

completed in July 2001. At that point, data were available for 81 wives, 70 of whom had gone on to complete the questionnaires at Time 2, indicating an attrition rate of 13.6%. The reasons cited by wives for not continuing included: not interested ( $n = 4$ ); moving to another city ( $n = 2$ ); marital breakup ( $n = 1$ ); trouble understanding questions ( $n = 1$ ); death of husband ( $n = 1$ ); husband too anxious ( $n = 1$ ); and husband's back pain (prostate is not a problem) ( $n = 1$ ).

The 11 subjects who did not complete data collection at time 2 were compared the 70 subjects who did in an independent samples t-test. There were no significant differences between the groups on the wives' age, years married, professional support sought, importance of religion, number of major events over the previous 2 years, or satisfaction with their own current state of health. There was no difference between groups on FACES, the OLQ, Urinary or Sexual Function, Impact, Mastery or POMS. A significant difference was found on the PAIS, with the non-continuing group showing higher scores corresponding to poorer adjustment ( $t(79df) = -2.788, p = .007$ ) than those who continued at time 2. All subsequent analyses proceeded using the data from the 70 wives who had completed questionnaires at both periods in the study.

### *Data Collection*

Home data collection was selected because of subjects' age and availability, the sensitive nature of some of the items, the time and space required for each partner to respond to the questions independently, and the need to create a climate that would foster retention of the participants over the course of the study. The principal investigator, and another nurse with knowledge of prostate cancer and expertise in data collection in nursing research carried out the data collection, each working with half the subjects. A protocol was developed for data collection in which the research assistant alternated between husband and wife in separate rooms, answered their questions, assisted with certain questionnaires, and ensured that all items were completed. Approximately an hour and 15 minutes were required by most couples to complete the questionnaires. The average length of time required for the first visit was about 2½

hours; the average time for the second was approximately 1½ hours. The additional time was spent in response to their need to share what was frequently sensitive information about their experiences. This was considered important to engaging the couples and maintaining their participation over the course of the study. Occasionally, couples requested that they receive the time 2 questionnaires by mail because they felt comfortable with completing them independently the second time. For those couples, the second visit was much shorter in duration, but was an opportunity for the researcher to verify that all questions had been answered.

### *Ethical Considerations*

At the time of the first home visit, any additional questions regarding the study were answered. Women and their husbands signed separate consent forms prior to the administration of the questionnaires (see Appendix 5). All questionnaires were identifiable only by number and were filed in a locked cabinet to which only the researcher had access. Provision was made at the outset of the study for referral of patients or spouses who, during the home visits, had physical or psychological problems that required attention. The referring physician was to be contacted first, and a clinical nurse specialist with advanced practice skills in family nursing was available for those who might need follow-up. Two situations arose over the course of the study that required referral for follow-up by a health professional.

### **Sample Characteristics**

A profile of the group of wives (N = 70) whose data from time 1 and 2 were available for hypothesis testing was generated through descriptive statistics and is presented in Table I. The mean age of the wives in the sample was 63.7 yrs (*SD* = 8.65), with a range of 42 to 82 years. The mean number of years married was 34.6 yrs (*SD* = 16.64), with a range of 1 to 60 years. The mean number of years of education was 11.62 (*SD* = 3.85), with a range of 5 to 29 years. Sixty per cent of wives had an income of less than \$55,000 and 28.6% reported higher incomes. Overall 92.8% of the whole group indicated that the revenue was sufficient to meet their needs. Wives

were employed outside of the home in 21.4% of cases, 32.9% were retired, and 41.4% were working as homemakers in the home. The group was evenly divided with 35 reporting English as mother tongue and 34 reporting French. There were four main types of treatment regimens reported, with 90% of their husbands having either radical prostatectomy, or radiotherapy with adjuvant hormone therapy.

**Table I. Socio-demographic Characteristics of Wives**

Variable	<i>M</i>	<i>SD</i>	Range
Age (yrs)	63.70	8.65	40-82
Years Married (yrs)	34.60	16.64	1-60
Years of Education (yrs)	11.62	3.85	5-29
Major Events (no.)	1.74	1.60	0-6

Variable	%	(n)
<b>Annual Household Income</b>		
<\$15,000	4.3	(3)
\$15,000-24,999	12.9	(9)
\$25,000-34,999	15.7	(11)
\$35,000-44,999	17.1	(12)
\$45,000-54,999	10.0	(7)
\$55,000-64,999	8.6	(6)
>\$75,000	20.0	(14)
unreported	11.4	(8)
<b>Current Work Status</b>		
Employed	21.4	(15)
Retired	32.9	(23)
On leave	2.9	(2)
Looking for work	1.4	(1)
Homemaker	41.4	(29)
<b>Nature of Major Events in 2 Previous Years</b>		
No major events	30.0	(21)
Personal illness	20.0	(14)
Retirement/change in my work	22.9	(16)
Change in living arrangements	10.0	(7)
Illness in an important other	7.1	(5)
Death of an important other	4.3	(3)
Other	4.3	(3)
<b>Language</b>		
French	48.6	(34)
English	50.0	(35)
Other	1.4	(1)
<b>Type of Treatment</b>		
Surgery with/without radiation	42.8	(30)
Radiation with/without hormones	47.2	(33)
Hormones only	7.1	(5)
Close observation	2.9	(2)

## **Data Analysis Procedures**

The process of data analysis began once data collection was well under way and consisted of a preliminary phase of data entry and screening, and preliminary analyses with descriptive statistics. The second phase of data analysis included multivariate tests to examine the hypotheses of the study.

### *Data Entry and Screening*

All data were entered using Epi Info Version 6 (1995). This program facilitates data entry and includes a data verification procedure that readily identifies errors. Epi-Info record files were subsequently converted into data files for analysis with SPSS-PC (Release 10.1) (2000). During the first phase of the analysis, data were examined for possible errors at the time of entry. Ten percent of the completed files at time 1 and 2 were recoded and re-entered by a second individual, using the data validation procedure in Epi Info to check for discrepancies. As an additional screening process, all PAIS-SR questionnaires were re-entered for both time 1 and 2. For all scales with the exception of the sexual function scale, no scale had more than 5% of items missing and missing items did not exceed the numbers suggested by the test developers. In all cases, missing items were assigned the individual's mean score on the scale.

Histograms of the variables were also examined to identify univariate outliers. Scores of more than 3 standard deviations away from the mean are generally considered to be outliers (extreme scores) (Tabachnik et al., 1989; Stevens, 1996). At time 1, one case showed scores just over 3 standard deviations away from the mean on two variables. A re-examination of the raw data indicated that this case was a true outlier. Exploratory regression analyses were run with the outlier excluded and again included, but the differences were minimal and the case was ultimately retained during the hypothesis testing regressions. At time 2, no outliers were identified.

As part of the screening process, verification of the assumptions underlying linear regression was conducted through the hypothesis testing phase of the analyses. Standardized residuals were plotted against the standardized predicted values to

validate the assumptions of linearity and homoscedasticity (Tabachnik et al., 1989; Stevens, 1996) and inspection of scatterplots revealed that these assumptions were met. A histogram of the standardized residuals was examined to validate the assumption of normality. The normality of the distribution of the residuals was further confirmed through the examination of a normal probability plot of residuals (Tabachnik et al., 1989).

### *Preliminary Analyses*

The characteristics of wives were described using descriptive statistics (i.e. mean, standard deviation, and range for continuous variables and percentages for categorical variables). Descriptive statistics were also used to describe wives scores on the self-report measures at two points in time – prior to treatment and 3 months after the onset of treatment of their husbands' prostate cancer. Where possible, wives scores on the study measures were compared with reported means of other groups whose situation could be considered similar.

*Scores on measures.* Table II provides a summary of the wives scores on the measures including the mean scores, standard deviation, and range for each of the independent and dependent variable for the 70 wives at time 1 and 2. For PAIS and POMS, the scores on the subscales are also reported for information, but only the final scores were used in the subsequent analyses. Data was complete for the 70 subjects on all measures with the exception of the urinary function and the sexual function scales of the PSSE. The number of subjects used in the calculations of mean scores and standard deviations of the PSSE is reported at the base of the Table.

Table II. *Wives Responses on Measures at Time 1 and 2*

Measure	Time 1			Time 2			Possible Range
	<i>M</i>	<i>SD</i>	Actual Range	<i>M</i>	<i>SD</i>	Actual Range	
PAIS-SR	20.71	10.30	5-56	22.55	12.25	0-56	0-138
Healthcare	5.65	2.74	0-12	5.41	2.89	0-12	0-24
Vocation	2.28	1.90	0-8	2.55	2.46	0-12	0-18
Domestic	1.56	1.78	0-7	2.04	2.54	0-14	0-24
Sexual	3.31	3.67	0-12	5.43	3.92	0-14	0-18
FamilyRelations	.57	1.10	0-6	.79	1.39	0-8	0-15
Social	1.91	2.79	0-14	2.02	2.88	0-11	0-18
Psychol	5.41	3.04	0-15	4.31	3.30	0-13	0-21
POMS	11.27	24.70	-33-98	8.22	27.25	-34 -74	-40-200
Tension	5.70	5.74	-4-23	4.70	6.33	-4-20.25	-4-36
Depression	7.90	7.58	0-35	6.76	7.07	0-28	0-60
Anger	5.74	5.70	4-27	5.19	5.52	0-20	0-48
Vigor	16.50	5.40	4-27	17.07	4.81	7-27	0-(-32)
Fatigue	6.41	4.23	0-19	6.50	4.75	0-19	0-28
Confusion	2.03	3.74	-4-15	2.13	4.38	-4 -15	-4-28
SARS							
Impact	18.49	7.91	5-36	14.43	7.36	5-37	5-40
Mastery	27.23	5.59	17-40	24.03	6.10	9-36	5-40
PSSE							
Urinary	94.50 <sup>a</sup>	13.84	26.60-100	75.92 <sup>c</sup>	28.57	0-100	0-100
Sexual	51.26 <sup>b</sup>	35.12	0-100	25.81 <sup>d</sup>	27.97	0-94.50	0-100
SOC	151.80	22.76	101-194	151.06	24.22	109-203	29-203
FACES	6.26	1.65	1.5-8	6.25	1.55	1-8	1-8
Cohesion	6.51	1.73	2-8	6.44	1.73	1-8	1-8
Adaptability	6.01	1.73	1-8	6.06	1.58	1-8	1-8

<sup>a</sup> n = 65; <sup>b</sup> n = 57; <sup>c</sup> n = 59; <sup>d</sup> n = 60



*Comparisons with other samples.* In order to compare the scores of wives on these measures with other groups, an attempt was made to find comparable groups with reported scores on the POMS, PAIS, the PSSE, SOC, FACES and SARS. The POMS mood disturbance scores of the wives in this study were compared to published norms (Cassileth et al., 1986). The wives scores at time 1 ( $M = 11.27$ ,  $SD = 24.7$ ) were similar to the mood disturbance score reported for relatives of breast cancer patients ( $M = 11.6$ ,  $SD = 29.1$ ) and relatives of patients with melanoma ( $M = 10.3$ ,  $SD = 23.3$ ). PAIS scores at time 1 ( $M = 20.71$ ,  $SD = 10.30$ ) were similar although slightly lower than the scores of caregivers' who were newly diagnosed with cancer ( $M = 26.68$ ,  $SD = 15.89$ ) or who were at first remission ( $M = 24.96$ ,  $SD = 14.90$ ) (Morse et al., 1998).

In an attempt to examine the psychometric properties of the PSSE, wives reports of urinary and sexual function at time 2 were compared with published data (Litwin et al., 2001) on men's urinary and sexual function three months after prostatectomy. Wives reports of urinary function ( $M = 75.92$ ,  $SD = 28.7$ ) and of sexual function ( $M = 25.81$ ,  $SD = 27.97$ ) at time 2 when treatment for prostate cancer had been well underway were lower than means for men on urinary function ( $M = 55.5$ ,  $SD = 27.6$ ) and similar to the means for sexual function ( $M = 21.7$ ,  $SD = 19.7$ ) reported by men after radical prostatectomy. In this comparison, although the respondents differ and the men's treatments are not exactly the same in both studies, some level of similarity would be expected. The means and standard deviations on the SOC scale across 21 samples have been reported for purposes of normative comparisons (Antonovsky, 1993). The means across samples ranged from 117.0 to 152.6, which was comparable to the scores for the wives in this study at time 1 ( $M = 151.8$ ,  $SD = 22.76$ ) and time 2 ( $M = 151.1$ ,  $SD = 24.2$ ). The wives scores on FACES at time 1 ( $M = 6.26$ ,  $SD = 1.65$ ) and at time 2 ( $M = 6.25$ ,  $SD = 1.55$ ) fall into the category of "balanced family types" described by Olson, Bell and Portner (1982), but no published reports of FACES scores from groups similar to the subjects in this study were available. Similarly, there were no reports available for SARS that could be compared to the scores of the subjects in this study.

*Selection of variables for testing.* First, the preliminary analyses also sought to identify potential variables that should be controlled in subsequent regression analyses. In addition to age, education, income and type of treatment that were originally postulated as control variables, seeking professional support, current health problems, maternal language, importance of religion and satisfaction with current health status were also examined as potential control variables at time 1 and time 2. Pearson's Product Moment correlations were used where the variables were continuous. Where variables were not continuous, the data were reduced and point bi-serial correlations were examined. Correlation matrices were then examined to see which variables should be considered in the subsequent analyses. To consider an extraneous variable as a control variable, that variable had to be significantly correlated with a dependent variable with a correlation of at least .32 (or 10% of the variance). A sample size of 70 achieves 87% power to detect a correlation of this strength with an alpha of 0.05. None of the control variables identified at the outset were significantly related to either PAIS or POMS at time 1 or time 2 (see Appendix 6). They were dropped from subsequent analyses.

Next, correlation matrices were examined for relationships between the independent variables and each dependent variable at time 1 and at time 2. Pearson's Product Moment correlations were used to identify any significantly correlated variables that should be retained in the analysis and to screen for collinearity between variables, a phenomenon of importance when multiple regression analyses will be conducted (Stevens, 1996). Pearson's correlations of .90 among the independent variables indicate multicollinearity, and including variables with a bivariate correlation of greater than .70 in multiple regression should be carefully considered (Tabachnik et al., 1989). The correlations between independent variables, mediators and the dependent variables for time 1 are seen in Table III. The same set of correlations for time 2 are presented in Table IV. There was no evidence of collinearity between independent variables at either period in data collection.

**Table III. Time 1 Correlations: Independent Variables, Mediators and Dependent Variables**

**Independent Variables with Dependent Variables**

	PAIS	<i>p</i> value	POMS	<i>p</i> value
SOC	-.428***	.000	-.622***	.000
FACES-II	-.210	.081	-.270*	.024
Urinary Function	-.306*	.013 <sup>a</sup>	-.363**	.003 <sup>a</sup>
Sexual Function	.194	.148 <sup>b</sup>	-.256	.055 <sup>b</sup>
Urinary bother	-.417***	.000 <sup>c</sup>	-.391**	.001 <sup>c</sup>
Sexual bother	-.117	.333	-.059	.629

**Independent Variables with Mediators**

	Impact	<i>p</i> value	Mastery	<i>p</i> value
SOC	-.278*	.020	.285*	.017
FACES-II	-.168	.164	.249*	.037
Urinary Function	-.075	.551 <sup>a</sup>	.187	.136 <sup>a</sup>
Sexual Function	-.126	.350 <sup>b</sup>	.111	.412 <sup>b</sup>
Urinary bother	-.295*	.014 <sup>c</sup>	.101	.407 <sup>c</sup>
Sexual bother	-.007	.953	.063	.605

**Mediators with Dependent Variables**

	PAIS	<i>P</i> value	POMS	<i>p</i> value
Impact	.372**	.002	.358**	.002
Mastery	-.169	.163	-.246*	.040

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p \leq .001$ , <sup>a</sup>  $n = 65$ , <sup>b</sup>  $n = 57$ , <sup>c</sup>  $n = 69$

**Table IV. Time 2 Correlations: Independent Variables, Mediators and Dependent Variables**

<b>Independent Variables with Dependent Variables</b>				
	PAIS	<i>p</i> value	POMS	<i>p</i> value
SOC	-.578***	.000	-.720***	.000
FACES-II	-.397**	.001	-.520***	.000
Urinary Function	-.407**	.001 <sup>a</sup>	-.359***	.005 <sup>a</sup>
Sexual Function	-.426**	.001 <sup>b</sup>	-.218	.097 <sup>b</sup>
Urinary Bother	-.255*	.034	-.178	.140
Sexual Bother	-.236*	.049 <sup>c</sup>	-.218	.072 <sup>c</sup>
<b>Independent Variables with Mediators</b>				
	Impact	<i>P</i> value	Mastery	<i>p</i> value
SOC	-.418***	.000	.313**	.008
FACES-II	-.237*	.048	.325**	.006
Urinary Function	-.271*	.037 <sup>a</sup>	-.110	.403 <sup>a</sup>
Sexual Function	-.174	.187 <sup>b</sup>	-.107	.421 <sup>b</sup>
Urinary Bother	-.089	.465	-.026	.832
Sexual bother	-.396**	.001 <sup>c</sup>	.004	.974 <sup>c</sup>
<b>Mediators with Dependent Variables</b>				
	PAIS	<i>p</i> value	POMS	<i>p</i> value
Impact	.526***	.000	.437***	.000
Mastery	-.030	.805	-.197	.102

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p \leq .001$ , <sup>a</sup>  $n = 60$ , <sup>b</sup>  $n = 59$ , <sup>c</sup>  $n = 69$

The correlation matrices were then examined to see which of the study variables should be retained for the subsequent analyses. In order to avoid redundancy with the Urinary and Sexual Function scales, and for psychometric reasons, the single item urinary and sexual bother scores were dropped. The Urinary Function scores were retained. Sexual function was correlated only with PAIS at time 2 and the decision was made to drop this scale for the subsequent analyses. Similarly, the Mastery subscale was correlated only with POMS at time 1 and it was also dropped.

Dropping the 4 demographic control variables and the mastery and the sexual function scales resulted in a reduction in the variable set from the 10 that were originally accounted for in the sample size calculations, to 4 study variables that would be used in the hypothesis-testing phase. This made it possible to stay within the parameters of an acceptable sample size, given the power and effect size that were postulated. Consequently, the independent variables that were retained for hypothesis testing are listed in Table 5 and include the Urinary Function Scale of the Prostate Specific Symptom Evaluation (Urinary Function), the Sense of Coherence Scale (SOC), the Family Adaptability and Cohesion Evaluation Scale (FACES), and the Impact Scale of the Stress Appraisal Rating Scale (Impact). The variables that were retained for the model tests are described in Table V.

**Table V. *Constructs and Associated Measures Retained for Hypothesis Testing***

Construct	Measure
Illness demands	Urinary Function Scale of PSSE (Urinary Function)
Personal resources	Sense of Coherence Scale (SOC)
Family resources	Family Adaptability and Cohesion Evaluation Scale (FACES)
Situational appraisal	Impact Scale of SARS (Impact)

The correlations between the PAIS and POMS at time 1 ( $r = .610, p \leq .000$ ), and at time 2 ( $r = .718, p \leq .000$ ) were high. A high correlation was expected as both measures were expected to reflect adaptation. Collinearity was not an issue as the model tests were independent.

In the final step of the preliminary analyses, a paired samples t-test was carried out to see whether there was a significant difference in the subjects' scores on the variables retained in the study between time 1 and time 2 (see Table VI). Significant differences were found on the Urinary Function scores and the Impact scores. No significant differences were found in subjects scores on either of the dependent variables (PAIS, POMS), nor on the other independent variables (SOC, FACES).

**Table VI. Paired t-tests of Study Variables at Time 1 and 2**

Paired measures	<i>t</i>	<i>df</i>	Sig. (2-tailed)
PAIS	-1.204	69	.233
POMS	.926	69	.358
SOC	.333	69	.358
Urinary Function	4.472***	56	.000
Impact	4.771***	69	.000
FACES	.084	69	.933

\*\*\*  $p \leq .001$ ;

### Hypothesis Testing

Following the procedure described by Baron & Kenny (1986), the hypotheses were tested using a series of multiple regression equations that estimate the amount of variance in the dependent variable that can be explained by the predictor variables, and at the same time test for the mediating effect of a variable in a causal chain. The series of 3 regression equations to be estimated when testing for mediation are: 1) regression of the mediator (Impact) on the independent variables (Urinary Function, SOC,

FACES); 2) regression of the dependent variable (PAIS) (POMS) on the independent variables (Urinary Function, SOC, FACES); 3) regression of the dependent variable (PAIS) (POMS) on the independent variables and on the mediator (Urinary Function, SOC, FACES, Impact). To establish mediation, 3 conditions must hold: 1) the independent variables must affect the mediator in the first equation, 2) the independent variables must affect the dependent variable in the second equation, and 3) the mediator must affect the dependent variable in the third equation. If the conditions hold in the predicted directions, then the effect of the independent variable on the dependent variable must be *less* in the third equation than in the second. Finally, the third equation examines the contributions of all the predictor variables in explaining the variance in the dependent variable.

Four sets of these regression equations were carried out, and were intended to: 1) verify the direction and the strength of the contributions of the independent and mediating variables to the dependent variable at time 1 and time 2 (examining hypotheses 1-3), 2) examine the relevance of the model at time 2 (hypothesis 4), 3) examine the contributions of the independent variable at time 1, the differences in their scores between time 1 and 2, and appraisal at time 2 to the dependent variable at time 2 (examining hypotheses 5-7), and 4) examine the contributions of the independent variables at time 1, the differences in their scores between time 1 and 2, and appraisal at time 2 to the change in the dependent variable at time 2 (examining hypotheses 8-10). These analyses were carried out separately for PAIS and for POMS.

**Chapter 4**  
**Results**



The model tests for PAIS and POMS, two independent measures of the dependent variable of adaptation, are presented separately. Four sets of regressions are presented for each measure. The first set verified the contributions of variables in the explanatory model at time 1; the second set of regressions confirmed the model and examined how it changed at time 2. The third set of regressions tested the contributions of the variables at time 1 and the change in their scores between time 1 and 2 (difference scores) to adaptation at time 2. The fourth tested the contributions of the variables at time 1 and the change in their scores (difference scores), to the change in adaptation between time 1 and 2. A schematic figure for each of the models is included. The chapter concludes with a summary of the findings.

### **Global Adaptation**

#### *Model Verification - PAIS Time 1*

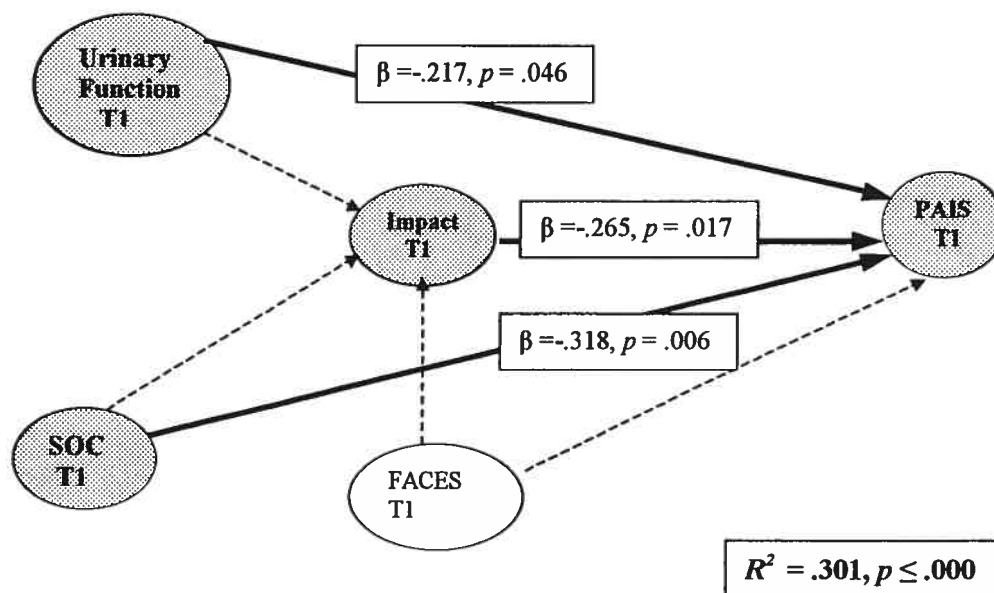
Equation 1 addressed hypothesis 1 and also examined Condition 1, which is required for testing mediation. Here Impact T1 was regressed on the independent variables Urinary Function T1, FACES T1, and SOC T1. The nature of the relationships between variables was in the expected direction but the independent variables together did not have a significant effect on Impact T1 ( $R^2 = .085, p = .116$ ). Condition 1 required for mediation was not met, and equation 2 was not interpreted. The contributions of all the variables in the model were then examined in Equation 3. Three variables were acting on the dependent variable and together explained 30.1% of the variance in PAIS T1. SOC T1 explained most of the variance ( $\beta = -.318, p = .006$ ), followed by Impact T1 ( $\beta = .265, p = .017$ ) and then by Urinary Function T1 ( $\beta = -.217, p = .046$ ). The equations are presented in Table VII.

Table VII. *Model Verification – PAIS T1*

	$R^2$	$p$		$\beta$	$p$
Equation 1	.085	.116	Urinary Function T1	-.021	.865
			FACES T1	-.087	.493
			SOC T1	-.248	.050*
Equation 2	.236	.000***	Urinary Function T1	-.222	.048*
			FACES T1	-.046	.688
			SOC T1	-.383	.001**
Equation 3	.301	.000***	Urinary Function T1	-.217	.046*
			FACES T1	-.023	.834
			SOC T1	-.318	.006**
			Impact T1	-.265	.017*

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

The retained model derived from equation 3 explaining adaptation on PAIS at time 1 is illustrated in Figure 2.

Figure 2. *Model verification – PAIS T1*

In summary, the relationships between the operational constructs described above supply evidence for the following hypotheses using PAIS as the measure of adaptation at time 1:

1) symptom distress, personal and family resources were not associated with appraisal - hypothesis 1 was not confirmed;

2) lower levels of symptom distress, higher levels of personal resources, and more positive appraisal were associated with better adaptation – hypothesis 2 was partly confirmed;

3) appraisal did not mediate the effect of symptom distress and personal resources on adaptation - hypothesis 3 was not confirmed.

#### *Model Confirmation - PAIS Time 2*

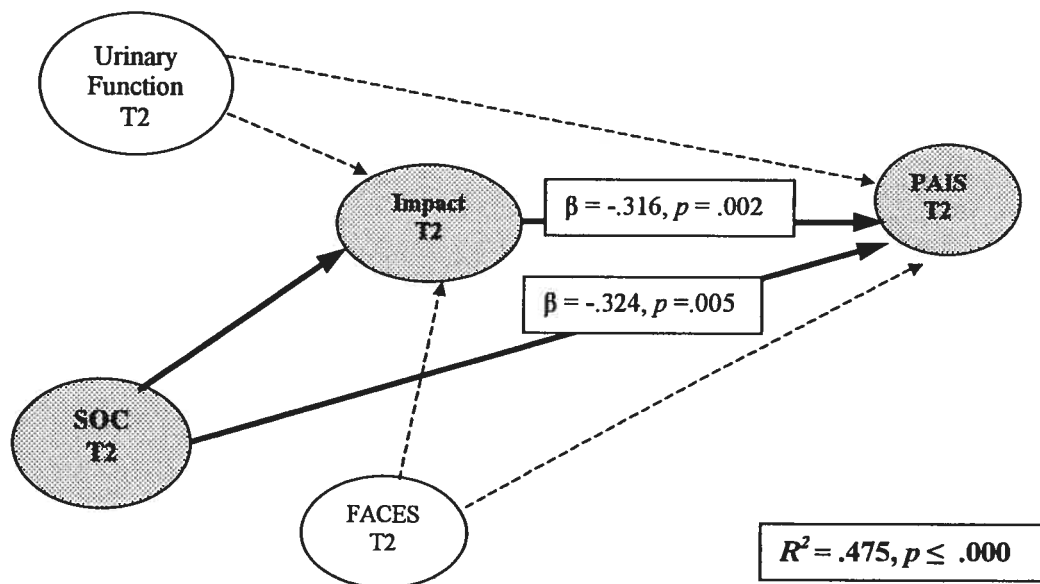
In the test of the stability of the model for PAIS, hypotheses 1-3 were re-examined using the data from time 2. In equation 1 when Impact T2 was regressed on the independent variables, the  $R^2$  was .203,  $p = .002$  and condition 1 was met. Only the SOC T2 made a significant contribution to explaining Impact T2 ( $\beta = -.341, p = .010$ ) while Urinary Function and FACES did not. In equation 2, regressing PAIS T2 on the independent variables showed a significant contribution of the independent variables in explaining adjustment ( $R^2 = .394, p \leq .000$ ) and condition 2 required for mediation was met. In this equation, only SOC T2 made a significant contribution ( $\beta = -.436, p \leq .000$ ). In equation 3, regressing PAIS T2 on the independent variables as well as the mediator showed a significant explanation of adjustment ( $R^2 = .475, p \leq .000$ ). With the addition of Impact T2 to the equation, the contribution of SOC T2 ( $\beta = -.324, p = .005$ ) remained significant with the beta weight dropping slightly from its level in equation 2. This fall in the beta weight of the SOC T2 met condition 3 required for mediation indicating that part of the relationship between SOC T2 and PAIS T2 was explained by the addition of Impact T2. The full model showed that the SOC T2 ( $\beta = -.324, p = .005$ ) and Impact T2 ( $\beta = -.316, p = .002$ ) contributed almost equally in explaining 47.5% of the variance in PAIS at time 2 with Impact mediating the effect of personal resources on adaptation (see Table VIII).

**Table VIII. Model Confirmation – PAIS T2**

	$R^2$	$p$		$\beta$	$p$
Equation 1	.203	.002**	Urinary Function T2	-.131	.271
			FACES T2	-.092	.460
			SOC T2	-.341	.010*
Equation 2	.394	.000***	Urinary Function T2	-.198	.056
			FACES T2	-.174	.107
			SOC T2	-.436	.000**
Equation 3	.475	.000***	Urinary Function T2	-.162	.095
			FACES T2	-.154	.130
			SOC T2	-.324	.005**
			Impact T2	-.316	.002**

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

The retained model is illustrated in Figure 3.

**Figure 3. Model Confirmation – PAIS T2**

In summary, the data for PAIS as the measure of adaptation at time 2 supply evidence for the following hypotheses:

- 1) higher levels of personal resources were associated with better appraisal – hypothesis 1 was partly confirmed;
- 2) higher levels of personal resources were associated with better adaptation – hypothesis 2 was partly confirmed;
- 3) the effect of personal resources were mediated by appraisal – hypothesis 3 was partially confirmed.
- 4) With PAIS as the measure of adaptation, a comparison of the models from Time 1 and 2 suggested some similarities and some differences. Personal resources (SOC) was the most important predictor of adaptation in both models and the amount it predicted remained quite stable over the 3 month period. Appraisal (Impact) also had a direct effect on adaptation in both models. Differences noted were: appraisal acted as a mediator at time 2 but not at time 1. Urinary Function, a second variable from the set of independent variables, contributed to explaining adaptation at time 1, but did not have a significant effect at time 2. Hypothesis 4, related to the relevance of the model, was partly confirmed.

#### *Projective Model - PAIS T2*

The first of the projective models estimated the contribution of the time 1 independent variables and their difference scores to explaining PAIS at Time 2 (PAIS T2). The first equation regressing Impact T2 on the independent variables at time 1 and on the difference scores of the same variables showed an  $R^2$  of .232,  $p = .010$ . Condition 1 for mediation was met. The SOC Difference score was the only variable from the set to make a significant contribution to explaining Impact T2 ( $\beta = -.316$ ,  $p = .054$ ). Equation 2 regressed PAIS T2 on the independent variables at time 1 and on their difference scores, and showed an  $R^2$  of .442,  $p \leq .000$ . Condition 2 for mediation was met, with both SOC T1 ( $\beta = -.323$ ,  $p = .005$ ) and SOC Difference ( $\beta = -.386$ ,  $p = .006$ ) accounting for a similar portion of the variance in PAIS T2. Urinary Function and FACES did not make a significant contribution. Equation 3 regressed PAIS T2 on the independent variables, their difference scores and Impact T2 and accounted for

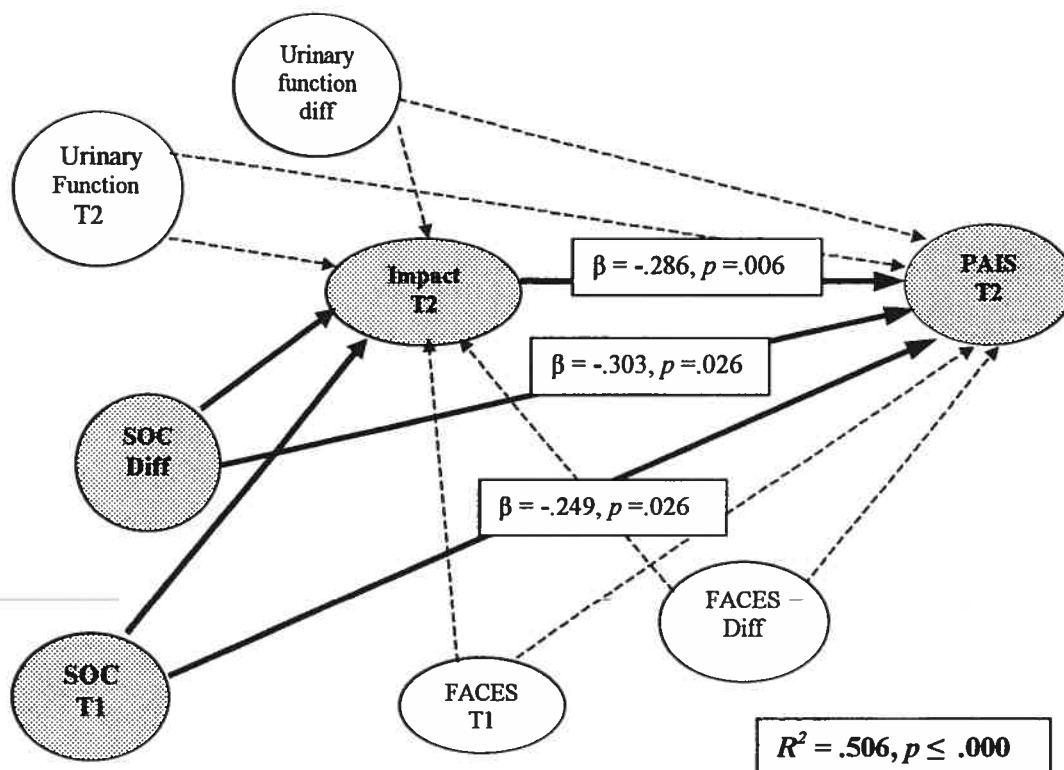
50.6% of the variance in PAIS at time 2 ( $R^2 = .506, p \leq .000$ ). SOC Difference ( $\beta = -.303, p = .006$ ), followed by Impact T2 ( $\beta = -.286, p = .006$ ) and SOC T1 ( $\beta = -.249, p = .026$ ) accounted for the variance explained. The contribution of FACES and Urinary Function was not significant. With the addition of Impact T2 in the final model, the contributions of SOC T1 and of SOC Difference dropped suggesting that Impact T2 had mediated their effects (see Table IX).

**Table IX. Projective Model PAIS T2**

	$R^2$	$P$		$\beta$	$p$
Equation 1	.232	.010*	Urinary Function T1	-.179	.186
			FACES T1	-.061	.663
			SOC T1	-.244	.070
			Urinary Difference	-.127	.321
			FACES Difference	-.098	.544
			SOC Difference	-.316	.054*
Equation 2	.442	.000**	Urinary Function T1	-.155	.175
			FACES T1	-.116	.326
			SOC T1	-.323	.005**
			Urinary Difference	-.208	.057
			FACES Difference	-.257	.064
			SOC Difference	-.386	.006**
Equation 3	.506	.000***	Urinary Function T1	-.106	.332
			FACES T1	-.110	.328
			SOC T1	-.249	.026*
			Urinary Difference	-.176	.091
			FACES Difference	-.226	.087
			SOC Difference	-.303	.026*
			Impact T2	-.286	.006**

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

The retained model derived from equation 3 is illustrated in Figure 4.



**Figure 4. Projective Model-PAIS T2**

In summary, the test of the first projective model using PAIS as the measure of adaptation provided evidence for hypotheses:

- 5) change in personal resources between time1 and time 2 was associated with more positive appraisal at time 2 – hypothesis 5 was partially confirmed;
- 6) personal resources at time 1 as well as change in personal resources between time 1 and 2 was associated with better adaptation at time 2 – hypothesis 6 was partially confirmed;
- 7) appraisal at time 2 mediated the effects of personal resources and change in personal resources on adaptation at time 2 – hypothesis 7 was partially confirmed.

*Projective Model - PAIS Difference*

The second projective model estimated the contribution of the time 1 independent variables and their difference scores to explaining the change PAIS between time 1 and 2 (PAIS Difference). As in the first projective model, equation 1 regressed Impact T2 on the independent variables at time 1 and on their difference scores and showed an  $R^2$  of .232,  $p = .010$ . Condition 1 for mediation was met. The SOC Difference score was the only variable from the set to make a significant contribution to explaining Impact T2 ( $\beta = -.316, p = .054$ ). Equation 2 regressed PAIS Difference on the time 1 independent variables and their difference scores, and the contribution of this set of variables accounted for a significant amount of the variance in the PAIS Difference score ( $R^2 = .397, p \leq .000$ ). FACES Difference ( $\beta = -.385, p = .009$ ) and SOC Difference ( $\beta = -.352, p = .016$ ) accounted for the largest portion of the variance and the contribution of the other variables was not significant. Condition 2 for mediation was met. Equation 3 added Impact T2 to the set of independent variables and together the variables explained a significant amount of the variance in the PAIS Difference score ( $R^2 = .404, p \leq .000$ ). Although the addition of Impact 2 reduced the contributions of FACES Difference ( $\beta = -.375, p = .011$ ) and SOC Difference ( $\beta = -.325, p = .029$ ) from their previous levels in equation 2, this variable did not make a significant unique contribution to the PAIS Difference score. It did not act as a mediator and also was not retained in the explanatory model (see Table X).

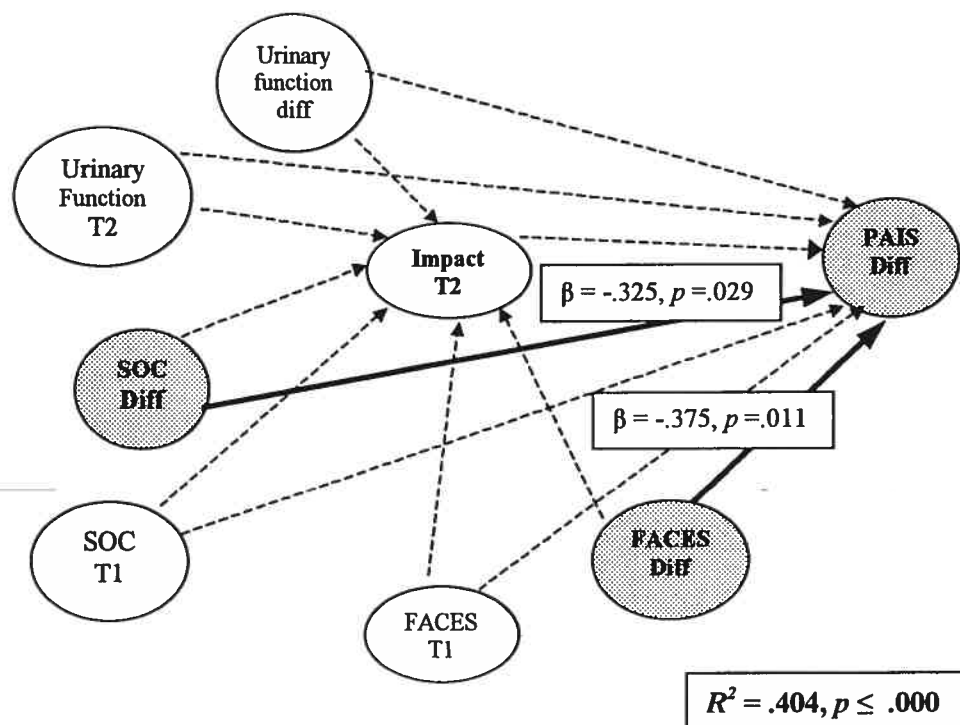


**Table X. Projective Model – PAIS Difference**

	$R^2$	$p$		$\beta$	$p$
Equation 1	.232	.010**	Urinary Function T1	-.179	.186
			FACES T1	-.061	.663
			SOC T1	-.244	.070
			Urinary Difference	-.127	.321
			FACES Difference	-.098	.544
			SOC Difference	-.316	.054*
Equation 2	.397	.000***	Urinary Function T1	.066	.575
			FACES T1	-.146	.235
			SOC T1	-.003	.980
			Urinary Difference	-.108	.338
			FACES Difference	-.385	.009**
			SOC Difference	-.352	.016*
Equation 3	.404	.000***	Urinary Function T1	.082	.495
			FACES T1	-.144	.243
			SOC T1	.021	.863
			Urinary Difference	-.097	.390
			FACES Difference	-.375	.011*
			SOC Difference	-.325	.029*
			Impact T2	-.091	.414

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

The retained model explaining the contributions of the independent variables to the PAIS difference scores is illustrated in Figure 5



**Figure 5. Projective Model - PAIS Difference**

In summary, the data from the second set of projective tests using PAIS difference scores as the measure of adaptation provided evidence for hypotheses:

8) change in personal resources between time 1 and 2 was associated with appraisal at time 2 – hypothesis 8 was partially confirmed;

9) change in personal resources and change in family resources was associated with change in adaptation over time – hypothesis 9 was partially confirmed;

10) appraisal at time 2 did not mediate the effect of symptom distress, personal resources, family resources at time 1 or change in those variables between time 1 and 2 on change in adaptation over time – hypothesis 10 was not confirmed.

The series of regressions were repeated using POMS as the dependent variable and are described below.

## Psychological Adaptation

### *Model Verification- POMS Time 1*

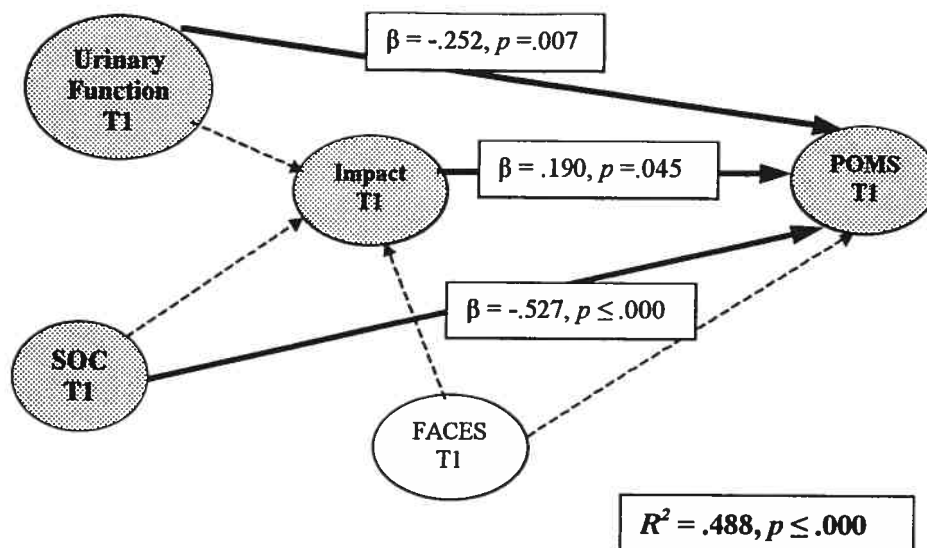
Equation 1 addressed hypothesis 1 and also examined Condition 1, which is required for testing mediation. In this equation Impact T1 was regressed on the independent variables Urinary Function T1, FACES T1, and SOC T1. The nature of the relationships between variables was in the expected direction, but the independent variables together did not have a significant effect on Impact T1 ( $R^2 = .085, p = .116$ ). Condition 1 required for mediation was not met, and equation 2 was therefore not interpreted. The contributions of all the variables in the model were then examined in Equation 3. Three variables had a direct effect on the dependent variable POMS T1 and together explained 48.8% of its variance at time 1. SOC T1 explained most of the variance ( $\beta = -.527, p \leq .000$ ), followed by Urinary Function T1 ( $\beta = -.252, p = .007$ ) and Impact T1 ( $\beta = .190, p = .045$ ) (see Table XI).

**Table XI. Model Verification- POMS T1**

	$R^2$	$p$		$\beta$	$p$
Equation 1	.085	.116	Urinary Function T1	.021	.865
			FACES T1	-.087	.493
			SOC T1	-.248	.050*
Equation 2	.455	.000***	Urinary Function T1	-.255	.008**
			FACES T1	-.040	.681
			SOC T1	-.575	.000**
Equation 3	.488	.000***	Urinary Function T1	-.252	.007**

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

The model that was retained to explain adaptation on POMS at time 1 is illustrated in Figure 6.



*Figure 6. Model Verification - POMS T1*

In summary, the data at time 1 using POMS as the measure of adaptation gave evidence for the following hypotheses:

- 1) symptom distress, personal and family resources did not predict appraisal – hypothesis 1 was not confirmed;
- 2) lower levels of symptom distress, higher levels of personal resources and more positive appraisal were associated with better adaptation – hypothesis 2 was partially confirmed;
- 3) appraisal did not mediate the relationship between the independent variables and adaptation – hypothesis 3 was not confirmed.

#### *Model Confirmation – POMS Time 2*

In the test of the stability of the model using POMS, the same procedure was followed using data from time 2. In equation 1 when Impact T2 was regressed on the independent variables, the  $R^2$  was .203,  $p = .002$  and condition 1 was met. Only the SOC T2 made a significant contribution to explaining Impact T2 ( $\beta = -.341$ ,  $p = .010$ ) while Urinary Function T2 and FACES T2 did not. In equation 2, regressing POMS T2 on the independent variables showed a significant contribution of the independent

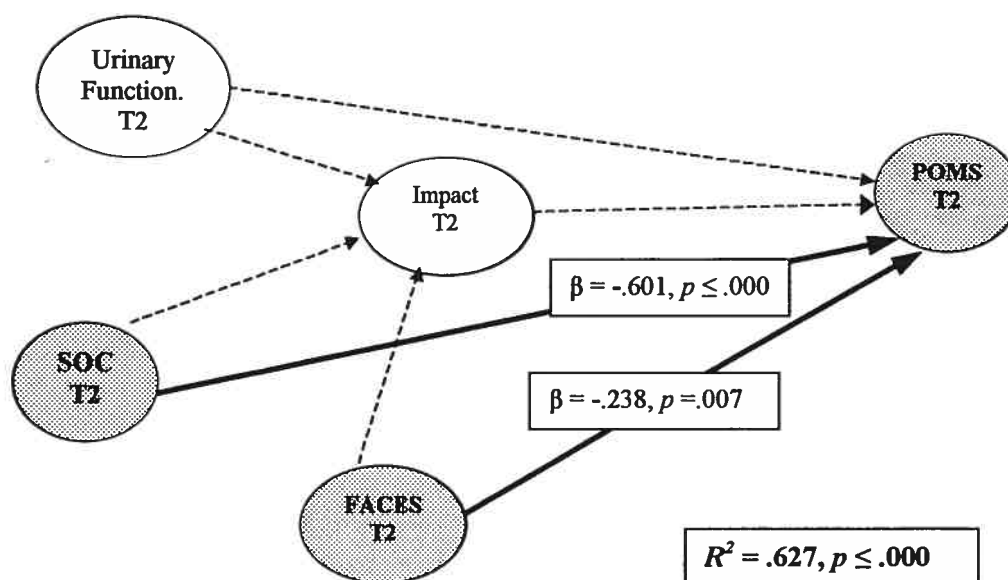
variables in explaining adjustment ( $R^2 = .626, p \leq .000$ ) and condition 2 required for mediation was met. In this equation, SOC T2 made a significant contribution ( $\beta = -.618, p < .000$ ) as did FACES T2 ( $\beta = -.240, p = .006$ ). In equation 3, regressing POMS T2 on the independent variables and Impact T2 resulted in a significant explanation of adjustment ( $R^2 = .627, p \leq .000$ ). SOC T2 accounted for most of the variance ( $\beta = -.601, p \leq .000$ ), followed by FACES T2 ( $\beta = -.238, p = .007$ ). The addition of Impact T2 to the equation did not make a significant contribution to the model and a mediating effect was not confirmed (see Table XII).

**Table XII. Model Confirmation - POMS T2**

	$R^2$	$p$		$\beta$	$P$
Equation 1	.203	.002**	Urinary Function T2	-.131	.271
			FACES T2	-.092	.460
			SOC T2	-.341	.010**
Equation 2	.626	.000***	Urinary Function T2	-.095	.242
			FACES T2	-.240	.006**
			SOC T2	-.618	.000***
Equation 3	.627	.000***	Urinary Function T2	-.090	.274
			FACES T2	-.238	.007**
			SOC T2	-.601	.000***
			Impact T2	-.044	.607

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

The retained model derived from equation 3 that explained adaptation on POMS at time 2 is illustrated in Figure 7.



**Figure 7. Model Confirmation – POMS T2**

In summary, the data at time 2 using POMS as the measure of adjustment provided evidence for the following hypotheses:

- 1) higher levels of personal resources were associated with more positive appraisal – hypothesis 1 was partially confirmed;
- 2) higher levels of personal and family resources were associated with better adjustment - hypothesis 2 was partially confirmed;
- 3) impact did not mediate the relationships between symptom distress, personal and family resources and adjustment – hypothesis 3 was not confirmed.
- 4) With POMS as the measure of adaptation, a comparison of the models from time 1 and 2 suggested some similarities and some differences. Personal resources (SOC) was a stable and strong predictor of adaptation in both models. Appraisal (Impact) did not act as a mediator in either model. At both time 1 and 2 other variables from the set of independent variables contributed to explaining adaptation, with symptom distress (Urinary Function) contributing at time 1, and personal resources

(FACES) contributing at time 2. Finally, appraisal had a direct effect on adaptation at time 1 but no significant effect at time 2. Hypothesis 4, related to the relevance of the model between time 1 and 2, was partially confirmed.

#### *Projective Model – POMS-T2*

The first of the projective models estimated the contribution of the time 1 independent variables and their difference scores to explaining POMS at time 2 (POMS T2). The first equation regressing Impact T2 on the independent variables at time 1 and on the difference scores of the same variables showed an  $R^2$  of .232,  $p = .010$ . Condition 1 for mediation was met. The SOC Difference score was the only variable from the set to make a significant contribution to explaining Impact T2 ( $\beta = -.316$ ,  $p = .054$ ). Equation 2 regressed POMS T2 on the independent variables at time 1 and on their difference scores, and showed an  $R^2$  of .635,  $p \leq .000$ . Condition 2 for mediation was met, with SOC T1 ( $\beta = -.537$ ,  $p \leq .000$ ), SOC Difference ( $\beta = -.493$ ,  $p \leq .000$ ), FACES T1 ( $\beta = -.236$ ,  $p = .017$ ) and FACES Difference ( $\beta = -.234$ ,  $p = .040$ ) accounting for the variance in POMS T2. Urinary Function T1 did not make a significant contribution. Equation 3 regressed POMS T2 on the independent variables, their difference scores and Impact T2 and accounted for 60.2% of the variance in POMS at time 2 ( $R^2 = .602$ ,  $p \leq .000$ ). SOC T1 ( $\beta = -.464$ ,  $p \leq .000$ ), followed by Soc Difference ( $\beta = -.455$ ,  $p \leq .000$ ), FACES T1 ( $\beta = -.241$ ,  $p = .019$ ) and FACES Difference ( $\beta = -.231$ ,  $p = .053$ ) accounted for the variance explained. The Urinary Function variables and Impact T2 did not make significant independent contributions and were not retained in the final model (see Table XIII).

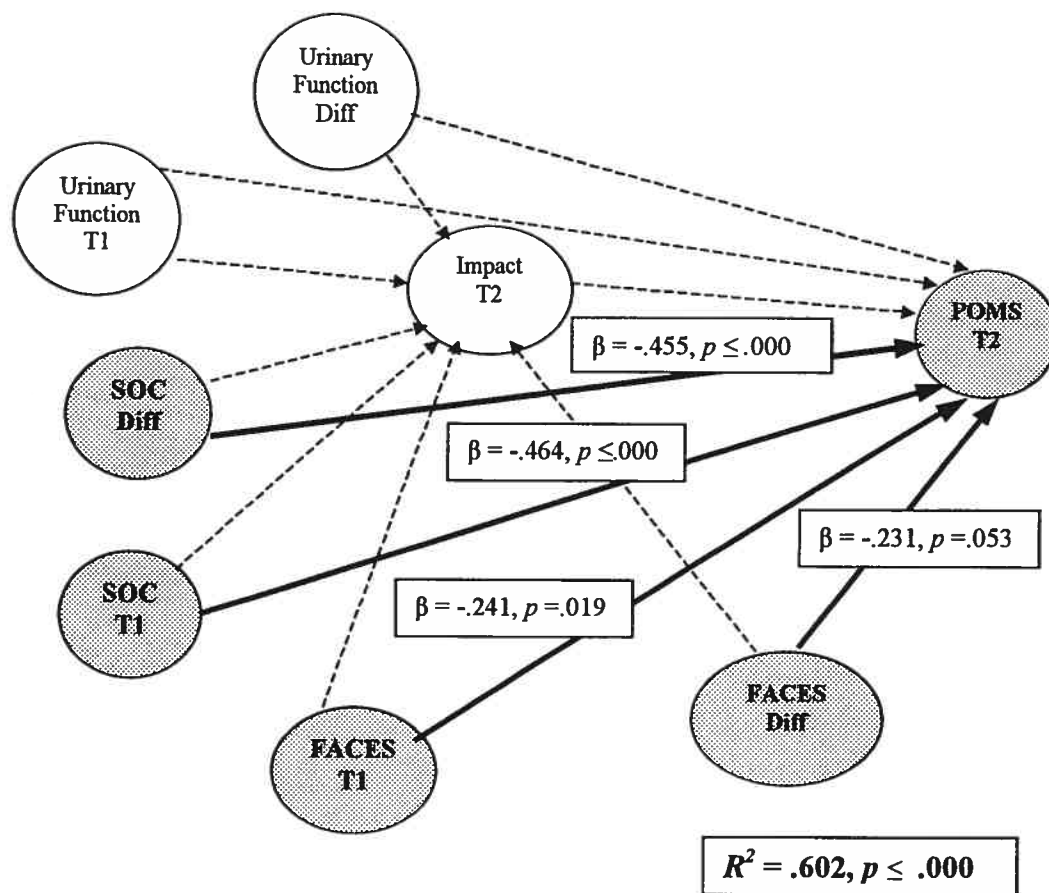
**Table XIII. Projective Model – POMS T2**

	$R^2$	$p$		$\beta$	$p$
Equation 1	.232	.010**	Urinary Function T1	-.179	.186
			FACES T1	-.061	.663
			SOC T1	-.244	.070
			Urinary Difference	-.127	.321
			FACES Difference	-.098	.544
			SOC Difference	-.316	.054*
Equation 2	.635	.000**	Urinary Function T1	-.118	.207
			FACES T1	-.236	.017*
			SOC T1	-.537	.000***
			Urinary Difference	-.096	.279
			FACES Difference	-.234	.040*
			SOC Difference	-.493	.000***
Equation 3	.602	.000**	Urinary Function T1	-.075	.488
			FACES T1	-.241	.019*
			SOC T1	-.464	.000***
			Urinary Difference	-.076	.410
			FACES Difference	-.231	.053*
			SOC Difference	-.455	.000***
			Impact T2	-.123	.178

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

The retained projective model derived from equation 3 and explaining adaptation on POMS at time 2 is illustrated in Figure 8





**Figure 8. Projective Model – POMS T2**

In summary, the data from the test of the first projective model on POMS at time 2 provided evidence for hypotheses:

5) only the change in personal resources was associated with more positive appraisal at time 2 - hypothesis 5 was partially confirmed:

6) higher levels of personal and family resources at time 1 as well as change in those variables between time 1 and 2 were associated with better adaptation at time 2 – hypothesis 6 was partially confirmed;

7) appraisal at time 2 did not mediate either the effects of symptom distress, personal and family resources nor the effects of change in those variables on adaptation – hypothesis 7 was not confirmed.

*Projective Model – POMS Difference*

The second projective model estimated the contribution of the time 1 independent variables and their difference scores between time 1 and 2 to explaining the change in POMS between Time 1 and 2 (POMS Difference). As in the first projective model, equation 1 regressed Impact T2 on the independent variables at time 1 and on their difference scores and showed an  $R^2$  of .232,  $p = .010$ . Condition 1 for mediation was met. The SOC Difference score was the only variable from the set to make a significant contribution to explaining Impact T2 ( $\beta = -.316, p = .054$ ).

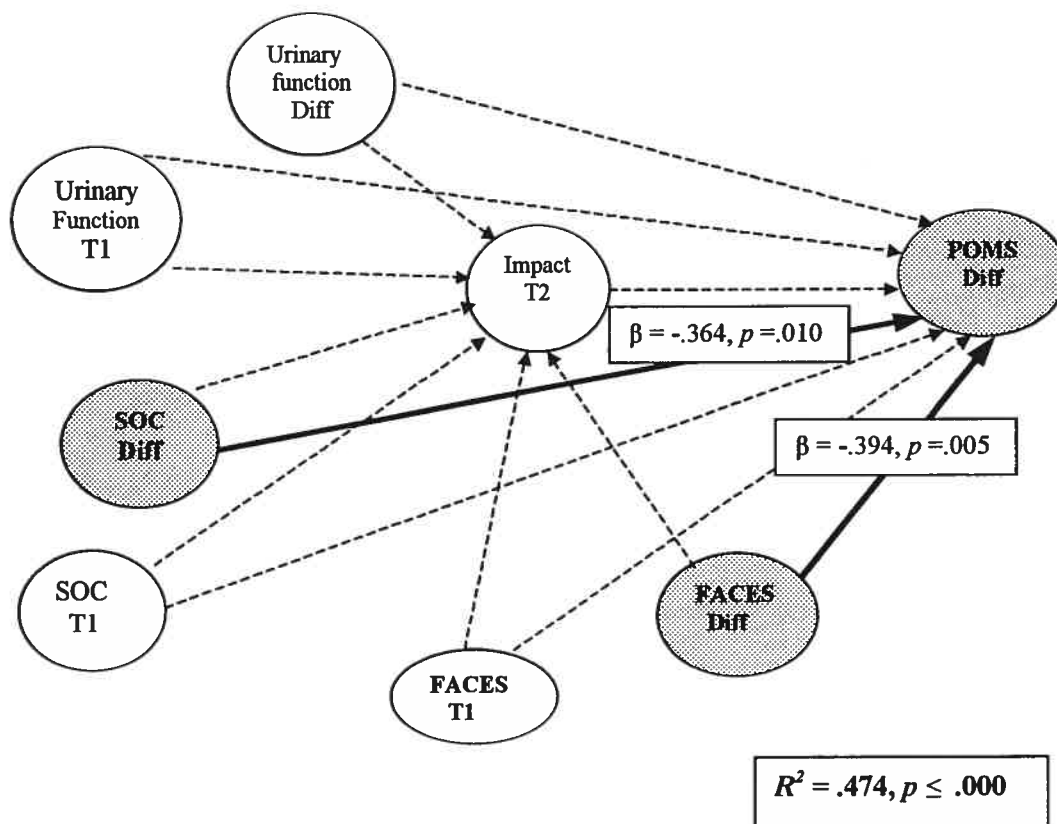
Equation 2 regressed POMS Difference on the time 1 independent variables and on their difference scores. The contribution of this set of variables accounted for a significant amount of the variance in the POMS Difference score ( $R^2 = .453, p < .000$ ). FACES T1 ( $\beta = -.285, p = .017$ ), FACES Difference ( $\beta = -.412, p = .003$ ) and SOC Difference ( $\beta = -.411, p = .003$ ) accounted for the variance explained. The contribution of the other variables was not significant. Condition 2 for mediation was met. Equation 3 added Impact T2 to the set of independent variables and again the total model explained a significant amount of the variance in the POMS Difference score ( $R^2 = .474, p \leq .000$ ). Impact 2 reduced the contributions of FACES T1 ( $\beta = -.282, p = .017$ ) FACES Difference ( $\beta = -.394, p = .005$ ) and SOC Difference ( $\beta = -.364, p = .010$ ), but did not make a significant unique contribution to POMS Difference. Therefore it was not retained in the model (see Table XIV).

**Table XIV. Projective Model – POMS Difference**

	$R^2$	$p$		$\beta$	$p$
Equation 1	.232	.010**	Urinary Function T1	-.179	.186
			FACES T1	-.061	.663
			SOC T1	-.244	.070
			Urinary Difference	-.127	.321
			FACES Difference	-.098	.544
			SOC Difference	-.316	.054*
Equation 2	.453	.000**	Urinary Function T1	-.146	.197
			FACES T1	-.285	.017*
			SOC T1	.039	.726
			Urinary Difference	-.020	.851
			FACES Difference	-.412	.003*
			SOC Difference	-.411	.003*
Equation 3	.474	.000**	Urinary Function T1	.174	.126
			FACES T1	-.282	.017
			SOC T1	.081	.474
			Urinary Difference	-.002	.988
			FACES Difference	-.394	.005**
			SOC Difference	-.364	.010*
			Impact T2	.163	.123

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

The retained model derived from equation 3 and explaining the POMS Difference score is illustrated in Figure 9.



**Figure 9. Projective Model - POMS Difference**

In summary, the data from the second set of projective tests for POMS as the measure of adaptation gave evidence for the following hypotheses:

8) personal resources at time 1 was associated with appraisal at time 2 – hypothesis 8 was partially confirmed;

9) changes in personal and family resources were associated with change in adaptation over time – hypothesis 9 was partially confirmed;

10) appraisal at time 2 did not mediate the effect of symptom distress, personal resources, family resources at time 1 nor the change in those variables between time 1 and 2 on change in adaptation over time – hypothesis 10 was not confirmed.

### **Overview of Results**

A summary of the contributions of the variables in explaining variance in PAIS and POMS at time 1 and 2 for the four sets of model test are summarized in Table XV. The table shows that the retained models explained between 30%-62% of variance across the 8 model tests and were moderate to strong predictors for PAIS, and consistently strong predictors for POMS. The variables retained in the models were the same for PAIS and POMS at time 1, but differed at time 2. All study variables contributed to explaining adaptation on at least one of the model tests. The strongest and most consistent predictor in the model was the SOC for both measures of adaptation, followed by FACES for POMS and Impact for PAIS. Urinary function as a measure of symptom distress also emerged as a predictor for both PAIS and POMS but only at time 1. The role of Impact as a mediator was limited to the model for PAIS at time 2.

Table XV. Predictors Across Model Tests

PAIS			POMS		
<b>Model verification (T1)</b> $R^2 = .301, p \leq .000^{***}$			<b>Model verification (T1)</b> $R^2 = .488, p \leq .000^{***}$		
	$\beta$	$p$		$\beta$	$p$
SOC T1	-.318	.000**	SOC T1	-.527	.000***
Impact T1	-.265	.017*	Urinary Function	-.252	.007**
Urinary Function	-.217	.046*	Impact T1	.190	.045*
<b>Model confirmation (T2)</b> $R^2 = .475, p \leq .000^{***}$			<b>Model confirmation (T2)</b> $R^2 = .627, p \leq .000^{***}$		
	$\beta$	$p$		$\beta$	$p$
SOC T2	-.324	.005**	SOC T2	-.601	.000***
Impact T2	-.316	.002**	FACES T2	-.238	.007**
<b>Projective model PAIS-T2</b> $R^2 = .506, p \leq .000^{***}$			<b>Projective model POMS-T2</b> $R^2 = .602, p \leq .000^{***}$		
	$\beta$	$p$		$\beta$	$p$
SOC Difference	-.303	.026*	SOC T1	-.464	.000***
Impact	-.286	.006**	SOC Difference	-.455	.000***
SOC T1	-.249	.026*	FACES T1	-.241	.019*
			FACES Difference	-.231	.053*
<b>Projective Model PAIS-Difference</b> $R^2 = .404, p \leq .000^{***}$			<b>Projective Model POMS-Difference</b> $R^2 = .474, p \leq .000^{***}$		
	$\beta$	$p$		$\beta$	$p$
FACES Difference	-.375	.011*	FACES Difference	-.394	.005**
SOC Difference	-.325	.029*	SOC Difference	-.364	.010*
			FACES T1	-.282	.017*

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

**Chapter 5**  
**Discussion**

This chapter places the study participants in the context of the population at large and compares them with wives in other prostate cancer studies and in other studies of family members dealing with cancer. The discussion then addresses the models that were retained in each of the model tests, considering first the results obtained on the global multidimensional measure of adaptation (PAIS), and then the results on the measure of psychological adaptation (POMS). The main themes that emerged across the model test are presented and their relevance for nursing practice is discussed. Methodological issues, theoretical implications, implications for the nursing discipline and suggestions for future research are also considered.

### **Study Participants**

The wives' scores on overall adaptation as well as on the dimension of psychological adaptation suggested that they were doing well at the time of diagnosis and also three months later. The high level of adaptation seen in the wives in this study has not been a consistent observation in spouses of cancer patients in the initial phase of illness, with some studies reporting lower levels of general adaptation and more psychological distress (Baider et al., 1998; Morse & Fife, 1998; Gray et al. 2000b). A significant proportion of the "bonadaptation" of the wives in this study - reflected by measures of psychological as well as overall functioning - was explained by the constructs in the theoretical model, and will be discussed here. However, it is helpful to begin with an examination of the sociodemographic characteristics of the sample that will help to situate this group of women within the larger population.

The wives in this study were women at the end of the middle adulthood years. Their mean age was the same as in Heyman & Rosner's study (1996), but is somewhat higher than the mean age of women in other prostate cancer studies that has hovered around 57 yrs (Butler et al., 2000; Gray et al., 2000a; Lavery & Clarke, 1999). The



mean age of spouses or caregivers reported in other cancer studies were also generally lower than the age of the women in this study (Carey et al. 1991b; Given et al., 1993; Morse & Fife, 1998; Northouse et al., 2000; Schumacher, Dodd, & Paul, 1993; Stetz, 1987). While some studies have suggested that age contributes to adaptation among caregivers (Blanchard et al. 1997; Ell et al., 1988; Stetz, 1987), this association is not strong and is not consistently observed. The absence of a relationship between age and adaptation in this study may also be related to the fact that the women were in good health and did not have major financial problems. However, it would be premature to draw a conclusion based on the data in this study that age is not a factor for all women who are dealing with prostate cancer. It may be that a relationship between age and adaptation would emerge in a cohort that includes a broader age range.

The women in this study have also been married for long periods of time, suggesting a relative stability in their relationships with their spouses. Their length of time married is similar to that reported in other prostate cancer studies (Butler et al., 2000; Lavery et al., 1999). With very few exceptions, they reported that their household income was adequate to meet their needs. Income has occasionally been reported as an issue in caregiver adaptation during cancer (Stetz, 1987), but was not associated with adaptation for this group of women. As with age, there was little variance in these variables, and it may be that in a cohort of wives who were married for shorter periods of time or had more substantial financial concerns, the length of time married and income could emerge as covariates of adaptation. Indeed, during the data collection visits, it was noted that wives who were in a second marriage and had been with their spouses for a relatively short period of time became very engaged in the discussions with the researchers. They expressed more anxiety about their partners and more concern about how best to help them, than did the wives who had been in longstanding relationships.

The group was evenly divided on type of treatment and language and no association was found between either of these variables and wives' adaptation in this study. The relationship between treatment type and wives' adaptation has not yet been

examined in prostate cancer. In fact, it has only recently been studied in men with this disease, with studies finding no differences in quality of life in men following radical prostatectomy for localized cancer and those who had surgery for benign prostatic hypertrophy (Fowler et al., 1995). Also, no differences were found between men with cancer who had been treated with surgery and those treated with radiation therapy (Yarbro & Ferrans, 1998). Language was entered as a possible covariate in consideration of the possibility that language reflected cultural differences that might account for differences in wives' adaptation. Socio-cultural differences are currently being studied as a possible contributory factor to adaptation by American researchers working with couples with prostate cancer (personal communication, B. Germino, 1996), but neither this study nor the findings published to date have confirmed such a relationship. Finally, according to both individual and family stress theories, an accumulation of life events could increase strain and compromise adaptation, but the number of stressful events reported by wives was not associated with their adaptation.

The women in the study had a strong sense of coherence; their scores on this personal resource were at the high end of the range of scores reported in other studies (Antonovsky, 1993). They saw the events in their environment as structured and explicable, the demands that come their way as worth addressing, and felt that in general, resources would be available to meet those demands. These were also women who perceived that they and their partners shared a set of values, and that there was a high level of emotional closeness in their marital relationship. They felt that the decisions made in their marital relationships were shared, and that there were flexible rules within the marriage regarding who does what. The level of family resources as reflected by these qualities in their marital relationship placed them at the upper end of scores for a "balanced" family, described by Olson (1993) as the most effective family type. As anticipated, their level of personal and family resources did not change and remained high, indicating that this was a strong and stable group of women.

At three months, the wives' problems related to their husbands' urinary function had increased significantly since the time of diagnosis. This increase was

expected, as the issues related to urinary symptoms associated with treatment were still active, particularly for those whose partners had undergone surgery. However, their appraisals of the threat of the prostate cancer had significantly decreased, despite the increase in symptoms. This may be explained by the amount of information that was relayed to them by their husbands following visits to the urologists, by the information they received directly when they accompanied their spouses, and also by their own information seeking activities with other individuals over the course of the three months. There were no other studies in the literature that have commented on an association decreasing threat appraisal and increase in symptom distress over time, but in this case of the women in this study, it suggests a sense of resilience that is consistent with the high level of personal resources that was observed in the group.

### **Patterns of Model Confirmation**

#### *Global Adaptation*

At the time of the diagnosis of prostate cancer, the wives' personal resource of sense of coherence, the symptoms related to urinary function and appraisal of threat were the major contributors to overall adaptation, explaining 30% of the variance in multiple dimensions of adaptation measured by the PAIS. While the appraisal of threat or loss in the illness situation was directly associated with wives' global adaptation, it did not attenuate the importance of the role that wives' personal resources and evaluations of urinary symptoms played in their adaptation. The absence of a relationship between family resources and wives adaptation at time 1 may have been due to the limited variance in the family resource variable among the wives in the study.

Three months later when the treatment plan was well under way, the predictors of global adaptation had changed. At this time women's sense of coherence and their appraisals of threat made an even greater contribution, together explaining 47.5% of variance in overall adaptation with appraisals of threat now attenuating the effect of sense of coherence on adaptation, as originally hypothesized. This meant that despite the decrease in the appraisal of threat observed in the group of wives at three months,

in those women who had higher levels of threat appraisal, the importance of the sense of coherence was reduced. The urinary symptoms had increased, but were no longer a factor in explaining how well the wives were adapting overall. The family resources of marital cohesion and adaptability again did not make the significant contributions that had been hypothesized. It would appear that much of the strength in the wives was coming from intrapersonal factors, and that these were more significant to their global adaptation than their husbands' symptoms or the qualities of their marital relationship.

The intent of the first projective test was to determine whether the absolute amount (either positive or negative) of change in wives' personal sense of coherence, in marital cohesion and flexibility, and in their appraisal of threat over the three month period would contribute to the explanation of variance in global adaptation at the end of the three months. As in the stability test of the model, sense of coherence and appraisals of threat again emerged as predictors, but change in SOC also made a significant contribution. In this projective test, the mediating effect of threat appraisal was again apparent, with threat appraisals mediating the effect of the sense of coherence measured at time 1 as well as the effect of the change in the SOC on global adaptation at three months.

The second projective test can be seen as a more stringent test, as it attempted to determine whether the independent variables at time 1, and the changes in those variables over the three months, would explain the change in global adaptation. The change in sense of coherence and the change in family resources were important predictors, explaining 40% of the variance in the change in global adaptation. This finding adds to the evidence provided by the three previous model tests, indicating that the sense of coherence construct is a particularly sensitive predictor of global adaptation. The finding that change in family resources emerged as a predictor of the change in global adaptation but not in the previous model tests, was also important. It suggests that the limited variance in this measure may have masked the contribution it makes to adaptation, and that this relationship only emerged when the change variables were introduced. Clearly, this relationship between family resources and

global adaptation has important implication for practice and needs further exploration. The role of this resource emerged more clearly in the model tests for psychological adaptation described below.

### *Psychological Adaptation*

The patterns that emerged in the model tests using psychological adaptation as the outcome measure showed similarities and differences with the tests using global adaptation. At the time of diagnosis, the same three variables (SOC, urinary symptoms and threat appraisal) explained the wives' psychological adaptation, but the proportion of variance explained (48.8%) was higher. As with the global measure at time 1, no mediating effect of appraisal was found between predictors and psychological adaptation.

At three months, the model did not remain stable. Sense of coherence continued to make a strong contribution, but urinary function problems and appraisals of threat were no longer significant predictors. Also, family resources, which had not been observed in the previous test, were now contributing to the equation. Together these two variables explained a large proportion of variance (62.7%) in psychological adaptation. In contrast to the model tests for global adaptation where threat appraisal acted as a mediator between independent variables and the time 2 data, no mediating effect of appraisal was observed in the tests for psychological adaptation.

In the first projective test, four variables reflecting the two constructs of personal and family resources were retained in a model that explained 60.2% of the variance in psychological adaptation at the three months period. That is, both the baseline measure of sense of coherence and of family resources, and the change in those variables were powerful predictors. In the second projective test, three of the four variables were also able to predict a significant proportion (47.4%) of the change in psychological adaptation, confirming the importance of the two predictor constructs. Both the projective tests confirmed the role of the construct of family resources in explaining psychological adaptation. While there was some evidence of

its importance to wives' global adaptation, the importance of this resource was much clearer when the focus was exclusively on the psychological dimension.

An overview of the model tests on the two measure of adaptation showed that:

- 1) The sense of coherence was a consistent and very strong predictor for adaptation for both measures and across all model tests.
- 2) The family cohesion and flexibility played a role in explaining both measures of adaptation, but only at three months.
- 3) The illness appraisal of threat mediated the effect of sense of coherence only when a global measure of adaptation was used. It never acted as a mediator for the psychological dimension of adaptation.
- 4) The same variables explained adaptation on each measure at the onset of the initial phase, but the contribution of the SOC continued over the three month, suggesting some stability in the model over time.

However the model explained consistently more of the variance in psychological adaptation than in global adaptation. The links between these findings and the existing literature are explored, and the relevance of this body of knowledge for clinical nursing practice are discussed below.

### **Relevance for Nursing Practice**

#### *The Sense of Coherence*

The strength of the contribution of the sense of coherence to adaptation was perhaps the most striking finding in the study. Women with a higher sense of coherence showed better overall adaptation as well as a better psychological outcome. The SOC also had indirect effects on global adaptation through appraisal, suggesting that wives with higher SOC and less threatening appraisals were making a better overall adaptation to the illness experience. These findings are consistent with recent studies of this resource in women. Nesbitt (2000) found that both SOC and illness appraisal had direct effects on quality of life and also mediated the effect of physical health limitations, reducing their impact on quality of life in older women with chronic illness. In addition, there was a strong relationship between SOC and illness appraisal such that the women viewed their chronic health problems more favourably when their sense of coherence was strong. Nyamathi's study of women with HIV (1993) also

showed direct as well as indirect effects of the SOC, through appraisal, on subsequent health outcomes. The importance of the sense of coherence has also been seen in studies of cancer patients. Tishelman, Taube & Sachs' study (1991) of possible explanatory variables in a mixed group of cancer patients found that the sense of coherence showed the strongest and most consistent relationship to the experience of symptom distress, with lower scores on the measure related to reports of increased distress. The strength of the contribution of the SOC to different outcomes in a variety of subjects suggests that further explorations are warranted.

From a clinical perspective, the findings suggest that an early identification of where women stand with respect to the three interrelated components of the sense of coherence can provide direction for interventions. Although the general literature in cancer provides support for the importance of these concepts during the cancer experience (Richer et al. 2000; Richer & Ezer, 2002), with the exception of the study by Strang and Strang (2001) few studies have linked them together within the construct of sense of coherence. Interventions can be directed towards building on an existing strong SOC, or finding ways to foster the elements of sense of coherence when it is low. Such interventions can be directed towards the three components of the sense of coherence – comprehensibility, manageability and meaningfulness. Providing women with information on the trajectory of the illness and treatment and on the impact it may have on family life and relationships will help them to feel that the cancer situation is structured, predictable and explicable. Assisting them to identify their own coping abilities and resources will help women to feel that they can manage the illness. Providing relevant and appropriate amounts of information at critical moments will also help them to feel that the situation is manageable. Helping women to believe that what they are able to do in the face of the threat of cancer has purpose and value is important in building the sense of meaningfulness. Women who would appear to be low on sense of coherence, might benefit from additional physical help and emotional support from other family members or from other support services early during the illness. These kinds of interventions can help women to mobilize their internal resources, and will help build and sustain them.

### *Family Resources*

The findings in this study indicated that family resources were important predictors of mood but only at time 2. This raises some important considerations about how resources come into play over the course of the illness experience. It may be that early on, at the time of diagnosis, the wives' experience of the illness is a more personal one, and that they call primarily upon their personal resources in the process of adaptation. As wives learn more about the course of the illness and once the treatment is underway, the cohesion, flexibility and communication within the marital relationship become more important. It may be that even when spouses have a perception of high levels of resources in the family, they are not able to mobilize those resources at the very early stages of the illness experience. It may also be that early on in the experience, other factors such as uncertainty may be related to the inability to mobilize resources. This may be the process that is being captured by the results at the two periods in the study, and may explain the emergence of the family resource variable only at three months. The literature provides some support for this idea, as a few studies have suggested that the contribution of family functioning variables to spouses' adaptation varies at different times during the illness experience. Hoskins (1995) reported that spouses of breast cancer patients were less satisfied with characteristics of the marital relationship in the 7-10 days after surgery, and were more satisfied at subsequent times in the first year. In Banthia's study (2003) of couples with prostate cancer, where the mean number of months since diagnosis was 5 months, direct effects of couples' dyadic functioning on wives' psychological distress were found. Northouse and her colleagues (2001) reported that marital satisfaction in spouses of breast cancer patients had direct effects on their global adaptation, as well as indirect effects through hopelessness, at 1 year following the diagnosis. Marital satisfaction played a similar role with spouses of colon cancer patients also at 1 year after diagnosis (Northouse, Darlene, Mood, 2000). Carey's study (1991a) found that caregivers who reported high levels of family hardiness, a family resource variable, were less likely to appraise the situation negatively, and that family hardiness had an indirect effect on mood through the mediating variable of appraisal. In contrast,



Baider's study (1998) did not show a relationship between cohesion and spouses' distress either at the time of diagnosis nor 2 years later.

In the current study, in addition to the quantitative data they provided, wives also spoke about family functioning. Consistently they described trying to be as helpful as they could, and "doing it his way". A number of women also volunteered that their own feelings and way of handling things were different from that of their partners. This allusion to differences between the wives' experiences in this study and that of their partners is consistent with the descriptive studies of couples' experiences with prostate cancer. Gray (2000) noted differences in the degree to which couples talked about feelings about the cancer, and found that women especially felt under pressure to stay on an even keel as a way of being supportive to their husbands, despite their own preferences for more open communication. Boehmer & Clarke (2001) found little spousal communication about the implications of prostate cancer on their lives, and little talk about emotions, fears and worries in couples being treated for metastatic cancer.

Generally, the results in this study and existing research suggest that the family functioning variables may not be a factor in the adaptation of spouses early in the experiences, but do become important when the treatments are under way. The pattern observed here need to be confirmed in other studies of women dealing with prostate cancer, and clearly, more systematic study of the role of family variables over the illness trajectory is needed. From a clinical perspective however, the assessment of family functioning is a critical point of departure for nursing practice. An exploration of the degree of closeness and sharing within the marital relationship, the flexibility of role assignment, and the usual patterns of communication between the couple, will help to determine the nature of subsequent nursing interventions. Wives who perceive their marital relationship to be less close and their roles more separate may benefit from the support of other family members or from the larger social network. They may also benefit from the opportunity to ask questions and talk about their own fears and concerns with health professionals if those feelings are not usually shared in the marital context. Wives who perceive their marital relationship to be very close and the

decisions shared, may also be reluctant to express their own anxiety particularly at the onset of the illness in order not to upset or discourage their spouses. Sensitive professional support and encouragement may be necessary at this early stage until the wives are ready to mobilize the strengths that exist within the marital relationship.

### *Situational Appraisal*

In this study, threat appraisals had clear and direct effects on global adaptation and on psychological state at the onset of illness. At three months, although threat appraisal had decreased for the groups as a whole, it still had a direct effect and also mediated the effect of personal resources on the global adjustment measure. The contribution of appraisal in this study is consistent with the findings reported in Carey's study (1991a) of patients receiving non-palliative chemotherapy in which negative appraisals contributed to explaining a large proportion of the variance in mood. With the exception of Oberst's (1989) description of associations between appraisal of stress and personal characteristics among cancer caregivers, no other study of appraisal among spouses or among caregivers was found. In addition, no longitudinal studies have been found that explored whether the contribution of appraisal remains consistent for spouse caregivers during the initial phase of illness. Given the central role that appraisal plays in both individual and family stress and adaptation theories, the absence of longitudinal studies is a problem that has been identified in the past (Lazarus, 1993) and remains a major concern. The problems related to the existence of multiple appraisals, the lack of conceptual clarity in the definition of the term, and the fact that appraisals could be expected to change within a phase as well as across psychosocial phases of illness, continue to create difficulties in the measurement of this construct.

From the perspective of the nursing framework that underlies the study, an understanding of appraisal of illness is particularly relevant to collaborative nursing practice and this requires an understanding of how each family member sees the experience. The importance of understanding individuals' perceptions of the illness experience is not a new idea for nursing (Germino, Fife & Funk, 1995; Johnson, 1995;

O'Connor & Wicker, 1995). The literature on interventions that address meaning is, however, more limited and tends to focus on existential meaning rather than on the more specific construct of situational meaning (see Richer et al. 2001), which was the focus of this study. The findings here suggest that because of possible associations between personal resources and appraisals of threat, the relationships between wives' perceptions of the world as manageable, meaningful and comprehensible and their perceptions of the threat that prostate cancer represents need to be explored. When the appraisal of threat is high, nurses need to explore women's core beliefs and previous experiences with cancer and engage them in the process of cognitive reframing of the illness event. This process of challenging, altering and modifying constraining beliefs has been described by Wright, Watson & Bell (1996) in the context of family nursing care. The findings in this study suggest that this is particularly important at the onset of the illness when threat levels are a significant feature of the illness experience.

#### *The Evaluation of Adaptation during the Initial Phase of Illness*

At the time of diagnosis it would seem that there was little difference in the measure selected for adaptation i.e. the same factors explained how well wives were managing across the variety of their social roles, as well as how they were doing on the psychological dimension alone. However, three months later the picture showed greater divergence, with those who perceived more cohesion and flexibility in their marital relationship doing better psychologically, and those who were perceiving the illness as a potential threat having more difficulty managing across their social roles. This suggests that careful assessment of all the dimensions of adaptation may be required to get a complete picture of the wives' experiences as the illness progresses. It may also be that different dimensions of adaptation may be more important at different phases of the illness. In this study, in order to capture different dimensions of the wives' experience, two separate dependent measures were used. This approach is consistent with other studies of cancer caregivers that have also used a global adjustment measure in conjunction with a measure of emotional distress, and found differences in the factors that were related to spouses' adaptation on each of the

measures (Morse et al., 1998; Northouse, Templin, & Mood, 2001; Northouse, Dorris, & Charron-Moore, 1995; Northouse et al., 2000; Peleg-Oren & Sherer, 2001).

The literature indicates that during the time of diagnosis and initiation of treatment for prostate cancer, wives' experiences are characterized by psychological stress, new information, and adjustment of roles. The critical nature of this period was also a central feature of the informal discussions that took place during the interviews with the wives in this study as they described their search for information about the disease, and the importance of the attitudes of health care providers. It was also captured in a recent study (Maliski, Heilemann, & McCorkle, 2002) in which couples with prostate cancer described their initial experiences as a frightening loss of control, with which they coped by putting themselves on a "crash course" which transformed their perception of this disease to a "good" cancer. From a clinical perspective, Rolland (1990) described this period as a highly emotional and vulnerable time for families and suggested that their "hypervigilant, anxious state makes families highly receptive to intended and unintended messages about how to navigate the uncertainties that confront them. What is actually said, unstated, or left unclear is critical. Who is included and excluded from these conversations influences how the family frames the experience at this time" (p.231).

In this study, much information was communicated to men at the beginning of the initial phase when decisions are made about treatment. Sometimes wives accompanied their husbands during the first doctor's visit, but this was not consistent. They rarely met with nurses before treatment was initiated. Their contacts with nurses were on surgical units in hospital, and were related to the immediate issues related to surgical intervention. After surgery and during the time of the radiation treatments, their only contacts were with urologists regarding complications of treatment. Over the course of the initial phase, little attention was given to wives' information needs, the instrumental help they might require, their need for emotional support, or to mobilizing existing resources within the family and network around them. Nursing leadership needs to be proactive in establishing a defined nursing role in preoperative

care, in urology and radiology clinics and during post-treatment followup care. Preoperative information and discussion sessions for wives would be invaluable in setting the stage for an informed transition to the “good” cancer that Maliski (2002) has described.

### **Methodological Considerations/Study Limitations**

A number of issues should be taken into consideration when interpreting the results of the study and considering the generalizability of the findings. First, it should be noted that while this inquiry was prospective, it remains a correlational design and causal inferences should not be drawn from the findings.

#### *Reduction of Study Variables*

During the preliminary analyses, the women’s scores on the study variables were examined for anticipated bivariate relationships among the complete set of study variables. Interestingly sexual function, which was included in the theoretical model as a potentially important predictor of adaptation, did not consistently emerge as a covariate of either global or psychological adaptation. A number of factors may have converged to explain why such a relationship did not appear. First, women in this study may have already experienced changes in the nature or importance of sexual expression that may be associated with increasing age. In Butler’s study (2000) of couples’ experiences after treatment for prostate cancer, a large proportion of the wives stated that the lack of intercourse was not a problem for them although some also recognized that it was for their husbands. Second, during the initial interviews, a number of wives volunteered that their partners had experienced an unexplained decrease in sexual desire during the prediagnostic period, and that sexual activities (specifically intercourse) had diminished or had ceased some months earlier. Others simply stated that sexual intercourse had ceased a long time earlier in their relationship, and that the absence of sexual activity did not constitute a problem for them or for their husbands. A final explanation for the absence of the expected association may be a measurement issue that resulted in missing data related to sexual function at time 1 and time 2. A number of wives who chose “do not know” to items on the sexual function scale said they could not rate their husbands’ level of sexual

feelings or performance because they did not discuss these issues, and they were not sexually active at that time. Therefore, the incomplete data may be from a subgroup of women for whom sexuality was in fact a significant concern but was not being measured.

The mastery subscale of the Stress Appraisal Rating Scale that reflected the ability to overcome or deal with the illness situation (secondary appraisal) also did not show a consistent significant correlation with adaptation in the preliminary analyses and was dropped from the hypotheses tests. The SARS has been used in women with breast cancer (Fillion et al. 1996), but its psychometric properties in other populations have not been described. For the mastery subscale, scores on five items reflecting coping, control and uncertainty are summed to reflect secondary appraisal or mastery. However, the factor analyses in Fillion's work and in this study suggested that this is not a unitary measure. A stronger measure of secondary appraisal may have more effectively captured the association between wives' feeling that they can handle the disease and their adaptation to prostate cancer. Despite the fact that the mastery scale was not retained in these analyses, the measurement of the concept of feeling able to manage an illness event remains important to understanding the experience of prostate cancer and to the empirical validation of family stress and adaptation theory.

In the theoretical model examined here, the concept of coping, which is also a central construct and a mediating variable in family stress and adaptation theory, was not considered. This decision was made because of the possible confounding of the variables, as coping is defined in part as the process of reappraisal. Attention needs to be given to this variable in subsequent studies, as there is some evidence that coping processes are associated with psychological outcomes during prostate cancer (Banthia et al. 2003). Care should be given to the operational measures that are selected, particularly if both appraisal and coping are to be measured in the study.

### *Sampling Issues*

*Non-response bias.* Less than half of the women who were eligible actually participated, and the estimated accrual rate may have resulted in a non-response bias. Most non-participants stated that they were not interested or indicated that they were too overwhelmed to participate, it was not possible to obtain a clear picture of those who did not participate. This was related to the difficulty in collecting information about the characteristics of eligible subjects because only the name of the patient and referring physician was available to urologists or radiotherapy personnel before a patient's first visit when information about the study was usually given. There was rarely any information related to sociodemographic characteristics recorded in the notes at that time.

*Attrition bias.* Attrition or loss of subjects is a common and potentially serious problem in longitudinal research, and can introduce bias by changing the composition of the sample that was initially drawn (Polit & Hungler, 1999). Eleven of the original group of 81 wives did not continue in the study representing an attrition rate of 13%. A comparison of those who stayed with those who withdrew suggested that the non-participants had poorer global adjustment scores than those who continued. This suggests that the sample may have been skewed towards better adaptation than would normally be evident in the population at large. This question could be addressed in subsequent analyses that include the data from the 81 wives who completed data collection at time 1. It may be that both the non-response and attrition bias were related to a loss of those subjects who were coping and adjusting less effectively than those who continued, with a skew of the sample in a more positive direction.

*Additional sample limitations.* The method of recruitment required that both husbands and wives agree to participate, and this may have skewed the original sample to reflect couples who were more cohesive and were generally functioning at higher levels. In addition, subjects in the study were almost exclusively speakers of French or English as a first language, and did not reflect the ethnic mix of the population at large. The relative homogeneity of the group may be related to language

difficulties or because of a reluctance of minority groups to participate in this kind of study.

### *Measures*

The PAIS, POMS, FACES-II, and the SOC measure are extensively used measures with good psychometric properties. The adapted wives version of the PSSE was the first time the measure was used with wives and the urinary and sexual function subscales showed good reliability in this study. However, a number of wives in this study left items unanswered because they felt they did have sufficient knowledge of their husbands' symptoms, particularly in relation to sexual function. This may be related to the timing of the data collection, when couples were choosing not to discuss sexual functioning as a way of avoiding a difficult situation. It may also be related to some women's reluctance to discuss sexual functioning altogether. These issues in the measurement of sexuality in relationships are not related to the actual structure of the PSSE, but will need to be considered in other studies where sexual functioning is a concern. However, there are other issues related to the PSSE as a measure of the wives' symptom distress. The scale deals predominantly with the amount of symptoms that are present, and to a lesser degree with the extent to which the symptoms were disturbing. An argument could be made that for wives, a measure that more closely reflects the distress created by symptoms would be more relevant as a predictor of wives' adaptation. An adapted version of this measure may provide a better measure of symptom distress in wives of men with prostate cancer.

The Stress Appraisal Rating Scale, which includes the Impact and Mastery scales, is a relatively new instrument. The Impact scale showed good reliability and validity in this study, but the alpha coefficients of the Mastery Scale were low and did not improve substantially with the successive deletion of items. Consequently it was left in its original form for the preliminary analyses, after which it was dropped from hypothesis testing. The weakness of this subscale may have also compromised the capacity of the scale to measure mastery (secondary appraisal) in this study. In subsequent studies, a different measure of secondary appraisal should be considered.



### *Generalizability*

The decision regarding the time of data collection at pretreatment and three months later was a purposeful attempt to remain within the initial phase of illness that has been considered to last at least three months. In addition, the findings may not be applicable to other types of cancer. For prostate cancer, considerable information is available and given at the time of diagnosis regarding the effectiveness of treatment options, and the likelihood that symptoms will eventually decrease or can be managed. For wives dealing with other cancers, the picture may remain more uncertain, and consequently their illness experiences during the initial phase may be different. Finally, the findings should not be generalized to male spouses, as they were based on female participants and therefore may be gender-specific.

### **Theoretical Implications**

No previous study of the factors associated with adaptation in wives of men with prostate cancer was available, and few studies had examined these factors in studies of spouses of persons with other types of cancer. The confirmation of the hypothesized variables in this study increased the understanding of wives' experiences, and indicates that family adaptation theory provides a verifiable basis for building nursing knowledge about spouses' adaptation to other types of cancer or life-threatening illness.

### *Considerations of Other Predictors in the Model*

While a large proportion of the variance in adaptation of the wives was accounted for in this study, a significant proportion of the variance remained unexplained. Two variables that constitute part of the family stress and adaptation theory were not included may have accounted for the remaining variance. These are the concepts of social support and coping.

Family stress theory differentiates between the support provided by family and by the larger community system. However, studies of social support combine the support provided by the spouse and other family members with that provided by health

professionals and others at the community level, and a distinction should be made between these sources of support. An association between social support and adaptation has been observed in studies of patients with cancer, but social support has received far less attention in the studies of spouses or other caregivers. Schumacher study of caregivers (1993) found that social support mediated the relation between patients' functional status and caregivers' depression. Morse & Fife (1998) found that support from all sources was significantly correlated with the adjustment of partners, while their multivariate analyses showed family support to be the most significant source of support. In a recent study that compared social support in spouses of prostate cancer and breast cancer patients (Ptacek et al., 1997), the authors suggested that gender, age, as well as perceived and received support were factors that should also be considered when modeling the contribution of social support to adaptation in caregivers.

The relationship of coping strategies to adjustment has received some attention in the literature on caregivers of cancer patients. In Schumacher's study (1993), perceived efficacy and perceived adequacy of coping strategies contributed to explaining caregivers' depression. A recent study (Ben-Zur, 2001) of the relationships between coping strategies and adjustment in breast cancer patients and their spouses suggested that the spouses' perceptions of their wives' emotion-focused coping were associated with their own adjustment, while for the patients, their own emotion-focused coping was more influential to their adjustment than their perceptions of their husbands' coping. In Banthia's study (2003) associations were found between the coping styles of avoidance, intrusiveness and hyperarousal and wives' psychological distress, but attempts to model the relationships between coping styles, dyadic adjustment and psychological distress of spouses did not confirm the mediating or moderating models that were proposed. The contribution of coping to adaptation warrants further exploration in subsequent studies of wives dealing with prostate cancer.

### *General Theoretical Considerations*

The sense of coherence was originally conceived as a construct that becomes stable by early adulthood. However, questions related to the stability of the SOC, the critical periods and the circumstances during which it could be influenced, and the amount of change required for it to have a meaningful effect on adaptation are important not only from a theoretical perspective, but also to clinical practice. These questions have been raised by in the empirical work of Post-White (1994) and by Antonovsky himself (1985) who said “ My original commitment was. . . to seeing the SOC as enduring. . . I gave little attention to the possibility of minor modifications, in both directions – changes that although undramatic, make considerable differences in the health of people. . . slight changes that lead to a bit less (or a bit more) suffering. For such changes, people bless (and curse)” (p.124). The findings of this study provided strong evidence that change in the sense of coherence is associated with change in adaptation. These findings suggest a need to shift the thinking about the stability of the construct, and to examine the critical moments in adult life in which it may be possible to build the sense of coherence.

The study also provides possible approaches to measuring other constructs in family adaptation theory. While this study focused on situational appraisal, it also may be helpful to the explication and measurement of family schema (third level of appraisal). Family schema are described as the family’s shared beliefs about the world (McCubbin, Thompson, Thompson, & McCubbin, 1993; Thompson & Janigian, 1998), but have received little attention in empirical work. In this study, the sense of coherence, an individual worldview, may be seen as a precursor or component of a family worldview. It can be argued that the extent to which there is similarity between individual family members’ levels of sense of coherence can be considered a measure of a family schema in which the family members share the view that the world is a meaningful and coherent place – a family sense of coherence (Antonovsky & Sourani, 1988; Patterson & Garwick, 1994 ). While there are some pitfalls in using individual data to measure constructs that exist at the family system level, there is value in creating this kind of relational family data (Ransom, 1985). This is an important direction for conceptual rethinking as well as for methodological and empirical study.

Finally, family stress and adaptation theory is primarily concerned with understanding the “bonadaptation” or “maladaptation” of the individual or of the family system to external circumstances. The general theory does not address the question of whether certain predictors are more salient than others during illness events, and whether the factors that influence adaptation may change as the illness event unfolds. The findings in this study suggest that some factors do indeed change over the course of an illness. Further theory-driven longitudinal studies will be needed to address these questions.

### **Implications for the Nursing Discipline**

Earlier in this discussion, the clinical relevance of the principal themes that emerged from the model tests were discussed and translated into nursing interventions that were consistent with the McGill Model of Nursing. However some general observations need to be made about the fit between the global nursing perspective and the middle range theory that was selected for this particular study.

Knowledge building for nursing within a model that is a broad philosophical framework must call upon a number of middle range theories. The selection of family adaptation theory proved to be a good fit with the McGill Model. The constructs of personal and family resources fit well with the importance given in the Model to working with the resources and potential of individuals and families. The findings related to the personal resource of sense of coherence and to the family resources of cohesion, adaptability and communication, provided empirical support for the importance the Model places on working with the strengths and potential of individuals and families. The finding that threat appraisals change and are more important at different periods during illness is relevant to the concept of collaborative practice, which calls for interventions that are responsive to the uniqueness of individuals and to changing circumstances. While this study focused on the spouses of persons with cancer, the same theoretical model can be examined in patients or other family members. The findings would help nurses to decide when to apply the family

perspective in their work with individual family members, and when to work with the family as a unit. For clinicians and researchers working within the framework of the McGill Model, knowledge that informs family nursing practice is critical.

Finally, the relevance of family stress and adaptation theory, and the links that have been described between the findings of this study and the McGill framework are equally applicable to other nursing models, all of which are concerned with promoting the health of individuals and groups. The findings of this study will be helpful to all nurses working with families in the initial psychosocial phase of prostate cancer and may provide insight into the experiences of those facing other types of serious illness. It will provide nurses involved in research with directions for continuing investigation.

### **Suggestions for Future Research**

The findings suggest a number of avenues for further research. First, the remarkable absence of quantitative research related to psychosocial adaptation in prostate cancer needs to be addressed. The literature is virtually silent on the experiences of the wives, and even in the few available studies of men's quality of life, the focus has been almost exclusively on the extent of their symptom experiences. Given that family stress and adaptation theory provides a comprehensive set of factors and postulates a well-elaborated set of relationships between them, a "next step" study would be to examine the same set of predictors in the husbands of the women in this study to see whether the predictors are the same or different. A further step would be to pursue the family systems perspective and examine the contributions that husbands and wives variables make to their partners adaptation.

This study was concerned with the nature of adaptation during the initial psychosocial phase of illness, a labile period of crisis related to the diagnosis and the initiation of treatment. Further model-testing studies are required to expand the understanding of the trajectory of illness for wives into the chronic and late stage of illness. Such studies would also be important for cancer care in general, as few family studies are available for these psychosocial phases. In further model tests derived from family adaptation theory, researchers could examine the contribution of community

sources of support, and the mediating role that coping may play in adaptation. Given the importance of the sense of coherence in this study, particular attention should be given in subsequent research to re-examining the mechanisms through which the SOC affects adaptation and considering whether it may have a mediating function between other predictors and adaptation.

This study was constrained by certain methodological issues that should be pursued as independent studies or taken into consideration in the planning of continuing research with this population. In this study, the mastery scale that was used to reflect secondary appraisal had low reliability. Additional work on this measure would be very useful as it has the advantage over other appraisal measures of being short and easily understood. This work would be particularly relevant to other research based on both individual and family stress and adaptation theories. The issues related to the assessment of sexuality and sexual functioning during cancer (Dobkin & Bradley, 1991) and with advancing age (Kingsberg, 2000) have been described in the literature, but much work remains to be done in this area. The measure used here addressed primarily the limitations related to sexual performance. Further work on the development of measures that capture the importance of sexuality would be particularly useful to studies of adaptation of spouses who are dealing with changes in sexuality in their partners.

From the perspective of the development of family nursing knowledge, the same variables should be examined in male spouses of breast cancer patients to examine the role of gender as an issue in spouses' adaptation to cancer. This would then provide an interesting basis for comparisons between breast and prostate cancer studies.

The findings from this study should also be followed up with evaluative studies of nursing interventions that address the comprehensibility, manageability and meaningfulness dimensions of the sense of coherence. Interventions that might augment the sense of unity or cohesion within the couple and increase their

willingness to try out different strategies should also be examined in nursing research. Nursing interventions such as cognitive reframing that target wives' negative appraisals of the situation should also be tried and evaluated.

From a knowledge building perspective, the study of these models of adaptation should be extended to other types of serious illness. It would then be possible to look across studies and draw conclusions that are relevant across situations. As the studies accumulate, as constructs are repeatedly examined, and the same measures are used, the data will be available for the meta-analyses that consolidate knowledge within the nursing discipline.

**Conclusion**



The last 15 years has seen a growing body of research on the impact of cancer on family members. Much of the work has been focused on comparisons of patients' and husbands' perceptions and experiences during breast cancer. Only recently have qualitative studies begun to address the experiences of couples during prostate cancer, but no work had yet addressed the factors that contribute to wives' adaptation to this illness.

This model testing study has broken new ground in the understanding of how family members adapt to prostate cancer. It has advanced nursing knowledge of the predictors of adaptation in women at the time of the diagnosis and treatment of prostate cancer in their spouses. The specific findings provided empirical evidence that supported the theoretical premises of the middle range theory on which the study was based. In addition, it offered exciting avenues for nurses concerned with assisting families and mobilizing resources in the face of the crisis of illness. Overall, the study reflects a synchrony that exists between the nursing perspective and the middle range theory on which the study was based.

The study also provided new data in areas of research that have not been well studied in the past. It is one of few studies available that provides information about factors affecting wives' adaptation to prostate cancer. The inclusion of variables that measured strengths is a shift in orientation from the traditional problem-centred perspective that is important for both nursing practice and research. The review of the research and the study findings related to the role of situational appraisal indicated that more work needs to be done in this area. Finally, the methodological issues identified here highlight a number of issues in family research in cancer that researchers must address in the future.

Clearly, the challenges to developing theory based nursing knowledge in this area are many, but the needs and the possibilities for research in this area are equally great. These include: model testing studies to examine the complex process of adaptation during subsequent psychosocial phases of illness, comparative models tests with husbands, examination of reciprocal influences between partners, and meta analyses that cut across cancer types, and nursing intervention studies that translate the study findings into practice. These are rich opportunities for building nursing knowledge and shaping nursing practice.

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**Appendix 1**  
**Measures of Study Variables**

NAME \_\_\_\_\_ DATE \_\_\_\_\_

SEX: Male (M) Female (F)

IDENTIFICATION

0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9
0	1	2	3	4	5	6	7	8	9

Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in ONE circle under the answer to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY.

The numbers refer to these phrases.

- 0 = Not at all
- 1 = A little
- 2 = Moderately
- 3 = Quite a bit
- 4 = Extremely

- 0 NOT AT ALL
- 1 A LITTLE
- 2 MODERATELY
- 3 QUITE A BIT
- 4 EXTREMELY

- 0 NOT AT ALL
- 1 A LITTLE
- 2 MODERATELY
- 3 QUITE A BIT
- 4 EXTREMELY

Col (C)      O.P. (O)	21. Hopeless . . . . .	0 1 2 3 4	45. Desperate . . . . .	0 1 2 3 4
	22. Relaxed . . . . .	0 1 2 3 4	46. Sluggish . . . . .	0 1 2 3 4
	23. Unworthy . . . . .	0 1 2 3 4	47. Rebellious . . . . .	0 1 2 3 4
	24. Spiteful . . . . .	0 1 2 3 4	48. Helpless . . . . .	0 1 2 3 4
1. Friendly . . . . .	25. Sympathetic . . . . .	0 1 2 3 4	49. Weary . . . . .	0 1 2 3 4
2. Tense . . . . .	26. Uneasy . . . . .	0 1 2 3 4	50. Bewildered . . . . .	0 1 2 3 4
3. Angry . . . . .	27. Restless . . . . .	0 1 2 3 4	51. Alert . . . . .	0 1 2 3 4
4. Worn out . . . . .	28. Unable to concentrate	0 1 2 3 4	52. Deceived . . . . .	0 1 2 3 4
5. Unhappy . . . . .	29. Fatigued . . . . .	0 1 2 3 4	53. Furious . . . . .	0 1 2 3 4
6. Clear-headed . . . . .	30. Helpful . . . . .	0 1 2 3 4	54. Efficient . . . . .	0 1 2 3 4
7. Lively . . . . .	31. Annoyed . . . . .	0 1 2 3 4	55. Trusting . . . . .	0 1 2 3 4
8. Confused . . . . .	32. Discouraged . . . . .	0 1 2 3 4	56. Full of pep . . . . .	0 1 2 3 4
9. Sorry for things done .	33. Resentful . . . . .	0 1 2 3 4	57. Bad-tempered . . . . .	0 1 2 3 4
10. Shaky . . . . .	34. Nervous . . . . .	0 1 2 3 4	58. Worthless . . . . .	0 1 2 3 4
11. Listless . . . . .	35. Lonely . . . . .	0 1 2 3 4	59. Forgetful . . . . .	0 1 2 3 4
12. Peeved . . . . .	36. Miserable . . . . .	0 1 2 3 4	60. Carefree . . . . .	0 1 2 3 4
13. Considerate . . . . .	37. Muddled . . . . .	0 1 2 3 4	61. Terrified . . . . .	0 1 2 3 4
14. Sad . . . . .	38. Cheerful . . . . .	0 1 2 3 4	62. Guilty . . . . .	0 1 2 3 4
15. Active . . . . .	39. Bitter . . . . .	0 1 2 3 4	63. Vigorous . . . . .	0 1 2 3 4
16. On edge . . . . .	40. Exhausted . . . . .	0 1 2 3 4	64. Uncertain about things .	0 1 2 3 4
17. Grouchy . . . . .	41. Anxious . . . . .	0 1 2 3 4	65. Bushed . . . . .	0 1 2 3 4
18. Blue . . . . .	42. Ready to fight . . . . .	0 1 2 3 4		
19. Energetic . . . . .	43. Good natured . . . . .	0 1 2 3 4		
20. Panicky . . . . .	44. Gloomy . . . . .	0 1 2 3 4		

MAKE SURE YOU HAVE ANSWERED EVERY ITEM.





**Psychosocial Adjustment to Illness Scale  
PAIS**

**Spouse Version**

Copyright 1978, 1983 by Leonard Derogatis, Ph.D.

1. Which of the following statements best describes your usual attitude about taking care of your health?

- a) I am very concerned and pay close attention to my personal health.
- b) Most of the time I pay attention to my health care needs.
- c) Usually, I try to take care of health matters but sometimes I just don't get around to it.
- d) Health care is something that I just don't worry too much about.

2. Your spouse's illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.

- a) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my spouse's illness.
- b) I try to do all the things I am supposed to do to take care of my spouse, but lots of times I forget or I am too tired or busy.
- c) I do a pretty good job taking care of my spouse's present illness.
- d) I pay close attention to all the needs of my spouse's present illness and do everything I can to take care of him.

3. In general, how do you feel about the quality of medical care available today and the doctors who provide it?

- a) Medical care has never been better, and the doctors who give it are doing an excellent job.
- b) The quality of medical care available is very good, but there are some areas that could stand improvement.
- c) Medical care and doctors are just not of the same quality they once were.
- d) I don't have much faith in doctors and medical care today.

4. During your spouse's present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?
- a) I am very unhappy with the treatment he has received and don't think the staff has done all they could have for my spouse.
  - b) I have not been impressed with the treatment he has received, but I think it is probably the best they can do.
  - c) The treatment has been pretty good on the whole, although there have been a few problems.
  - d) The treatment and the staff have been excellent.
5. When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.
- a) I am sure that my spouse is going to overcome the illness and its problems quickly and get back to being himself.
  - b) My spouse's illness has caused some problems for me, but I feel he will overcome them fairly soon, and get back to the way he was before.
  - c) My spouse's illness has really been a great strain, both physically and mentally, but I am trying very hard to overcome it, and feel sure that my spouse will be back to his old self one of these days.
  - d) My spouse feels worn out and very weak from the illness, and there are times when I don't know if he is really ever going to be able to overcome it.
6. Being ill can be a confusing experience, and some patients and the people close to them feel that they do not receive enough information and detail from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.
- a) The doctor and the medical staff have told me very little about my spouse's illness even though I have asked more than once.
  - b) I do have some information about spouse's illness but I feel I would like to know more.
  - c) I have a pretty fair understanding about my spouse's illness and feel that if I want to know more I can always get the information.
  - d) I have been given a very complete picture of my spouse's illness, and the doctor and the medical staff have given me all the details I wish to have.

7. In an illness such as your spouse's , people have different ideas about the treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your spouse's treatment.

- a) I believe the doctors and medical staff are quite able to direct my spouse's treatment and feel it is the best treatment he could receive.
- b) I have trust in the doctor's direction of my spouse's treatment; however, sometimes I have doubts about it.
- c) I don't like certain parts of the treatment which are very unpleasant, but the doctors say he should go through it anyway.
- d) In many ways I think the treatment is worse than the illness, and I am not sure it is worth going through it.

8. In an illness such as your spouse's, patients and the people close to them are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your spouse's treatment.

- a) I have been told almost nothing about my spouse's treatment and feel left out about it.
- b) I have some information about my spouse's treatment, but not as much as I would like to have.
- c) My information concerning treatment is pretty complete, but there are one or two things I still want to know.
- d) I feel my information concerning treatment is very complete and up-to-date.

9. Has your spouse's illness interfered with your ability to do your job?

- a) No problems with my job.
- b) Some problems, but only minor ones.
- c) Some serious problems.
- d) Spouse's illness has totally prevented me from doing my job.

10. How well do you physically perform your job now?

- a) Poorly.
- b) Not too well.
- c) Adequately.
- d) Very well.

11. During the past 30 days, have you lost any time at work due to your spouse's illness?
- a) 3 days or less.
  - b) 1 week.
  - c) 2 weeks.
  - d) More than 2 weeks.
12. Is your job as important to you now as it was before your spouse's illness?
- a) Little or no importance to me now.
  - b) A lot less important.
  - c) Slightly less important.
  - d) Equal or greater importance than before.
13. Have you had to change your goals concerning your job as a result of your spouse's illness?
- a) My goals are unchanged.
  - b) There has been a slight change in my goals.
  - c) My goals have changed quite a bit.
  - d) I have changed my goals completely.
14. Have you noticed any increase in problems with your co-workers since your spouse's illness?
- a) A great increase in problems.
  - b) A moderate increase in problems.
  - c) A slight increase in problems.
  - d) None.
15. How would you describe your relationship with your husband since his illness?
- a) Good.
  - b) Fair.
  - c) Poor.
  - d) Very poor.
16. How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?
- a) Very poor.
  - b) Poor.
  - c) Fair.
  - d) Good.

17. How much has your spouse's illness interfered with your work and duties around the house?
- a) Not at all.
  - b) Slight problems, easily overcome.
  - c) Moderate problems, not all of which can be overcome.
  - d) Severe difficulties with household duties.
18. In those areas where your spouse's illness has caused problems with your household work, how has the family shifted duties to help you out?
- a) The family has not been able to help out at all.
  - b) The family has tried to help but many things are left undone.
  - c) The family has done well except for a few minor things.
  - d) No problem.
19. Has your spouse's illness resulted in a decrease in communication between you and members of your family?
- a) No decrease in communication.
  - b) A slight decrease in communication.
  - c) Communication has decreased, and I feel somewhat withdrawn from them.
  - d) Communication has decreased a lot, and I feel very alone.
20. Some people with a spouse who is ill like yours feel they need help from other people (friends, neighbours, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?
- a) I really need help but seldom is anyone around to help.
  - b) I get some help, but I don't count on it all the time.
  - c) I don't get all the help I need all of the time, but most of the time help is there when I need it.
  - d) I don't feel I need such help, or the help I need is available from my family or friends.
21. Have you experienced any physical illness since your spouse's illness was diagnosed?
- a) No physical disability.
  - b) A slight physical disability.
  - c) A moderate physical disability.
  - d) A severe physical disability.

22. An illness such as your spouse's can sometimes cause a drain on the family's finances; are you having any difficulties meeting the financial demands of your spouse's illness?
- a) Severe financial hardship.
  - b) Moderate financial problems.
  - c) A slight financial drain.
  - d) No money problems.
23. Sometimes having an illness can cause problems in a relationship. Has your spouse's illness led to any problems between the two of you?
- a) There has been no change in our relationship.
  - b) We are a little less close since his illness.
  - c) We are definitely less close since the illness.
  - d) We have had serious problems or a break in our relationship since my spouse's illness.
24. Sometimes when family members or close friends are ill, people report a loss of interest in sexual activities. Have you experienced less sexual interest since your spouse's illness?
- a) Absolutely no sexual interest since illness.
  - b) A marked loss of sexual interest.
  - c) A slight loss of sexual interest.
  - d) No loss of sexual interest.
25. Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?
- a) No decrease in sexual activities.
  - b) Slight decrease in sexual activities.
  - c) Marked decrease in sexual activities.
  - d) Sexual activities have stopped.
26. Has there been any change in the pleasure or satisfaction you normally experience from sex?
- a) Sexual pleasure and satisfaction have stopped.
  - b) A marked loss of sexual pleasure or satisfaction.
  - c) A slight loss of sexual pleasure or satisfaction.
  - d) No change in sexual satisfaction.

27. Sometimes an illness will cause interference in a person's ability to perform sexual activities even though the person is still interested in sex. Has this happened to you, and if so, to what degree?
- a) No change in my ability to have sex.
  - b) Slight problems with my sexual performance.
  - c) Constant sexual performance problems.
  - d) Totally unable to perform sexually.
28. Sometimes an illness will interfere with a couple's normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?
- a) Constant arguments.
  - b) Frequent arguments.
  - c) Some arguments.
  - d) No arguments.
29. Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your spouse's illness?
- a) Contact is the same or greater since illness.
  - b) Contact is slightly less.
  - c) Contact is markedly less.
  - d) No contact since illness.
30. Have you remained as interested in getting together with these members of your family since your spouse's illness?
- a) Little or no interest in getting together with them.
  - b) Interest is a lot less than before.
  - c) Interest is slightly less.
  - d) Interest is the same or greater since illness.
31. Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
- a) I need no help, or they give me all the help I need.
  - b) Their help is enough, except for some minor things.
  - c) They give me some help but not enough.
  - d) They give me little or no help even though I need a great deal.



32. Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your spouse's illness reduced such socializing?
- a) Socializing with them has been pretty much eliminated.
  - b) Socializing with them has been reduced significantly.
  - c) Socializing with them has been reduced somewhat.
  - d) Little or no socializing, or slight or no effect of illness.
33. In general, how have you been getting along with these members of your family recently?
- a) Good.
  - b) Fair.
  - c) Poor.
  - d) Very poor.
34. Are you still as interested in your leisure time activities and hobbies as you were prior to your spouse's illness?
- a) Same level of interest as previously.
  - b) Slightly less interest than before.
  - c) Significantly less interest than before.
  - d) Little or no interest remaining.
35. How about actual participation? Are you still actively involved in doing these activities?
- a) Little or no participation at present.
  - b) Participation reduced significantly.
  - c) Participation reduced slightly.
  - d) Participation remains unchanged.
36. Are you as interested in leisure time activities with your family (i.e., playing cards and games, taking trips, going swimming, etc.) as you were prior to your spouse's illness?
- a) Same level of interest as previously.
  - b) Slightly less interest than before.
  - c) Significantly less interest than before.
  - d) Little or no interest remaining.
37. Do you still participate in those activities to the same degree you once did?
- a) Little or no participation at present.
  - b) Participation reduced significantly.
  - c) Participation reduced slightly.
  - d) Participation remains unchanged.

38. Have you maintained your interest in social activities since your spouse's illness (e.g., social clubs, church groups, going to the movies, etc.)?
- a) Same level of interest as previously.
  - b) Slightly less interest than before.
  - c) Significantly less interest than before.
  - d) Little or no interest remaining.
39. How about participation? Do you still go out with your friends and do those things?
- a) Little or no participation present.
  - b) Participation reduced significantly.
  - c) Participation reduced slightly.
  - d) Participation remains unchanged.
40. Recently, have you felt afraid, tense, nervous, or anxious?
- a) Not at all.
  - b) A little bit.
  - c) Quite a bit.
  - d) Extremely.
41. Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?
- a) Extremely.
  - b) Quite a bit.
  - c) A little bit.
  - d) Not at all.
42. Recently, have you felt angry, irritable, or had difficulty controlling your temper?
- a) Not at all.
  - b) A little bit.
  - c) Quite a bit.
  - d) Extremely.
43. Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?
- a) Extremely.
  - b) Quite a bit.
  - c) A little bit.
  - d) Not at all.

44. Recently, have you worried much about your spouse's illness or other matters?

- a) Not at all.
- b) A little bit.
- c) Quite a bit.
- d) Extremely.

45. Recently, have you been feeling down on yourself or less valuable as a person?

- a) Extremely.
- b) Quite a bit.
- c) A little bit.
- d) Not at all.

46. Recently, have you been concerned that your spouse's illness has caused changes in his appearance that make him less attractive?

- a) Not at all.
- b) A little bit.
- c) Quite a bit.
- d) Extremely.

## PSSE - Wives

The following questions deal with your knowledge of your husband's urinary function, his sexual feelings and performance. The questions also deal with how important these issues are for you. These questions are quite personal, but your answers are invaluable in helping us to understand the issues you face every day. Please answer the questions honestly and **to the best of your knowledge**. There are no right or wrong answers. Remember that **your answers to the questions are confidential** and that your name does not appear anywhere on the questionnaire.

Please refer to the last 4 weeks when answering the questions. Choose the number that **best** reflects your husband's urinary and sexual function; please select "don't know" **only** when you have **absolutely no idea** and cannot estimate.

1. Over the past four weeks, how often has your husband leaked urine?

- Every day..... 1
- About once a week..... 2
- Less than once a week..... 3
- Not at all..... 4
- Don't know..... 5

2. Which of the following best describes his urinary control?

- No control whatsoever..... 1
- Frequent dribbling..... 2
- Occasional dribbling..... 3
- Total control..... 4
- Don't know..... 5

3. How many pads or adult diapers per day did he usually use to control leakage?

- 3 or more pads per day..... 1
- 1-2 pads per day..... 2
- No pads..... 3
- Don't know..... 4

4. How big a problem, if any, has each of the following been for your husband? (circle one number for each question)

	No Problem	Very small Problem	Small Problem	Moderate Problem	Big Problem	Don't Know
a. dripping urine or wetting his pants.....	0	1	2	3	4	5
b. urine leakage interfering with his sexual activity .....	0	1	2	3	4	5

5a. Overall, how big a problem has urinary function been for your husband during the last 4 weeks? (circle one number for each question)

- No Problem..... 1
- Very small problem..... 2
- Small problem..... 3
- Moderate problem..... 4
- Big problem..... 5
- Don't know..... 6

5b. Overall, how big a problem has your husband's urinary function been for you?

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

6. How would you rate your husband's sexual feelings or abilities in each of the following areas during the past 4 weeks? (circle one number for each question)

	Very Poor	Poor	Fair	Good	Very Good	Don't Know
a. his level of sexual desire.....	1	2	3	4	5	6
b. his ability to have an erection .....	1	2	3	4	5	6
c. his ability to reach orgasm.....	1	2	3	4	5	6

7. How would you describe the usual **quality** of his erections?

- None at all..... 1
- Not firm enough for any sexual activity..... 2
- Firm enough for masturbation and foreplay only..... 3
- Firm enough for intercourse..... 4
- Don't know..... 5

8. How would you describe the **frequency** of his erections?

- He **never** had an erection when he wanted one ..... 1
- He had an erection **less than half** the time he wanted one..... 2
- He had an erection **about half** the time he wanted one..... 3
- He had an erection **more than half** the time he wanted one..... 4
- He had an erection **whenever** he wanted one ..... 5
- Don't know..... 6

9. How often has he awakened in the morning or night with an erection during the past 4 weeks?

- Never..... 1
- Seldom (less than 25% of the time)..... 2
- Not often (less than half the time) ..... 3
- Often (more than half the time)..... 4
- Very often (more than 75% of the time)..... 5
- Don't know..... 6

10. Did he have sexual intercourse?

- No..... 1
- Yes, once..... 2
- Yes, more than once..... 3
- Don't know..... 4

11. Overall, how would you rate his ability to function sexually?

- Very poor..... 1
- Poor..... 2
- Fair..... 3
- Good..... 4
- Very good..... 5
- Don't know..... 6

12a. Overall, how big a problem has sexual functioning been for your husband over the last 4 weeks?

- No problem ..... 1
- Very small problem..... 2
- Small problem..... 3
- Moderate problem..... 4
- Big Problem..... 5
- Don't know..... 6

12b. Overall, how big a problem has your husband's sexual functioning been for you over the last 4 weeks?

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

## SOC

Here is a series of questions relating to various aspects of our lives. Each question has seven possible answers. Please mark the number which expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1; if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. Please give only one answer to each question.

1. When you talk to people, do you have the feeling that they don't understand you?

1	2	3	4	5	6	7
never have this feeling						always have this feeling

2. In the past, when you had to do something which depended upon cooperation with others, did you have the feeling that it:

1	2	3	4	5	6	7
surely wouldn't get done						surely would get done

3. Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?

1	2	3	4	5	6	7
you feel that they're strangers						you know them very well

4. Do you have the feeling that you don't really care about what goes on around you?

1	2	3	4	5	6	7
very seldom or never						very often

5. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?

1	2	3	4	5	6	7
never happened						always happened

6. Has it happened that people whom you counted on disappointed you?

1	2	3	4	5	6	7
never happened						always happened

7. Life is:  
1 2 3 4 5 6 7  
full of interest completely routine

8. 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

9. Do you feel that you're being treated unfairly?  
1 2 3 4 5 6 7  
very often very seldom or never

10. In the past ten years your life has been:  
1 2 3 4 5 6 7  
full of changes without your knowing what will happen next completely consistent and clear

11. Most of the things you do in the future will probably be:  
1 2 3 4 5 6 7  
completely fascinating deadly boring

12. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?  
1 2 3 4 5 6 7  
very often very seldom or never

13. What best describes how you see life:  
1 2 3 4 5 6 7  
one can always find a solution to painful things in life there is no solution to painful things in life



14. When you think about your life, you very often:

1                      2                      3                      4                      5                      6                      7  
feel how good it                      ask yourself why  
is to be alive                      you exist at all

15. When you face a difficult problem, the choice of a solution is:

1                      2                      3                      4                      5                      6                      7  
always confusing                      always completely  
and hard to find                      clear

16. 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

17. Your life in the future will probably be:

1                      2                      3                      4                      5                      6                      7  
full of changes                      completely con-  
without your                      sistent and clear  
knowing what  
will happen  
next

18. When something unpleasant happened in the past your tendency was:

1                      2                      3                      4                      5                      6                      7  
"to eat yourself                      to say "ok  
up" about it                      that's that, I  
have to live with  
it" and go on

19. Do you have very mixed-up feelings and ideas?

1                      2                      3                      4                      5                      6                      7  
very often                      very seldom  
or never

20. When you do something that gives you a good feeling:

1	2	3	4	5	6	7
it's certain that you'll go on feeling good						it's certain that something will happen to spoil the feeling

21. Does it happen that you have feelings inside you would rather not feel?

1	2	3	4	5	6	7
very often						very seldom or never

22. You anticipate that your personal life in the future will be:

1	2	3	4	5	6	7
totally without meaning or purpose						full of meaning and purpose

23. Do you think there will *always* be people whom you'll be able to count on in the future?

1	2	3	4	5	6	7
you're certain there will be						you doubt there will be

24. Does it happen that you have the feeling that you don't know exactly what's about to happen?

1	2	3	4	5	6	7
very often						very seldom or never

25. 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?

1	2	3	4	5	6	7
never						very often

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

1	2	3	4	5	6	7
you over estimated or underestimated its importance						you saw things in the right proportion

27. When you think of difficulties you are likely to face in important aspects of your life, do you have the feeling that:

1	2	3	4	5	6	7
you will always succeed in over- coming the difficulties						you won't succeed in over- coming the difficulties

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

1	2	3	4	5	6	7
very often						very seldom or never

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

1	2	3	4	5	6	7
very often						very seldom or never

FACES - II - C

1	2	3	4	5
Almost never	Once in a while	Sometimes	Frequently	Almost always

**Describe your marriage:**

- \_\_\_\_\_ 1. We are supportive of each other during difficult times.
- \_\_\_\_\_ 2. In our relationship, it is easy for both of us to express our opinion.
- \_\_\_\_\_ 3. It is easier to discuss problems with people outside the marriage than with my partner.
- \_\_\_\_\_ 4. We each have input regarding major family decisions .
- \_\_\_\_\_ 5. We spend time together when we are home.
- \_\_\_\_\_ 6. We are flexible in how we handle differences.
- \_\_\_\_\_ 7. We do things together.
- \_\_\_\_\_ 8. We discuss problems and feel good about the solutions.
- \_\_\_\_\_ 9. In our marriage, we each go our own way.
- \_\_\_\_\_ 10. We shift household responsibilities between us.
- \_\_\_\_\_ 11. We know each other's close friends.
- \_\_\_\_\_ 12. It is hard to know what the rules are in our relationship.
- \_\_\_\_\_ 13. We consult each other on personal decisions.
- \_\_\_\_\_ 14. We freely say what we want.
- \_\_\_\_\_ 15. We have difficulty thinking of things to do together.
- \_\_\_\_\_ 16. We have a good balance of leadership in our marriage.
- \_\_\_\_\_ 17. We feel very close to each other .
- \_\_\_\_\_ 18. We operate on the principle of fairness in our marriage.
- \_\_\_\_\_ 19. I feel closer to people outside the marriage than to my partner.
- \_\_\_\_\_ 20. We try new ways of dealing with problems.
- \_\_\_\_\_ 21. I go along with what my partner decides to do.
- \_\_\_\_\_ 22. In our marriage, we share responsibilities.
- \_\_\_\_\_ 23. We like to spend our free time with each other.
- \_\_\_\_\_ 24. It is difficult to get a rule changed in our relationship.
- \_\_\_\_\_ 25. We avoid each other at home.
- \_\_\_\_\_ 26. When problems arise, we compromise.
- \_\_\_\_\_ 27. We approve of each other's friends.
- \_\_\_\_\_ 28. We are afraid to say what is on our minds.
- \_\_\_\_\_ 29. We tend to do more things separately.
- \_\_\_\_\_ 30. We share interests and hobbies with each other.

## SARS

Concerning the situation of the diagnosis and follow-up for prostate cancer, you are asked to choose a number for each of the following questions which best indicates how **you feel at this time.**

On a scale of 1 to 8,

1	2	3	4	5	6	7	8
not at all	not really	very little	a bit	somewhat	quite a lot	very much	extremely

**At this time, to what extent do you feel that:**

- |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|
| 1. this situation has negative consequences?.....   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 2. this situation has positive consequences?.....   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 3. this situation involves a loss?.....<br>(of a person, a thing, health or a cherished idea)   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 4. this situation constitutes a threat?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 5. this situation constitutes a challenge?.....<br>(in terms of assuming new responsibilities or roles, or<br>in terms of succeeding) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 6. this situation represents a failure with respect to<br>a highly valued goal?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 7. you have control over this situation?.....<br>(i.e. you can influence how it evolves)  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 8. you can cope with it?.....   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 9. this situation involves uncertainty?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 10. this situation is of central importance to you?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |

**"PAIS" SPOUSE REPORT**

**AJUSTEMENT PSYCHOSOCIAL À LA MALADIE**  
Copyright 1978, 1983 par Leonard R. Derogatis, Ph. D.

## **INSTRUCTIONS**

Le présent questionnaire contient une série de questions concernant les effets que la maladie récente de votre conjoint/e, a eu sur vous. Nous sommes intéressés à savoir quels effets la maladie de votre conjoint/e a eu sur vos relations interpersonnelles et sur votre performance à la maison et au travail ainsi que sur vos relations familiales et personnelles. D'autres questions traitent des effets de sa maladie sur vos temps de loisir et d'activités sociales et comment vous vous êtes senti(e) émotionnellement.

En répondant à chaque question, veuillez inscrire un crochet ( ) à côté de la réponse qui décrit le mieux votre expérience. Veuillez répondre à toutes les questions en essayant d'en oublier aucune. Si aucune des réponses d'une question ne correspond exactement à votre expérience, veuillez choisir la réponse qui ressemble le plus à l'expérience que vous avez eu.

Nous souhaiterions que vous vous référeriez aux 30 derniers jours incluant aujourd'hui. Répondez à chaque question selon votre expérience durant cette période de temps. Si votre conjoint/e est présentement hospitalisé/e, répondez selon votre expérience en vous référant aux 30 jours précédent l'hospitalisation.

Quelques questions de ce questionnaire assument que vous êtes marié(e) ou que vous avez un(e) partenaire. D'autres questions s'intéressent aux relations familiales. Le terme conjoint/e inclut les partenaires mariés et ceux vivant en union de fait. Essayez de répondre à toutes les questions qui s'appliquent à votre cas.

La section II comporte des questions traitant de votre performance au travail. Si vous avez eu un emploi à temps plein ou un emploi substantiel à temps partiel, veuillez répondre en fonction de votre travail. Si vous êtes étudiant/e, veuillez répondre en fonction de votre travail scolaire. Si vous travaillez comme maîtresse ou maître de maison, veuillez répondre en considérant votre résidence, votre voisinage, etc. comme étant votre environnement de travail.

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Nous apprécions le temps que vous avez pris pour remplir ce questionnaire. Veuillez bien à vous assurer que vous avez répondu à toutes les questions.

Si vous avez quelques questions à propos du questionnaire, veuillez nous le demander. Si vous répondez par la poste, veuillez écrire les réponses dans l'espace réservé plus bas. Veuillez retourner le questionnaire aussitôt que vous l'avez complété.

**Merci de votre collaboration!**

**Veillez commencer en remplissant les informations suivantes sur vous**

**NOM:** \_\_\_\_\_

**ADRESSE:** \_\_\_\_\_

Numéro civique

Rue

Appartement

\_\_\_\_\_

Ville/village

Etat/Province

Code Postal

**TÉLÉPHONE:** (\_\_\_\_\_) \_\_\_\_\_

code régional

Numéro

**DATE:** \_\_\_\_\_

Mois

Jour

Année



## SECTION I

- (1) Lequel des énoncés suivants décrit le mieux votre attitude habituelle par rapport au fait de prendre soin de votre santé?
- ( ) a) Je suis très concerné/e par ma santé et j'y porte une grande attention.
  - ( ) b) La plupart du temps, je porte attention aux besoins nécessaires pour ma santé.
  - ( ) c) Habituellement, j'essaie de m'occuper des questions de santé mais parfois je n'y arrive pas.
  - ( ) d) Je m'inquiète peu des soins à accorder à ma santé.
- (2) La maladie de votre conjoint/e requiert probablement une attention spéciale et des soins particuliers de votre part. Parmi les énoncés suivants, choisissez celui qui décrit le mieux votre réaction.
- ( ) a) Je me comporte (ou j'agis) à peu près comme d'habitude et je ne m'inquiète pas ou ne tiens pas compte (de façon spéciale) de la maladie de mon/ma conjoint/e.
  - ( ) b) J'essaie d'accomplir toutes les choses que je suis censé/e faire pour prendre soin de mon/ma conjoint/e mais souvent j'oublie ou je suis trop fatigué/e ou occupé/e.
  - ( ) c) Je prends bien soin de la présente maladie de mon/ma conjoint/e.
  - ( ) d) Je prête une attention particulière à tous les soins à accorder à la maladie de mon/ma conjoint/e et je fais tout ce que je peux pour prendre soin de lui/elle.
- (3) En général, comment considérez-vous la qualité des soins médicaux disponibles aujourd'hui et les médecins qui procurent ces soins?
- ( ) a) Les soins médicaux n'ont jamais été aussi bons et les médecins qui les dispensent font un excellent travail.
  - ( ) b) La qualité des soins médicaux disponibles est très bonne mais quelques aspects pourraient être améliorés.
  - ( ) c) La qualité des soins médicaux et des médecins n'est plus ce qu'elle était.
  - ( ) d) Je n'ai pas tellement confiance aux médecins et aux soins médicaux d'aujourd'hui.

(4) Comment considérez-vous les traitements reçus lors de la maladie de votre conjoint/e et comment considérez-vous les médecins et le personnel médical qui ont fourni ces traitements?

a) Je suis très insatisfait/e du traitement qu'il/elle a reçu et je ne pense pas que le personnel a fait tout ce qu'il pouvait faire pour lui/elle.

b) Je n'ai pas été impressionné/e par le traitement qu'il/elle a reçu mais je pense que c'est probablement le mieux qu'ils puissent faire.

c) Le traitement a été assez bon dans l'ensemble malgré quelques problèmes.

d) Le traitement et le personnel ont été excellents.

(5) Devant la maladie, les gens ont des attentes et des attitudes différentes. Veuillez cocher l'énoncé ci-dessous qui décrit le mieux ce que vous ressentez.

a) Je suis certain/e que mon/ma conjoint/e va surmonter rapidement sa maladie et les problèmes qui en découlent et qu'il/elle redeviendra ce qu'il/elle était auparavant.

b) La maladie de mon/ma conjoint/e m'a causé des problèmes, mais je crois qu'il va les surmonter bientôt et ainsi redevenir ce qu'il/elle était auparavant.

c) La maladie de mon/ma conjoint/e a vraiment été une dure épreuve tant physiquement que mentalement mais il/elle essaie très fort de la surmonter et je suis convaincu/e qu'un de ces jours il/elle redeviendra ce qu'il/elle était auparavant.

d) Mon/ma conjoint/e se sent épuisé/e et très faible à cause de sa maladie et il y a des moments où je ne sais plus si il/elle arrivera vraiment à la surmonter un jour.

(6) Être malade peut être une expérience bouleversante et certains/es patients/es et les personnes proches d'eux ont l'impression de ne pas recevoir assez d'informations et de détails de la part des médecins et du personnel médical à propos de leur maladie. Veuillez choisir l'énoncé ci-dessous qui décrit le mieux vos impressions à ce sujet.

- a) Le médecin et le personnel médical ne m'ont dit que très peu de choses concernant la maladie de mon/ma conjoint/e même si j'ai posé des questions plus d'une fois.
- b) Je possède quelques informations à propos de la maladie de mon/ma conjoint/e mais j'aimerais en savoir davantage.
- c) Je comprends assez bien la maladie de mon/ma conjoint/e et j'ai l'impression que si je désirais en connaître plus je pourrais toujours recevoir d'autres informations.
- d) On m'a fourni un tableau très complet de la maladie de mon/ma conjoint/e et les médecins ainsi que le personnel médical m'ont donné tous les détails que je désirais savoir.

(7) Avec une maladie comme celle de votre conjoint/e, les gens ont des conceptions différentes concernant le traitement et ce qu'ils peuvent en attendre. Veuillez choisir l'énoncé ci-dessous qui décrit le mieux vos attentes face au traitement de votre conjoint/e.

- a) Je crois que les médecins et le personnel médical sont tout à fait capables d'appliquer adéquatement le traitement et j'ai l'impression que c'est le meilleur traitement qu'il/elle puisse recevoir.
- b) J'ai confiance aux médecins pour l'application du traitement bien qu'il m'arrive parfois d'avoir des doutes face au traitement.
- c) Je n'apprécie pas certains aspects déplaisants du traitement mais mon médecin me dit qu'il/elle doit les subir obligatoirement.
- d) Sous plusieurs aspects, j'estime que le traitement est plus désagréable que la maladie et je doute que cela vaille la peine de le recevoir.

(8) Avec une maladie comme celle de votre conjoint/e, les patients/es et les personnes proches d'eux reçoivent des quantités différentes d'informations à propos du traitement. Veuillez choisir l'énoncé ci-dessous qui décrit le mieux la quantité d'information que vous avez reçue sur le traitement de votre conjoint/e.

- a) On ne m'a pratiquement rien dit en ce qui concerne son traitement et je me sens mis/e de côté à ce sujet.
- b) J'ai quelques informations à propos de son traitement mais pas autant que je le voudrais.
- c) L'information que j'ai reçue concernant le traitement est assez complète mais il y a une ou deux choses que j'aimerais savoir.
- d) J'ai l'impression que l'information reçue concernant le traitement est très complète et à jour.

## **SECTION II**

(1) Est-ce que la maladie de votre conjoint/e a influencé vos capacités au travail (ou à l'étude)?

- a) Aucun problème au travail.
- b) Quelques problèmes mineurs.
- c) Quelques problèmes importants.
- d) Sa maladie m'a empêché totalement d'effectuer mon travail.

(2) Physiquement jusqu'à quel point faites-vous bien votre travail ou études aujourd'hui?

- a) Médiocrement.
- b) Pas très bien.
- c) Correctement.
- d) Très bien.

(3) Durant les 30 derniers jours, avez-vous été absent/e au travail (ou à l'école) à cause de la maladie de votre conjoint/e?

- a) 3 jours ou moins.
- b) 1 semaine.
- c) 2 semaines.
- d) Plus de 2 semaines.

- (4) Est-ce que votre travail (ou études) est aussi important pour vous maintenant qu'il l'était avant la maladie de votre conjoint/e?
- a) Peu ou pas d'importance maintenant.
  - b) Beaucoup moins important.
  - c) Un peu moins important.
  - d) Également ou plus important qu'avant.
- (5) Avez-vous à changer vos objectifs face à votre carrière (ou éducation) à cause de la maladie de votre conjoint/e?
- a) Mes objectifs sont inchangés.
  - b) Mes objectifs ont peu changé.
  - c) Mes objectifs ont changé passablement.
  - d) J'ai changé mes objectifs complètement.
- (6) Avez-vous remarqué s'il y a plus de problèmes avec vos compagnons/es de travail (ou étudiants/es, voisin/es) depuis le début de la maladie de votre conjoint/e?
- a) Une augmentation importante.
  - b) Une augmentation modérée.
  - c) Une augmentation légère.
  - d) Aucune.

### **SECTION III**

- (1) Comment décrivez-vous votre relation avec votre conjoint/e depuis le début de sa maladie?
- a) Bonne.
  - b) Correcte.
  - c) Pauvre.
  - d) Très pauvre.

- (2) Comment décrivez-vous votre relation avec les autres personnes qui habitent avec vous (par exemple: enfants, parents, tantes, etc.)?
- a) Bonne.
  - b) Correcte.
  - c) Pauvre.
  - d) Très pauvre.
- (3) Jusqu'à quel point la maladie de votre conjoint/e a-t-elle influencé vos capacités au travail et vos responsabilités à la maison?
- a) Pas du tout.
  - b) Petits problèmes, facilement surmontés.
  - c) Problèmes moyens, tous ne pouvant être surmontés.
  - d) Difficultés sévères à effectuer les tâches ménagères.
- (4) Face à ces problèmes avec certaines tâches ménagères, comment votre famille a-t-elle réparti les responsabilités pour vous aider?
- a) La famille n'a pas pu aider du tout.
  - b) La famille a essayé d'aider mais plusieurs choses n'ont pas été faites.
  - c) La famille a bien fait les choses sauf pour quelques petits travaux mineurs.
  - d) Aucun problème.
- (5) Est-ce que la maladie de votre conjoint/e a provoqué une baisse de la communication entre vous et les membres de votre famille?
- a) Aucune baisse de communication.
  - b) Une baisse légère de communication.
  - c) La communication a diminué et je me sens quelque peu à l'écart.
  - d) La communication a beaucoup diminué et je me sens très seul/e.

(6) Certaines personnes ayant un/e conjoint/e qui est malade comme le/la vôtre ont l'impression d'avoir besoin d'aide de la part de d'autres personnes (amis/es, voisin/es, famille, etc.) pour que les tâches quotidiennes soient accomplies. Avez-vous l'impression que vous avez besoin d'une telle aide et y a-t-il quelqu'un pour vous aider?

a) J'ai vraiment besoin d'aide mais il y a rarement quelqu'un pour m'aider.

b) Je reçois de l'aide mais je ne puis compter sur cette aide tout le temps.

c) Je ne reçois pas constamment l'aide dont j'ai besoin mais, la plupart du temps, je reçois l'aide requise.

d) Je n'ai pas l'impression que j'ai besoin d'aide ou l'aide requise est accessible de la part de mes amis et ma famille.

(7) Avez-vous expérimenté quelconque incapacité physique depuis la maladie de votre conjoint/e?

a) Aucune incapacité physique.

b) Une incapacité physique légère.

c) Une incapacité physique modérée.

d) Une incapacité physique sévère.

(8) Une maladie comme celle de votre conjoint/e peut quelquefois représenter une charge financière pour la famille. Avez-vous quelques difficultés à répondre aux demandes financières dues à cette maladie?

a) Problèmes financiers sévères.

b) Problèmes financiers modérés.

c) Problèmes financiers légers.

d) Aucun problème financier.

## SECTION IV

- (1) Quelquefois, la maladie peut entraîner des difficultés au plan d'une relation. Est-ce que la maladie de votre conjoint/e a provoqué des problèmes entre vous deux?
- a) Il n'y a eu aucun changement dans notre relation.
  - b) Nous sommes quelque peu moins près l'un de l'autre depuis sa maladie.
  - c) Nous sommes définitivement moins près l'un de l'autre depuis la maladie.
  - d) Nous avons eu des problèmes sérieux ou il y a eu une rupture depuis la maladie de mon/ma conjoint/e.
- (2) Quelquefois, lorsque les membres de la famille ou des amis proches sont malades, les personnes rapportent avoir moins d'intérêt aux activités sexuelles. Avez-vous moins d'intérêt sexuel depuis la maladie de votre conjoint/e?
- a) Absolument aucun intérêt sexuel depuis sa maladie.
  - b) Une diminution marquée d'intérêt sexuel.
  - c) Une perte légère d'intérêt sexuel.
  - d) Aucune perte d'intérêt sexuel.
- (3) La maladie amène quelquefois une baisse d'activité sexuelle. Est-ce qu'il y a eu diminution de la fréquence de vos activités sexuelles?
- a) Aucune diminution de mes activités sexuelles.
  - b) Une diminution légère de mes activités sexuelles.
  - c) Une diminution marquée de mes activités sexuelles.
  - d) Mes activités sexuelles ont cessé.
- (4) Est-ce que le plaisir (ou la satisfaction) que vous éprouvez habituellement durant une activité sexuelle a changé?
- a) Le plaisir (ou la satisfaction) sexuel n'est plus là.
  - b) Une perte marquée de plaisir (ou de satisfaction) sexuel.
  - c) Une perte légère de plaisir (ou de satisfaction) sexuel.
  - d) Aucun changement de satisfaction sexuelle.



(5) Quelquefois, une maladie peut influencer les capacités d'une personne à participer à des activités sexuelles même si elle demeure intéressée à celles-ci. Est-ce que ça vous est arrivé et, si oui, jusqu'à quel point?

a) Aucun changement de mes capacités à participer à des activités sexuelles.

b) Problèmes légers de performance sexuelle.

c) Problèmes constants de performance sexuelle.

d) Totalement incapable d'accomplir des activités sexuelles.

(6) Quelquefois, une maladie influence la relation sexuelle d'un couple et amène des disputes entre eux. Est-ce que vous et votre partenaire avez eu de telles disputes et, si oui, jusqu'à quel point?

a) Disputes constantes.

b) Disputes fréquentes.

c) Quelques disputes.

d) Aucune dispute.

## SECTION V

(1) Avez-vous conservé le contact que vous aviez habituellement (en personne ou au téléphone) avec les membres de votre famille extérieure à votre domicile depuis le début de la maladie de votre conjoint/e?

a) Le contact est le même ou plus intense depuis la maladie.

b) Le contact a quelque peu diminué.

c) Le contact a grandement diminué.

d) Aucun contact depuis sa maladie.

(2) Avez-vous conservé votre intérêt à rencontrer ces membres de votre famille depuis la maladie de votre conjoint/e?

a) Aucun ou peu d'intérêt à les rencontrer.

b) Mon intérêt a beaucoup diminué.

c) Mon intérêt a quelque peu diminué.

d) Mon intérêt est le même ou plus grand depuis la maladie.

(3) Quelquefois, lorsque les gens sont malades, ils sont forcés de dépendre des membres de leur famille extérieure à leur domicile pour recevoir de l'assistance physique. Avez-vous besoin d'assistance physique de leur part et est-ce qu'ils vous la fournissent?

- a) Je n'ai besoin d'aucune aide ou ils me donnent toute l'aide dont j'ai besoin.
- b) L'aide fournie est suffisante sauf pour quelques petites choses.
- c) Ils me donnent de l'aide mais elle est insuffisante.
- d) Ils me donnent peu ou aucune aide même si j'en ai grandement besoin.

(4) Quelques personnes fréquentent beaucoup les membres de leur famille extérieure à leur domicile. Fréquentez-vous beaucoup ces membres de votre famille et est-ce que la maladie de votre conjoint/e a réduit ces fréquentations?

- a) Mes fréquentations avec eux ont été presque éliminées.
- b) Mes fréquentations avec eux ont été réduites significativement.
- c) Mes fréquentations avec eux ont été réduites quelque peu.
- d) Généralement, je les fréquente peu ou pas, ou la maladie de mon/ma conjoint/e n'a eu aucun effet sur mes fréquentations avec eux.

(5) En général, quelle a été récemment la qualité de votre relation avec ces membres de votre famille?

- a) Bonne.
- b) Correcte.
- c) Pauvre.
- d) Très pauvre.

## **SECTION VI**

(1) Êtes-vous aussi intéressé/e à vos loisirs et à vos passe-temps que vous l'étiez avant la maladie de votre conjoint/e?

- a) Même niveau d'intérêt qu'auparavant.
- b) Un peu moins d'intérêt qu'auparavant.
- c) Significativement moins d'intérêt qu'auparavant.
- d) Peu ou pas d'intérêt subsiste.

- (2) Qu'en est-il de votre participation actuelle? Demeurez-vous activement engagé/e dans vos activités de loisirs?
- a) Peu ou aucune participation actuellement.
  - b) Ma participation a significativement baissé.
  - c) Ma participation a légèrement baissé.
  - d) Ma participation demeure inchangée.
- (3) Portez-vous autant d'intérêt aux activités de loisirs avec votre famille (par exemple, jouer aux cartes ou à des jeux de société, faire des voyages, aller se baigner, etc.) que vous le faisiez avant la maladie de votre conjoint/e?
- a) Même niveau d'intérêt qu'auparavant.
  - b) Un peu moins d'intérêt qu'auparavant.
  - c) Significativement moins d'intérêt qu'auparavant.
  - d) Peu ou pas d'intérêt subsiste.
- (4) Participez-vous encore à ces activités de loisirs autant que vous le faisiez?
- a) Peu ou aucune participation actuellement.
  - b) Ma participation a significativement baissé.
  - c) Ma participation a légèrement baissé.
  - d) Ma participation demeure inchangée.
- (5) Avez-vous maintenu votre intérêt aux activités sociales depuis la maladie de votre conjoint/e (par exemple, les organisations sociales, les groupes religieux, aller au cinéma, etc.)?
- a) Même niveau d'intérêt qu'auparavant.
  - b) Un peu moins d'intérêt qu'auparavant.
  - c) Significativement moins d'intérêt qu'auparavant.
  - d) Peu ou pas d'intérêt subsistent.
- (6) Quant à votre participation, continuez-vous à rencontrer des amis/es et à participer à des activités sociales?
- a) Peu ou aucune participation actuellement.
  - b) Ma participation a significativement baissé.
  - c) Ma participation a légèrement baissé.
  - d) Ma participation demeure inchangée.

## SECTION VII

- (1) Récemment, avez-vous été inquiet/e, tendu/e, nerveux/se ou anxieux/se?
- a) Aucunement.
  - b) Un peu.
  - c) Passablement.
  - d) Beaucoup.
- (2) Récemment, avez-vous été triste, déprimé/e, ou sans intérêt ou sans espoir?
- a) Beaucoup.
  - b) Passablement.
  - c) Un peu.
  - d) Aucunement.
- (3) Récemment, avez-vous été en colère, irritable ou avez-vous eu de la difficulté à contrôler vos émotions?
- a) Aucunement.
  - b) Un peu.
  - c) Passablement.
  - d) Beaucoup.
- (4) Récemment, vous êtes-vous blâmé/e pour quelque chose, vous êtes-vous senti/e coupable ou avez-vous eu l'impression d'avoir déçu les gens?
- a) Beaucoup.
  - b) Passablement.
  - c) Un peu.
  - d) Aucunement.
- (5) Récemment, avez-vous été préoccupé/e par la maladie de votre conjoint/e ou autre chose?
- a) Aucunement.
  - b) Un peu.
  - c) Passablement.
  - d) Beaucoup.

(6) Récemment, avez-vous été déçu/e de vous-même ou avez-vous trouvé que vous aviez moins de valeur en tant que personne?

- a) Beaucoup.
- b) Passablement.
- c) Un peu.
- d) Aucunement.

(7) Récemment, avez-vous été préoccupé/e par le fait que la maladie de votre conjoint/e ait provoqué des changements dans son apparence physique qui le/la rendent moins attrayant/e?

- a) Aucunement.
- b) Un peu.
- c) Passablement.
- d) Beaucoup.

# POMS - PROFILE OF MOOD STATES

NOM \_\_\_\_\_

DATE \_\_\_\_\_

SEXE  Masculin  Féminin

Lisez attentivement la liste des mots ci-dessous:

ils décrivent des sentiments ou états humains. Remplissez la bulle sous le nombre correspondant le mieux à ce que vous avez ressenti pendant la semaine dernière, aujourd'hui y compris.

Les nombres correspondent à l'échelle suivante:

- 0 = Pas du tout
- 1 = Un peu
- 2 = Modérément
- 3 = Beaucoup
- 4 = Extrêmement

T

D

A

V

F

C

	21. Sans espoir . . . . . 0 1 2 3 4	45. Désespéré . . . . . 0 1 2 3 4
	22. Détendu . . . . . 0 1 2 3 4	46. Lent . . . . . 0 1 2 3 4
	23. Méprisable . . . . . 0 1 2 3 4	47. Révolté . . . . . 0 1 2 3 4
	24. Vindictif . . . . . 0 1 2 3 4	48. Impuissant . . . . . 0 1 2 3 4
1. Amical . . . . . 0 1 2 3 4	25. Compréhensif . . . . . 0 1 2 3 4	49. Lassé . . . . . 0 1 2 3 4
2. Tendu . . . . . 0 1 2 3 4	26. Mal à l'aise . . . . . 0 1 2 3 4	50. Tourmenté . . . . . 0 1 2 3 4
3. Irrité . . . . . 0 1 2 3 4	27. Agité . . . . . 0 1 2 3 4	51. Alerté . . . . . 0 1 2 3 4
4. Épuisé . . . . . 0 1 2 3 4	28. Distrait . . . . . 0 1 2 3 4	52. Trompé . . . . . 0 1 2 3 4
5. Malheureux . . . . . 0 1 2 3 4	29. Fatigué . . . . . 0 1 2 3 4	53. Furieux . . . . . 0 1 2 3 4
6. Vif d'esprit . . . . . 0 1 2 3 4	30. Serviable . . . . . 0 1 2 3 4	54. Efficace . . . . . 0 1 2 3 4
7. Animé . . . . . 0 1 2 3 4	31. Ennuyé . . . . . 0 1 2 3 4	55. Confiant . . . . . 0 1 2 3 4
8. Confus . . . . . 0 1 2 3 4	32. Découragé . . . . . 0 1 2 3 4	56. Plein d'énergie . . . . . 0 1 2 3 4
9. Repentant . . . . . 0 1 2 3 4	33. Rancunier . . . . . 0 1 2 3 4	57. De mauvaise humeur . . . . . 0 1 2 3 4
10. Tremblant . . . . . 0 1 2 3 4	34. Nerveux . . . . . 0 1 2 3 4	58. Bon à rien . . . . . 0 1 2 3 4
11. Apathique . . . . . 0 1 2 3 4	35. Isolé . . . . . 0 1 2 3 4	59. Oublieux . . . . . 0 1 2 3 4
12. Fâché . . . . . 0 1 2 3 4	36. Misérable . . . . . 0 1 2 3 4	60. Insouciant . . . . . 0 1 2 3 4
13. Prévenant . . . . . 0 1 2 3 4	37. Perturbé . . . . . 0 1 2 3 4	61. Terrifié . . . . . 0 1 2 3 4
14. Triste . . . . . 0 1 2 3 4	38. Joyeux . . . . . 0 1 2 3 4	62. Coupable . . . . . 0 1 2 3 4
15. Actif . . . . . 0 1 2 3 4	39. Plein d'amertume . . . . . 0 1 2 3 4	63. Vigoureux . . . . . 0 1 2 3 4
16. Agacé . . . . . 0 1 2 3 4	40. Fourbu . . . . . 0 1 2 3 4	64. Hésitant . . . . . 0 1 2 3 4
17. Grognon . . . . . 0 1 2 3 4	41. Angoissé . . . . . 0 1 2 3 4	65. Étenué . . . . . 0 1 2 3 4
18. Cafardeux . . . . . 0 1 2 3 4	42. Agressif . . . . . 0 1 2 3 4	N'omettez aucune réponse
19. Énergique . . . . . 0 1 2 3 4	43. Aimable . . . . . 0 1 2 3 4	
20. Paniqué . . . . . 0 1 2 3 4	44. Déprimé . . . . . 0 1 2 3 4	

## PSSE- Conjointes

Les questions suivantes portent sur votre connaissance des fonctions urinaires de votre conjoint, de ses désirs et de son comportement sexuels lors des quatre dernières semaines. Nous aimerions également savoir dans quel mesure ces questions sont importantes pour vous. Les dites questions sont très personnelles, mais sachez que vos réponses ont une valeur inestimable nous permettant de mieux comprendre les situations auxquelles vous devez faire face quotidiennement. Répondez franchement à ces questions, au meilleur de votre connaissance. Il n'y a pas de bonnes ou de mauvaises réponses. Soyez assurées que **vos réponses demeurent confidentielles et que votre nom n'apparaît nul part sur le questionnaire.**

Ces questions concernent **les quatre dernières semaines.** Pour chaque question, encerclez le chiffre qui correspond le mieux aux fonctions urinaires de votre conjoint, à ses désirs affectifs et à son comportement sexuel; sélectionnez 'je ne sais pas' **seulement** quand vous ignorez la réponse et/au que vous vous sentez incapable d'évaluer la situation.

1. Au cours des 4 dernières semaines, est-ce que votre conjoint a souvent présenté de l'incontinence urinaire (perdu de l'urine de façon involontaire)?

- |                                    |   |
|------------------------------------|---|
| Chaque jour.....                   | 1 |
| Environ une fois par semaine.....  | 2 |
| Moins de une fois par semaine .... | 3 |
| Pas du tout.....                   | 4 |
| Je ne sais pas.....                | 5 |

2. Dans quelle mesure était-il capable de maîtriser le besoin d'uriner?

- |                                    |   |
|------------------------------------|---|
| Aucune maîtrise.....               | 1 |
| Fuites d'urine fréquentes.....     | 2 |
| Fuites d'urine occasionnelles..... | 3 |
| Maîtrise totale.....               | 4 |
| Je ne sais pas.....                | 5 |

3. Combien de coussinets ou de couches pour adultes a-t-il utilisé par jour, à cause de son incontinence urinaire (fuites d'urine involontaires)?

- |                                 |   |
|---------------------------------|---|
| 3 couches ou plus par jour..... | 1 |
| 1-2 couches.....                | 2 |
| aucune couches.....             | 3 |
| je ne sais pas .....            | 4 |

4. Dans quelle mesure les situations suivantes ont-elles posé un problème pour votre conjoint?

	Aucun Problème	Problème Très mineur	Problème Mineur	Problème Modéré	Problème Important	Je ne Sais pas
a. Fuite d'urine ou pantalon mouillé.....	0	1	2	3	4	5
b. Manque de maîtrise de la fonction urinaire nuisant à l'activité sexuelle.....	0	1	2	3	4	5

5a. En général, la maîtrise de la fonction urinaire a-t-elle posé un problème **pour votre conjoint** au cours des 4 dernières semaines?

- Aucun problème..... 1
- Problème très mineur..... 2
- Problème mineur..... 3
- Problème modéré..... 4
- Problème important..... 5
- Je ne sais pas..... 6

5b. En général, la maîtrise de la fonction urinaire a-t-elle posé un problème **pour vous**?

- Aucun problème..... 1
- Problème très mineur..... 2
- Problème mineur..... 3
- Problème modéré..... 4
- Problème important..... 5

6. Comment évaluez-vous chaque élément suivant? (Encerclez un chiffre par ligne)

	Très				Très		Je ne
	<u>Mauvais</u>	<u>Mauvais</u>	<u>Acceptable</u>	<u>Bon</u>	<u>Bon</u>	<u>Sais pas</u>	
a. son désir sexuel?.....	1	2	3	4	5	6	
b. sa capacité à obtenir une érection?	1	2	3	4	5	6	
c. sa capacité à atteindre l'orgasme?	1	2	3	4	5	6	

7. Comment évaluez-vous la qualité de ses érections?

- Aucune érection.....1
- Pas suffisamment ferme pour une activité sexuelle quelle qu'elle soit...2
- Suffisamment ferme pour la masturbation.....3
- Suffisamment ferme pour la pénétration.....4
- Je ne sais pas .....6

8. Combien de fois a-t-il eu des érections?

- Il n'a **jamais** eu une érection quand il le voulait..... 1
- Il a eu une érection **moins de la moitié** des fois où il le voulait..... 2
- Il a eu une érection **environ la moitié** des fois où il le voulait..... 3
- Il a eu une érection **plus de la moitié** des fois où il le voulait..... 4
- Il a **toujours** eu une érection quand il le voulait..... 5
- Je ne sais pas .....6



9. Combien de fois s'est-il réveillé le matin ou la nuit avec une érection, au cours des 4 dernières semaines?

- |  |   |
|--|---|
| Jamais.....                                    | 1 |
| Rarement (moins de 25% du temps).....          | 2 |
| Peu souvent (moins de la moitié du temps)..... | 3 |
| Souvent (plus de 75% du temps).....            | 4 |
| Très souvent (plus de 75% du temps).....       | 5 |
| Je ne sais pas.....                            | 6 |

10. A-t-il réussi à pénétrer pendant l'activité sexuelle?

- |                           |   |
|---------------------------|---|
| Non.....                  | 1 |
| Oui, une seule fois.....  | 2 |
| Oui, plus d'une fois..... | 3 |
| Je ne sais pas.....       | 4 |

11. Comment évaluez-vous son fonctionnement sexuel?

- |                     |   |
|---------------------|---|
| Très mauvais.....   | 1 |
| Mauvais.....        | 2 |
| Acceptable.....     | 3 |
| Bon.....            | 4 |
| Très bon.....       | 5 |
| Je ne sais pas..... | 6 |

12a. Au cours des 4 dernières semaines est-ce que le fonctionnement sexuel a été un problème **pour votre conjoint?**

- |                           |   |
|---------------------------|---|
| Aucun problème.....       | 1 |
| Problème très mineur..... | 2 |
| Problème mineur.....      | 3 |
| Problème modéré.....      | 4 |
| Grand problème.....       | 5 |
| Je ne sais pas.....       | 6 |

12b. Est-ce que la fonction sexuelle de votre conjoint a été un problème **pour vous?**

- |                           |   |
|---------------------------|---|
| Aucun problème.....       | 1 |
| Problème très mineur..... | 2 |
| Problème mineur.....      | 3 |
| Problème modéré.....      | 4 |
| Problème important.....   | 5 |

## SOC

Nous aimerions maintenant connaître vos réactions face aux événements de la vie en général. Choisissez le chiffre qui correspond le mieux à votre réponse.

1. Lorsque vous parlez avec des gens, avez-vous le sentiment qu'ils ne vous comprennent pas?

1	2	3	4	5	6	7
jamais eu ce sentiment						toujours eu ce sentiment

2. Dans le passé, lorsque vous aviez à faire quelque chose qui nécessitait la coopération des autres, avez-vous eu le sentiment que...

1	2	3	4	5	6	7
ce ne serait pas fait						ce serait sûrement fait

3. Pensez aux gens que vous côtoyez quotidiennement, sauf vos proches; pouvez-vous affirmer que vous connaissez bien ces gens?

1	2	3	4	5	6	7
vous sentez qu'ils sont des étrangers						vous les connaissez très bien

4. Avez-vous le sentiment que vous ne vous préoccupez pas de ce qui se passe autour de vous?

1	2	3	4	5	6	7
très rarement ou jamais						très souvent

5. Vous est-il déjà arrivé dans le passé d'être surpris par le comportement des gens que vous pensiez bien connaître?

1	2	3	4	5	6	7
jamais arrivé						toujours arrivé

6. Avez-vous déjà été déçu par des gens sur lesquels vous comptiez?

1	2	3	4	5	6	7
jamais arrivé						toujours arrivé

7. La vie est....

1	2	3	4	5	6	7
remplie d'intérêt						totalemt routinière

8. Jusqu'à présent, votre vie avait....

1	2	3	4	5	6	7
aucun objectif clair ou but précis						des objectifs clairs et un but précis

9. Avez-vous l'impression d'être traité d'une manière inéquitable?

1	2	3	4	5	6	7
très souvent						très rarement ou jamais

10. Depuis les dix dernières années, votre vie a été....

1	2	3	4	5	6	7
remplie de changements sans savoir ce qui allait arriver						très cohérente et claire

11. La plupart des choses que vous ferez dans l'avenir seront....

1	2	3	4	5	6	7
totalement passionnante						mortellement ennuyante

12. Avez-vous l'impression d'être dans une situation peu familière et que vous ne savez pas quoi faire?

1	2	3	4	5	6	7
très souvent						très rarement ou jamais

13. Qu'est-ce qui décrit le mieux la façon dont vous voyez la vie?

1	2	3	4	5	6	7
on peut toujours trouver une solution aux situations pénibles de la vie						il n'y a pas de solutions aux situations pénibles de la vie

14. Lorsque vous pensez à votre vie, très souvent....

1	2	3	4	5	6	7
vous vous sentez comment c'est bon d'être en vie						vous vous demandez pourquoi vous existez au juste

15. Devant une situation difficile, le choix d'une solution est....

1	2	3	4	5	6	7
toujours confus et difficile à trouver						toujours complètement clair

16. Faire les choses que vous faites tous les jours est....

1	2	3	4	5	6	7
une source de plaisir et de satisfaction					une source d'inconfort et d'ennui	

17. Votre vie future sera probablement....

1	2	3	4	5	6	7
remplie de changements sans que vous sachiez ce qui arrivera par la suite					complètement claire et cohérente	

18. Dans le passé, lorsque quelque chose de déplaisant arrivait, vous aviez tendance à:

1	2	3	4	5	6	7
vous tourmenter					vous dire, "OK, c'est la vie, et je continue"	

19. Avez-vous des idées et des sentiments très confus (mêlés)?

1	2	3	4	5	6	7
très souvent					très rarement ou jamais	

20. Lorsque vous faites quelque chose qui vous procure de la satisfaction, c'est assuré que...

1	2	3	4	5	6	7
vous aller continuer à vous sentir bien					quelque chose va venir tout gâcher	

21. Vous arrive-t-il d'avoir des sentiments que vous aimeriez mieux ne pas ressentir?

1	2	3	4	5	6	7
très souvent					très rarement ou jamais	

22. Vous prévoyez que votre vie personnelle sera...

1	2	3	4	5	6	7
totalement sans signification et sans but					remplie de signification et avec un but	

23. Dans le futur, croyez-vous qu'il y aura *toujours* des gens sur qui vous pourrez compter?

1	2	3	4	5	6	7
vous êtes certaine qu'il y en aura					vous doutez qu'il y en aura	

24. Vous arrive-t-il d'avoir l'impression de ne pas savoir exactement ce qui est sur le point d'arriver?

1	2	3	4	5	6	7
très souvent						très rarement ou jamais

25. Plusieurs personnes, même les gens très forts de caractère, se sentent parfois des perdants devant certaines situations. Combien de fois vous êtes vous sentie ainsi dans le passé?

1	2	3	4	5	6	7
jamais						très souvent

26. Quand quelque chose arrive, en général vous trouvez que:

1	2	3	4	5	6	7
vous sous-estimez ou surestimez son importance						vous voyez les choses de façon juste

27. Parmi les situations importantes auxquelles vous aurez à faire face dans la vie, diriez-vous que:

1	2	3	4	5	6	7
vous réussirez toujours à surmonter les difficultés						vous ne réussirez pas à surmonter les difficultés

28. Vous arrive-t-il fréquemment de ressentir que les choses que vous faites quotidiennement ont peu de signification?

1	2	3	4	5	6	7
très souvent						très rarement ou jamais

29. Vous arrive-t-il fréquemment de ressentir que vous n'êtes pas certaine de pouvoir garder les choses sous contrôle?

1	2	3	4	5	6	7
très souvent						très rarement ou jamais

## Faces II - C

1	2	3	4	5
Presque jamais	De temps en temps	Parfois	Souvent	Presque toujours

---

### **Décrivez votre relation de couple:**

- \_\_\_\_\_ 1. Nous nous entraisons dans les périodes difficiles.
- \_\_\_\_\_ 2. Dans notre relation de couple, chacun peut exprimer son opinion facilement.
- \_\_\_\_\_ 3. Il est plus facile de discuter de mes problèmes avec des personnes extérieures à ma relation de couple qu'avec mon partenaire.
- \_\_\_\_\_ 4. Chacun a son mot à dire dans les décisions familiales importantes.
- \_\_\_\_\_ 5. Nous passons du temps ensemble quand nous sommes à la maison.
- \_\_\_\_\_ 6. Nous sommes flexibles dans notre façon de gérer nos différences d'opinion.
- \_\_\_\_\_ 7. Nous faisons des choses ensemble.
- \_\_\_\_\_ 8. Nous discutons de nos problèmes et nous sommes satisfaits des solutions.
- \_\_\_\_\_ 9. Dans notre relation de couple, nous allons chacun de notre côté.
- \_\_\_\_\_ 10. Nous échangeons les responsabilités domestiques.
- \_\_\_\_\_ 11. Nous connaissons les amis intimes de l'un et l'autre.
- \_\_\_\_\_ 12. Il est difficile de savoir quelles sont les règles dans notre relation de couple.
- \_\_\_\_\_ 13. Nous nous consultons dans nos décisions personnelles.
- \_\_\_\_\_ 14. Nous exprimons librement ce que nous voulons.
- \_\_\_\_\_ 15. Il nous est difficile de penser à ce que nous pourrions faire ensemble.
- \_\_\_\_\_ 16. Il y a un équilibre du "leadership" dans notre relation de couple.
- \_\_\_\_\_ 17. Nous nous sentons très près l'un de l'autre.
- \_\_\_\_\_ 18. Nous fonctionnons à partir du principe d'équité dans notre relations de couple.
- \_\_\_\_\_ 19. Je me sens plus près des personnes extérieures à ma relation de couple qu'à mon partenaire.
- \_\_\_\_\_ 20. Nous essayons de nouvelles façons de faire face aux problèmes.
- \_\_\_\_\_ 21. Je me conforme aux décisions de mon partenaire.
- \_\_\_\_\_ 22. Dans notre relation de couple, nous partageons les responsabilités.
- \_\_\_\_\_ 23. Nous aimons passer notre temps libre ensemble.
- \_\_\_\_\_ 24. Dans notre relation de couple, il est difficile de changer une règle.
- \_\_\_\_\_ 25. A la maison, nous nous évitons.
- \_\_\_\_\_ 26. Quand des problèmes surgissent, nous faisons des compromis.
- \_\_\_\_\_ 27. Dans notre relation de couple, chacun approuve le choix des amis de l'autre.
- \_\_\_\_\_ 28. Nous avons peur d'exprimer ce que nous pensons.
- \_\_\_\_\_ 29. Nous avons plus tendance à faire des activités individuellement.
- \_\_\_\_\_ 30. Nous partageons nos intérêts et nos passe-temps.

## GESS

Nous aimerions connaître vos perceptions face à la situation que vous vivez actuellement en regard du diagnostic et du suivi du cancer de la prostate. Choisissez un chiffre pour chacune des questions qui correspond le mieux à **vos perceptions en ce moment**.

Sur une échelle de 1 à 8,

1	2	3	4	5	6	7	8
pas du tout	un peu	plutôt	assez	moyennement	passablement	beaucoup	extrêmement

**Jusqu'à quel point jugez-vous qu'actuellement :**

- |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|
| 1. la situation a des conséquences négatives?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 2. la situation a des conséquences positives?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 3. la situation comporte une perte?.....<br>(d'une personnes, de biens, de santé ou d'idées)  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 4. la situation comporte un danger?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 5. la situation représente un défi à relever?.....<br>(dans le sens de nouvelles responsabilités ou de nouveaux rôles à jouer et de l'importance de bien réussir) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 6. la situation est un échec<br>face à un but fortement désiré?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 7. vous avez du contrôle, c'est à dire<br>de l'influence sur son déroulement?.. ..  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 8. vous pouvez y faire face?.....   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 9. la situation comporte l'inconnu?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 10. la situation concerne un domaine primordiale<br>dans votre vie?.....  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |

**Appendix 2**  
**Socio-demographic Data Questionnaire**



**Demographic Information Tear off sheet      Time 1**

Research number \_\_\_\_\_

Date of interview    year \_\_\_\_\_    month \_\_\_\_\_    day \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone number \_\_\_\_\_

Additional phone # \_\_\_\_\_

Hospital \_\_\_\_\_

Hospital number \_\_\_\_\_

Physician \_\_\_\_\_

Date of diagnosis    year \_\_\_\_\_    month \_\_\_\_\_    day \_\_\_\_\_

Gleason \_\_\_\_\_

Treatment            surgery \_\_\_\_\_    radiotherapy \_\_\_\_\_    observation \_\_\_\_\_

Date of treatment    year \_\_\_\_\_    month \_\_\_\_\_    day \_\_\_\_\_

Other treatment \_\_\_\_\_

**Demographic Information Time 1**

Please respond to the following questions by circling the answer or answers that best apply to you, and by providing further information where requested. Please answer the questions to the best of your knowledge, remembering that your answers are confidential and your name does not appear anywhere on the questionnaire.

Research number \_\_\_\_\_

Today's Date: \_\_\_\_\_

1. What is your date of birth? year \_\_\_\_\_ month \_\_\_\_\_ day \_\_\_\_\_

2. What is your current marital status?

married ..... 1

living with someone ..... 2

3. How many years have you been married to and/or living with your present spouse/partner? \_\_\_\_\_

4. What was your marital status prior to this present relationship?

single, never married ..... 1

married ..... 2

living with someone ..... 3

widowed ..... 4

separated or divorced ..... 5

5. Do you have any children?

yes (how many? \_\_\_\_\_)..... 1

no ..... 2

6. If you answered yes to question 5, please provide the following information regarding each of your children:

	sex (M or F)	age	place of residence (i.e., do they live with you, in the Montreal area, or elsewhere)
1)	_____	_____	_____
2)	_____	_____	_____
3)	_____	_____	_____
4)	_____	_____	_____
5)	_____	_____	_____
6)	_____	_____	_____
7)	_____	_____	_____
8)	_____	_____	_____
9)	_____	_____	_____
10)	_____	_____	_____

7. Do you have any dependents?

no ..... 1

yes ..... 2

if yes, are they:

children            total number \_\_\_\_\_

other                total number \_\_\_\_\_

8. Since the diagnosis of prostate cancer, have you attended a support group or sought any other type of professional support (e.g., from a counsellor, therapist, health care professional, religious leader, etc.)?

yes ..... 1

no ..... 2

9. In reference to question 8, please specify from whom support was sought:

	Yes	No
physician .....	_____	_____
nurse .....	_____	_____
social worker .....	_____	_____
counsellor / therapist .....	_____	_____
support group .....	_____	_____
religious leader .....	_____	_____
other (please specify: _____ )	_____	_____

10. What is your religion?

Catholic .....	1
Protestant .....	2
Jewish .....	3
Muslim .....	4
other (please specify: _____ )	5
none .....	6

11. How important is religion to you?

extremely important .....	1
moderately important .....	2
somewhat important .....	3
not at all important .....	4

12. What level of education do you have?

never attended school .....	1
some grade school .....	2
completed grade school .....	3
some high school .....	4
completed high school .....	5
some CEGEP .....	6
completed CEGEP .....	7
technical school (please specify: _____ )	8
some university (baccalaureate level) .....	9
completed university (baccalaureate level) .....	10
some university (postgraduate level) .....	11
completed university (postgraduate level) .....	12
other (please specify: _____ )	13

13. What is the total number of years you attended school? \_\_\_\_\_

14. What is your maternal (first) language?

- French ..... 1
- English ..... 2
- other (please specify: \_\_\_\_\_ ) ..... 3

15. Where were you born (i.e., in what country)? \_\_\_\_\_

16. Which of the following best describes you?

- currently employed (full-time or part-time) ..... 1
- retired ..... 2
- on leave from employment ..... 3
- unemployed ..... 4
- homemaker (not employed)..... 5

17. What is your current or most recent occupation?

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18. What is your total annual household income (before taxes)?

- less than \$15 000 ..... 1
- \$15 000 - \$24 999 ..... 2
- \$25 000 - \$34 999 ..... 3
- \$35 000 - \$44 999 ..... 4
- \$45 000 - \$54 999 ..... 5
- \$55 000 - \$64 999 ..... 6
- \$65 000 - \$74 999 ..... 7
- \$75 000 or more ..... 8

19. Do you consider your total revenues to be sufficient to meet your needs?

- yes ..... 1
- no ..... 2

20. How many major events have you experienced in the past two years (e.g., death of a family member or close friend, wedding within your family, a move, a change in job, etc.)? \_\_\_\_\_

21. Please describe the major event(s) referred to in question 20 and state the year in which they took place:

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22. Within the last ten years, how many times have you been hospitalized or had a serious illness? \_\_\_\_\_

23. Please describe the hospitalization(s) or illness(es) referred to in question 22 and state the year in which they took place:

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24. When was the prostate cancer diagnosed? \_\_\_\_\_

25. How is the prostate cancer being treated?

surgery (date: \_\_\_\_\_)..... 1

radiotherapy (date started: \_\_\_\_\_)..... 2

close observation and follow-up ..... 3

26. In addition to the treatment specified in question 25, has the prostate cancer been treated in any other manner?

- hormone therapy...(date started: \_\_\_\_\_)..... 1
- medications ...(specify: \_\_\_\_\_)..... 2
- other (specify: \_\_\_\_\_) ....3
- no ..... 4

27. How would you describe **your** current state of health?

- excellent .....1
- very good ..... 2
- good ..... 3
- fair .....4
- poor ..... 5

28. Are you currently experiencing any health problems?

- yes ..... 1
- no ..... 2

29. If you answered yes to question 28, please explain:

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30. How satisfied are you with **your** current state of health?

- very satisfied ..... 1
- somewhat satisfied ..... 2
- not very satisfied ..... 3
- not at all satisfied ..... 4

## Données Démographiques Période 1

Numéro de recherche \_\_\_\_\_

Date de la rencontre jour \_\_\_\_\_ mois \_\_\_\_\_ année \_\_\_\_\_

Nom \_\_\_\_\_

Adresse \_\_\_\_\_

Numéro de téléphone \_\_\_\_\_

Autre numéro de téléphone \_\_\_\_\_

Hôpital \_\_\_\_\_

Numéro de la carte de l'hôpital \_\_\_\_\_

Médecin traitant \_\_\_\_\_

Date du diagnostic jour \_\_\_\_\_ mois \_\_\_\_\_ année \_\_\_\_\_

Gleason \_\_\_\_\_

Traitement chirurgie \_\_\_\_\_ radiothérapie \_\_\_\_\_ observation \_\_\_\_\_

Date du traitement \_\_\_\_\_

Autre traitement \_\_\_\_\_



## Données Démographiques Période 1

Veillez répondre aux questions suivantes en encerclant le chiffre qui correspond le mieux à votre situation en fournissant des renseignements supplémentaires, s'il y a lieu. Répondez franchement à ces questions, au meilleur de votre connaissance. Soyez assurés que vos réponses demeureront confidentielles et que votre nom n'apparaîtra nul part sur la questionnaire.

Numéro de recherche \_\_\_\_\_

Date d'aujourd'hui jour \_\_\_\_\_ mois \_\_\_\_\_ année \_\_\_\_\_

1. Quel est votre date de naissance? jour \_\_\_\_\_ mois \_\_\_\_\_ année \_\_\_\_\_

2. Quelle est votre statut?

marié(e) ..... 1

conjoint(e) ..... 2

3. Depuis quand habitez-vous avec votre conjoint(e)? \_\_\_\_\_

4. Quel était votre statut avant votre relation actuelle?

célibataire, jamais marié(e).....1

marié(e) ..... 2

vivant avec un conjoint(e)..... 3

veuf (veuve) ..... 4

séparé(e) ou divorcé(e) .....5

5. Avez-vous des enfants?

oui (specifiez combien: \_\_\_\_\_)..... 1

non .....2

6. Si vous avez répondu oui à la question 5, veuillez fournir les renseignements suivants pour chacun de vos enfants:

	sexe (M ou F)	âge	lieu de résidence (e.g., habitent-ils avec vous, à Montréal, ou ailleurs)
1)	_____	_____	_____
2)	_____	_____	_____
3)	_____	_____	_____
4)	_____	_____	_____
5)	_____	_____	_____
6)	_____	_____	_____
7)	_____	_____	_____
8)	_____	_____	_____
9)	_____	_____	_____
10)	_____	_____	_____

7. Avez-vous des personnes à charge?

non ..... 1  
oui ..... 2  
si oui, sont-elles des enfants? (specifiez combien) \_\_\_\_\_  
sont-elles des adultes? (specifiez combien) \_\_\_\_\_

8. Depuis le diagnostic, avez-vous assisté aux groupes de soutien ou avez-vous cherché de l'aide auprès de personnes ressources (e.g., professionnels médicaux, para-médicaux ou religieux)?

oui ..... 1  
non ..... 2

9. Indiquez qui vous a aidé:	Oui	Non
le médecin .....	_____	_____
l'infirmière .....	_____	_____
le travailleur social.....	_____	_____
le conseiller .....	_____	_____
le groupe de soutien.....	_____	_____
le personnel religieux.....	_____	_____
tout autre (spécifiez _____) .....	_____	_____

10. Quel est votre religion?

Catholique .....	1
Protestant .....	2
Juif .....	3
Musulman .....	4
autre (lequel? _____) .....	5
aucune religion .....	6

11. Quel est l'importance de la religion pour vous?

extrêmement important .....	1
plutôt important .....	2
peu important .....	3
pas du tout .....	4

12. Quel est votre niveau de scolarité?

jamais fréquenté l'école .....	1
primaire inachevé.....	2
primaire .....	3
secondaire inachevé.....	4
secondaire, diplômé(e).....	5
collégial inachevé .....	6
collégial, diplômé(e).....	7
études techniques (spécifiez: _____).....	8
études universitaires .....	9
études universitaires (baccalauréat) premier cycle .....	10
études supérieures universitaires .....	11
diplômé(e) d'études supérieures .....	12
autre (précisez: _____).....	13

13. Donnez le nombre total de vos années d'études \_\_\_\_\_

14. Quel est votre langue maternelle?

- Français ..... 1
- Anglais ..... 2
- autre (specifiez laquelle: \_\_\_\_\_) ..... 3

15. Où êtes-vous né(e)? (i.e. dans quel pays)? \_\_\_\_\_

16. Laquelle des réponses suivantes correspond à votre situation?

- le travail à temps plein ou à temps partiel ..... 1
- à la retraite ..... 2
- en congé de travail ..... 3
- à la recherche d'un emploi ..... 4
- responsable de la maisonnée ..... 5

17. Quel est votre occupation actuelle ou votre occupation la plus récente?

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18. Quel est le revenu total de votre famille (avant les déductions)?

- moins que \$15 000 ..... 1
- entre \$15 000 et \$24 999 ..... 2
- entre \$25 000 et \$34 999 ..... 3
- entre \$35 000 et \$44 999 ..... 4
- entre \$45 000 et \$54 999 ..... 5
- entre \$55 000 et \$64 999 ..... 6
- entre \$65 000 et \$74 999 ..... 7
- \$75 000 ou plus ..... 8

19. Considérez-vous que vos revenus totaux soient suffisants pour combler vos besoins?

- oui ..... 1
- non ..... 2

20. Combien d'événements importants avez-vous vécus dans les deux dernières années (tels un décès, la maladie d'un proche, un mariage, un changement d'emploi, etc.)? \_\_\_\_\_

21. Veuillez identifier l'événement ou les événements de la question 20 et l'année qu'il(s) s'est ou se sont produit(s):

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22. Depuis les dix dernières années, combien de fois avez- vous été hospitalisé(e), ou avez eu une maladie sérieuse? \_\_\_\_\_

23. Veuillez identifier l'(les) hospitalisation(s) ou la(les) maladie(s) de la question 22 et l'(les) année(s) qu'elle(s) se sont produite(s):

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24. Quand le cancer de la prostate a-t-il été diagnostiqué? \_\_\_\_\_

25. Quel type de traitement sera suivi?

la chirurgie (date prévue: \_\_\_\_\_) ..... 1

le radiothérapie (débutant le: \_\_\_\_\_) ..... 2

l'observation et le suivi continu ..... 3

26. A part ces types de traitements et suivis, le cancer de la prostate a-t-il été géré d'une autre façon?

la thérapie hormonale (débutant le: \_\_\_\_\_) .... 1

les médicaments (lesquels? \_\_\_\_\_) ... 2

autres traitements (lesquels? \_\_\_\_\_) ..... 3

non ..... 4

27. Comment décrivez-vous **votre** état actuel de santé?

excellent .....	1
très bon .....	2
bon .....	3
plus ou moins bon .....	4
mauvais .....	5

28. Connaissez-vous des problèmes de santé en ce moment?

oui .....	1
non .....	2

29. Si vous avez répondu oui à la question 28, veuillez décrire le (les) problème(s):

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30. Êtes-vous satisfait(e) de votre état actuel de santé?

très satisfait .....	1
plus ou moins satisfait .....	2
pas vraiment satisfait .....	3
pas du tout satisfait .....	4

**Appendix 3**  
**Scientific and Ethical Reviews**



**McGill**

Faculty of Medicine  
3655 Drummond Street  
Montreal, QC H3G 1Y6  
Fax: (514) 398-3595

Faculté de médecine  
3655, rue Drummond  
Montréal, QC, H3G 1Y6  
Télécopieur: (514) 398-3595

January 22, 1997

Professor Helene Ezer  
School of Nursing  
3506 University Street  
Montreal, Quebec  
H3A 2A7

Dear Professor Ezer:

We are writing in response to the request for continuing review by the Institutional Review Board, Faculty of Medicine of the study entitled "*A Study of Adaptation in Men with Non-Metastatic Prostate Cancer and in Their Wives During the First Year Following Diagnosis*"

The progress report was reviewed and we are pleased to inform you that approval for the study was provided on January 22, 1997, valid until December 1998. The certification of annual review document has been enclosed.

Should any study revision or an unanticipated development occur prior to the next review, please advise the IRB promptly.

We trust this will prove satisfactory to you.

Best regards,

  
Veronica Klein  
Ethics Review Officer  
Institutional Review Board

Encl.

cc: Dr. D. Cournoyer  
Dr. J. Mendelson  
Ms. J. Turner  
REB Files JGH/MGH/RVH  
A12-B22-96





# McGill

Faculty of Medicine  
3655 Drummond Street  
Montreal, QC H3G 1Y6  
Fax: (514) 398-3595

Faculté de médecine  
3655, rue Drummond  
Montréal, QC, H3G 1Y6  
Télécopieur: (514) 398-3595

July 5, 2000

Professor Helene Ezer  
School of Nursing  
3506 University Street  
Montreal, Quebec  
H3A 2A7

Dear Professor Ezer:

We are writing in response to the request for continuing review by the Institutional Review Board, Faculty of Medicine of the study A12-B22-96 entitled "A Study of Adaptation in Men with Non-Metastatic Prostate Cancer and in Their Wives During the First Year Following Diagnosis"

The progress report was reviewed and we are pleased to inform you that re-approval for the study was provided on July 5, 2000 valid until December 2000. The certification of annual review document has been enclosed.

Please take note that review of all research involving human subjects is required on an annual basis in accord with the date of initial approval. Moreover, should any modification to the study or unanticipated development occur prior to the next review, please advise the IRB promptly.

Yours sincerely,



J. Lawrence Hutchison, MD  
Chair  
Institutional Review Board

cc: Ms. F. Cantini  
Ms. E. Boyle  
Ms. L. Fateen  
REB Files JGH/MGH/RVH  
A12-B22-96

# CENTRE DE RECHERCHE LOUIS-CHARLES SIMARD

1560, rue Sherbrooke Est  
Montréal (Québec), Canada H2L 4M1

M - PAVILLON NOTRE-DAME  
téléphone: (514) 281-6051  
télécopieur: (514) 896-4762

INSTITUT DU CANCER DE MONTRÉAL  
téléphone: (514) 281-6055  
télécopieur: (514) 896-4689

Le 11 mars, 1997.

Madame Louise Bouchard  
Faculté des sciences infirmières  
Université de Montréal


**Projet: A proposal to study the adaptation in men with non-metastatic prostate cancer and in their wives during the first years following diagnosis.**

Chère Madame Bouchard,

La présente est pour vous informer qu'à sa réunion du 10 mars dernier, le comité d'éthique a approuvé votre projet après avoir pris connaissance de votre lettre du 3 février 1997.

Le tout est transmis aux Conseils d'administration pour information.

Je vous prie d'agréer, chère madame Bouchard, l'expression de mes sentiments les meilleurs.

  
M<sup>re</sup> Christine Truesdell  
Présidente  
Comité d'éthique

CT:ll

**Appendix 4**  
**Letters of Information**

## Letter of Introduction

### A Study of Adaptation in Men and their Wives to Non-Metastatic Prostate Cancer During the First Year Following Diagnosis

#### Objectives of the study

You are being asked to participate in a study whose purpose is to explore how men and their wives adapt to the demands created by the diagnosis and treatment of localized prostate cancer. Your participation and that of your spouse will help us to understand the impact of the illness and its treatments, how people view this experience, and the factors that may influence the way in which men and their wives adapt to the situation.

At this time there are very few studies which examine the effects of treatments for localised prostate cancer on mens' quality of life or overall adaptation. In addition, there are no studies which examine the non-illness related factors that might influence adaptation in men or in their wives, despite the fact that prostate cancer is one of the most common forms of cancer. Your participation and that of your spouse will help us to better understand your perceptions of the situation, the impact of the illness and its treatment on your quality of life, and the factors that might influence how you adapt to this situation during the first year following the diagnosis. This information will be extremely useful to physicians, nurses, and other health professionals who are involved in the care of families facing this challenge.

The principle investigator in the study is Dr. Louise Bouchard, N. Ph.D., Associate Professor and Nurse Researcher, Faculty of Nursing, University of Montreal. The other investigators participating in the project are:

Hélène Ezer, N., Ph.D (Cand.) University of Montreal,  
Associate Professor, School of Nursing, McGill University;

Mostafa Elhilaly, M.D., Professor & Chairman, Division of Urology,  
Faculty of Medicine, McGill University;

Luis Souhami, M.D., Radiation Oncology,  
Montreal General Hospital;

Armen Aprikian, M.D., Urology,  
Montreal General Hospital;

Claude Trudel, M.D., Director, Department of Urology,  
Centre Hospitalier Cité de la Santé;

Fred Saad, M.D., Urology,  
Centre Hospitalier Notre Dame.

This study is also known and supported by a larger group of urologists in the Montreal area including your own physician, Dr. \_\_\_\_\_.

### Participation Requested

Your participation and that of your spouse will consist of meeting with a researcher on three occasions at your home (or in another place that is convenient to you). The researcher will assist you to complete six questionnaires that include questions about your general perceptions of life events, your husband's symptoms, your family life, your reactions to this particular situation, and finally about your feelings and overall adjustment. These questionnaires include items about sexual desire and sexual activity that are often of concern during prostate cancer. Additional general information including your age, education, work status, and the medical follow-up that each of you are receiving will also be requested. These questionnaires will take about an hour to complete, and will be given to you the first time just after the onset of treatment, the second time three months after the diagnosis, and the third time one year later.

### Confidentiality

Every attempt will be made to ensure the anonymity of your responses. All of the information collected over the course of the study will remain strictly confidential and will be identifiable only by a number, to which only the principle researchers will have access. The information you give will be combined with that of the other men and the other wives participating in the study; the final reports will describe the responses of the group and not those of any particular individual. Upon completion of the study, a summary of the findings will be made available to you.

### Voluntary Participation

Your participation in this study is voluntary. You are free to refuse to participate. You may also withdraw from the study at any time, simply by letting the researcher know of your decision. Your decision not to participate in the study, or to withdraw from the study, will not affect the care either you or your husband would otherwise receive.

Participation in the study may not bring you any immediate advantage, although it may result in more discussion between you and your spouse. However, your participation will help us to understand the impact of the different approaches to treatment for localized prostate cancer. It will also help us to identify the factors that make adaptation easier for both husbands and wives.

### Contact Persons

If you have any questions to ask about the study, or if any unforeseen circumstances arise, or if you wish to withdraw from the study, you may contact Dr. Louise Bouchard (tel.) 343-6111 ext 2327 at the University of Montreal or H el ene Ezer (tel.) 398-4162 at McGill University, at any time. If questions or problems of a medical nature arise over the course of the study, they will be referred to your attending physician.

If you choose not to participate in this study, please return the card which accompanies this letter, indicating your decision. In that case, you will not be contacted again. If you agree to participate, please let us know as well by returning the card. The researcher will contact you to arrange an appropriate time for the first visit. If after two weeks no card is returned, you will also be contacted by phone to give you the opportunity to ask additional questions and to decide about participation.

Louise Bouchard, N., Ph.D.  
or  
H el ene Ezer, N., Ph.D.(cand.)

## Lettre d'Introduction

### Une étude sur l'adaptation d'hommes et de leurs conjointes au cancer non-métastatique de la prostate au cours de la première année suivant le diagnostic

#### Objectifs de la recherche

Votre participation est sollicitée à une étude désirant explorer comment des hommes et leurs conjointes peuvent s'adapter à un diagnostic de cancer de la prostate et à son traitement.

En ce moment, il y a un nombre restreints d'études portant sur l'effet des traitements sur la qualité de vie d'hommes atteints d'un cancer de la prostate. De plus, aucune étude n'a examiné les facteurs non reliés à la maladie qui peuvent influencer leur adaptation et celle de leurs conjointes, et ceci malgré le fait que le cancer de la prostate est un des cancers les plus communs. Votre participation et celle de votre conjoint(e) nous aideront à mieux comprendre votre perception de la situation, l'impact de la maladie et du traitement sur votre qualité de vie, et les facteurs qui pourraient influencer votre adaptation au cours de l'année suivant le diagnostic. Ces renseignements seront fort utiles pour les médecins, les infirmières et les autres professionnels de la santé impliqués dans les soins aux familles ayant à faire face à ce défi.

#### Les responsables de l'étude

Dr. Louise Bouchard, Infirmière, Ph.D., professeure agrégée et chercheuse à la Faculté des Sciences Infirmières de l'Université de Montréal est le chercheur principal de cette étude. Les autres chercheurs impliqués dans le projet sont:

Hélène Ezer, N., Ph.D (Cand.) à l'Université de Montréal,  
Professeure Agrégée, École des Sciences Infirmières,  
Université McGill;

Mostafa Elhilaly, M.D., Professeur & Chef, Division d'Urologie,  
Faculté de Médecine,  
Université McGill;

Luis Souhami, M.D., Département de Radio-Oncologie,  
Hôpital Général de Montreal;

Armen Aprikian, M.D., Département d'Urologie,  
Hôpital Général de Montreal;

Claude Trudel, M.D., Chef du Service de l'Urologie,  
Centre Hospitalier Cité de la Santé;

Fred Saad, M.D., Département d'Urologie,  
Centre Hospitalier Notre Dame.

Cette étude est connue et également soutenue par un groupe plus large d'urologues incluant votre propre médecin, le docteur \_\_\_\_\_.

### Participation demandée

Votre participation et celle de votre conjointe consistera à rencontrer un chercheur à trois reprises à votre domicile (ou à un autre endroit qui vous convient). Le chercheur vous aidera à compléter six questionnaires qui portent sur vos perceptions des symptômes reliés à la maladie, vos perceptions des événements dans la vie quotidienne, vos perceptions de la vie familiale, l'évaluation de l'événement du cancer, et finalement vos émotions et votre adaptation générale. Des renseignements supplémentaires qui portent sur votre âge, votre niveau de scolarité, votre travail, le traitement et le suivi médical seront recueillis. Il est possible que le chercheur consulte le dossier médical des hommes afin de se renseigner sur le traitement médical. Répondre à ces questions demandera environ une heure de votre temps. À trois reprises, chacun des conjoints répondra séparément aux questionnaires: une première fois au début de votre traitement, une deuxième fois trois mois suivant le diagnostic, et une dernière fois un an plus tard.

### Confidentialité

L'anonymat le plus complet sera assuré. Tous les renseignements obtenus durant cette étude demeureront strictement confidentiels; vous ne serez identifié que par un numéro de code auquel seulement les chercheurs principaux auront accès. Les renseignements obtenus seront combinées à ceux d'autres hommes et leurs conjointes participant à l'étude; les rapports écrits traiteront des réponses du groupe et non des individus en particulier. À la fin du projet, un sommaire des résultats vous sera disponible sur demande.

### Participation volontaire

Votre participation à cette étude est volontaire. Vous êtes libre de refuser d'y participer. Vous pouvez également vous retirer de l'étude à n'importe quel moment, tout simplement en faisant connaître votre décision au chercheur. Votre décision de ne pas participer à l'étude ou de vous en retirer n'aura aucune conséquence sur les soins qui vous seront fournis par la suite.

Vous ne retirerez pas d'avantage immédiat en participant à cette étude; il est possible cependant, que l'étude suscite plus de discussions entre vous et votre conjoint(e). D'autre part, votre participation nous aidera à mieux comprendre les effets sur la qualité de vie des différents traitements utilisés pour un cancer de la prostate. Elle nous aidera aussi à identifier les facteurs qui facilitent l'adaptation autant pour les hommes que pour leurs conjointes.



**Personnes à contacter**

Si vous avez des questions à poser au sujet de cette étude, si un incident quelconque vous survient, ou si vous désirez vous retirer de l'étude, vous pouvez contacter en tout temps: Dr. Louise Bouchard (tel.) 343-6111 poste 2327, ou Hélène Ezer (tel.) 398-4162.

Si jamais des questions ou des problèmes d'ordre médical se présentent au cours de l'étude, ils seront rapportés par les chercheurs à votre médecin traitant.

Si vous ne voulez pas participer, veuillez l'indiquer en renvoyant la carte-réponse qui accompagne cette lettre. Dans ce cas, vous ne serez plus contactés. Si vous acceptez de participer, veuillez l'indiquer également sur la carte et la renvoyer aux chercheurs qui vous rejoindront pour planifier une première visite. Si, après deux semaines, votre carte-réponse n'a pas été reçue, le chercheur vous appellera afin de vous fournir l'occasion d'obtenir des réponses à vos questions et de participer à l'étude si vous le désirez.

Nous vous remercions pour l'attention que vous accorderez à notre demande.

Dr. Louise Bouchard, Infirmière, Ph.D.

Hélène Ezer, Infirmière, Ph.D. (Cand.)

**Appendix 5**  
**Consent Forms**

Wives' Consent  
A Study of Adaptation in Men and their Wives to  
Non-Metastatic Prostate Cancer During the First Year Following Diagnosis

The purpose of this study is to explore how men and their wives adapt to the demands created by the diagnosis and treatment of localized prostate cancer. The nature of my participation, as well as the confidential nature of the information that will be collected have been explained to me. I am aware that some questions will deal with issues of a personal nature related to sexuality. I have had the opportunity to ask questions about the study, and have received satisfactory answers.

I, \_\_\_\_\_, voluntarily accept to participate in the study of husbands' and wives' adaptation to localized prostate cancer and its treatment. I know that I am free to withdraw from the study at any time, without jeopardizing my relationship with my husbands' physician or with any other health professionals, or the care that I or my husband might receive.

I acknowledge having received a written description of the study, and that a copy of my consent to participate will be sent to me.

Name of Participant: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

The principal investigator for this study is Dr. Louise Bouchard, N., Ph.D., Faculty of Nursing, University of Montreal. Co-investigators are:

Hélène Ezer, N., Ph.D (Cand.), Associate Professor,  
School of Nursing, McGill University;

Mostafa Elhilaly, M.D., Professor & Chairman, Division of Urology,  
Faculty of Medicine, McGill University;

Luis Souhami, M.D., Radiation Oncology,  
Montreal General Hospital;

Armen Aprikian, M.D., Urology,  
Montreal General Hospital;

Claude Trudel, M.D., Director, Department of Urology,  
Centre Hospitalier Cité de la Santé;

Fred Saad, M.D., Urology,  
Centre Hospitalier Notre Dame.

Formulaire de consentement - conjointes

Une étude sur l'adaptation d'hommes et de leurs conjointes  
au cancer non-metastatique de la prostate  
au cours de la première année suivant le diagnostic

La nature de l'étude, les procédés qui seront utilisés ainsi que le caractère confidentiel des informations requis au cours de l'étude m'ont été expliqués. J'ai eu l'occasion de poser toutes les questions concernant les différents aspects de l'étude et de recevoir des réponses satisfaisantes.

Par la présente, je \_\_\_\_\_, accepte volontairement de participer à cette étude. Je reconnais être libre de me retirer en tout temps sans que cela nuise aux relations avec le médecin et les autres intervenants, et sans préjudice d'aucune sorte.

Je reconnais avoir reçu une lettre d'introduction à cette étude, le nom et numéro de téléphone des personnes à contacter, et qu'une copie de ce formulaire de consentement me sera envoyée.

Nom de la Participante: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Nom du Témoin: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigateur: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Le chercheur principal de cette étude est Dr. Louise Bouchard, Inf., Ph.D., Faculté des Sciences Infirmières, Université de Montréal. Les co-chercheurs sont:

Hélène Ezer, Inf., Ph.D (Cand.), Professeure Agrégée,  
École des Sciences Infirmières, Université McGill;

Mostafa Elhilaly, M.D., Professeur & Chef, Division d'Urologie,,  
Faculté de Médecine, Université McGill;

Luis Souhami, M.D., Département de Radio-Oncologie,  
Hôpital Général de Montreal;

Armen Aprikian, M.D., Département d'Urologie,  
Hôpital Général de Montreal;

Claude Trudel, M.D., Chef du Service de l'Urologie,  
Centre Hospitalier Cité de la Santé;

Fred Saad, M.D., Département d'Urologie;  
Centre Hospitalier Notre Dame.

Mens' Consent

A Study of Adaptation in Men and their Wives to  
Non-Metastatic Prostate Cancer During the First Year Following Diagnosis

The purpose of the study, the nature of my participation, as well as the confidential nature of the information that will be collected have been explained to me. I have had the opportunity to ask questions about the study, and have received satisfactory answers.

I, \_\_\_\_\_, voluntarily accept to participate in the study of husbands' and wives' adaptation to localized prostate cancer and its treatment. I know that I am free to withdraw from the study at any time, without jeopardizing my relationship with my physician or with any other health professionals, or the care that I might receive.

I agree to allow the principal investigator to have access to my record in order to complete the medical information that I may not be able to provide: yes ( ) no ( )

I acknowledge having received a written description of the study, and that a copy of my consent to participate will be returned to me.

Name of Participant: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

The principal investigator for this study is Dr. Louise Bouchard, N., Ph.D., Faculty of Nursing, University of Montreal. Co-investigators are:

Hélène Ezer, N., Ph.D (Cand.), Associate Professor,  
School of Nursing, McGill University;

Mostafa Elhilaly, M.D., Professor & Chairman, Division of Urology,  
Faculty of Medicine, McGill University;

Luis Souhami, M.D., Radiation Oncology,  
Montreal General Hospital;

Armen Aprikian, M.D., Urology,  
Montreal General Hospital;

Claude Trudel, M.D., Director, Department of Urology,  
Centre Hospitalier Cité de la Santé;

Fred Saad, M.D., Urology,  
Centre Hospitalier Notre Dame.

Formulaire de consentement - hommes

Une étude sur l'adaptation d'hommes et de leurs conjointes  
au cancer non-métastatique de la prostate  
au cours de la première année suivant le diagnostic

La nature de l'étude, les procédés qui seront utilisés ainsi que le caractère confidentiel des renseignements requis au cours de l'étude m'ont été expliqués. J'ai eu l'occasion de poser toutes les questions concernant les différents aspects de l'étude et de recevoir des réponses satisfaisantes.

Par la présente, je \_\_\_\_\_, accepte volontairement de participer à cette étude. Je reconnais être libre de me retirer en tout temps sans que cela nuise aux relations avec mon médecin et les autres intervenants, et sans préjudice d'aucune sorte.

J'accepte que mon dossier médical soit consulté par l'investigateur (trice) pour compléter mon profil médical. ( ) oui ( ) non.

Je reconnais avoir reçu une lettre d'introduction à cette étude, le nom et numéro de téléphone des personnes à contacter, et qu'une copie de ce formulaire de consentement me sera envoyée.

Nom du Participant: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Nom du Témoin: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigateur: \_\_\_\_\_  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Le chercheur principal de cette étude est Dr. Louise Bouchard, Inf., Ph.D., Faculté des Sciences Infirmières à l'Université de Montréal. Les co-chercheurs sont:

Hélène Ezer, Inf., Ph.D (Cand.), Professeure Agrégée,  
École des Sciences Infirmières, Université McGill;

Mostafa Elhilaly, M.D., Professeur & Chef, Division d'Urologie,  
Faculté de Médecine, Université McGill;

Luis Souhami, M.D., Département de Radio-Oncologie,  
Hôpital Général de Montreal;

Armen Aprikian, M.D., Département d'Urologie,  
Hôpital Général de Montreal;

Claude Trudel, M.D., Chef du Service de l'Urologie,  
Centre Hospitalier Cité de la Santé;

Fred Saad, M.D., Département d'Urologie;  
Centre Hospitalier Notre Dame.

**Appendix 6**  
**Correlations Between Control Variables and Dependent Variables**

## Appendix 6

### Correlations Between Control and Dependent Variables

	PAIS		POMS	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Age	.000	.997	.058	.636
Years married	.161	.183	.160	.186
Years education	-.043	.723	-.194	.109
No.of major events	.212	.081	.151	.216
Income	-.115	.335	-.200	.092
Treatment type	.013	.919	.017	.891
Language	.017	.888	.083	.496
Personal health problems	-.237	.048	-.161	.182
Professional help sought	-.245	.041	.095	.436



