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Gwendolyn M. Hooper, Student Dr. Dorothy Y. Brockopp, Major Professor Dr. Terry A. Lennie, Director of Graduate Studies



# INFLUENCE OF COPING STYLES ON EMOTIONAL STATE, ILLNESS PERCEPTION, AND INFORMATION SOURCES OF MEN WITH PROSTATE CANCER

# DISSERTATION

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing at the University of Kentucky

> By Gwendolyn Moffett Hooper

> > Lexington, Kentucky

Director: Dr. Dorothy Y. Brockopp, Professor of Nursing

Lexington, Kentucky

2013

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# ABSTRACT OF DISSERTATION

# INFLUENCE OF COPING STYLES ON EMOTIONAL STATE, ILLNESS PERCEPTION, AND INFORMATION SOURCES OF MEN WITH PROSTATE CANCER

Prostate cancer (PCa) has been the leading cause of cancer death in men since1930. While studies pertaining to PCa have primarily focused on the disease and the subsequent side effects of treatment, psychological distress in this group has yet to be adequately addressed. The purpose of this dissertation was to: 1) conceptualize health related quality of life (HRQL) and health seeking behavior of men by describing lifestyle, cultural and health risks associated with being male, 2) evaluate the psychometric properties of the SF-12 Health Survey (SF-12) combined with the urinary and sexual portions of the UCLA PCa Index (UCLA-PCI), 3) investigate the psychological impact, coping styles and informational needs of a group of men diagnosed with PCa who have not yet undergone treatment.

Men have been observed to underutilize health care services despite the fact that they are in poorer health, have higher mortality rates and lower life expectancies than women. Restricting emotions, being oriented toward success, having limited social networks and taking health risks are often associated with being male. Because incontinence and sexual dysfunction, the two most common side effects of PCa treatments impact men's quality of life, portions of the UCLA-PCI and the SF12 were analyzed. The psychometric analysis of the SF-12/UCLA-PCI and its three subcomponents confirmed the validity of the instrument. The SF-12 component had a Cronbach's alpha of 0.87, while the urinary and sexual subscales had a Cronbach's alpha of .86 and .91 respectively. All three scales were found to have good internal consistency.

KEYWORDS: prostate cancer, health related quality of life, coping styles, psychological distress.



Gwendolyn Moffett Hooper Student's Signature

January 23, 2013

Date



# INFLUENCE OF COPING STYLES ON EMOTIONAL STATE, ILLNESS PERCEPTION, AND INFORMATION SOURCES OF MEN WITH PROSTATE CANCER

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January 23, 2013



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iii



which come from Christopher Robin, who said to Winnie the Pooh, "You're braver than you believe, and stronger than you seem, and smarter than you think."



# TABLE OF CONTENTS

| ACKNOWLEDGMENTS  | iii  |
|--|------|
| LIST OF TABLES   | vii  |
| LIST OF FIGURES  | viii |
| CHAPTER ONE  | 1    |
| Introduction   |      |
| Background and Conceptual Framework                                  | 1    |
| Psychological Distress   |      |
| Illness Perception   |      |
| Information needs  |      |
| CHAPTER TWO Health Seeking Behavior in Men: Concept Analysis         | 6    |
| Synopsis   | 6    |
| Introduction   |      |
| Definitions and Uses of the Term Health                              |      |
| Definitions of the Word Seek/ Seeking                                | 9    |
| Definitions of the Word Gender                                       | 10   |
| Definitions of the Word Male   | 10   |
| Lenz's Model of Information Seeking Behavior                         | 11   |
| Men and Healthcare Literature Review                                 | 11   |
| Gender/ Norms/ Attitudes   | 12   |
| Masculinity and Health Seeking                                       | 12   |
| Social Attitudes Affect Men's Health Seeking                         |      |
| Health Care Practices  | 13   |
| Health Risks   | 14   |
| Systems Barriers Affecting Men's Health                              | 14   |
| Defining Attributes of the Concept of Health Seeking Behavior in Men | 14   |
| Attributes and Antecedents   | 14   |
| Assumptions  | 15   |
| Consequences   | 15   |
| Empirical Referents  | 15   |
| Discussion and Indications for Research                              | 16   |
| Conclusions  | 16   |
| CHAPTER THREE Psychometric Properties of a Combined Instrument to    |      |
| Measure Quality of Life in Men with Prostate Cancer                  | 19   |
| Introduction   | 19   |
| Background   | 19   |
| Measures   | 20   |
| SF-12 Health Survey  | 20   |
| UCLA Prostate Cancer Index   | 20   |
| Methods  |      |
| Sample   | 21   |



|      | Procedures   |                |
|------|--|----------------|
|      | Data Analysis  |                |
|      | Results  |                |
|      | Reliability Assessment   |                |
|      | Principal Component Factor Analysis                                    |                |
|      | Discussion   |                |
|      |  |                |
| CHAI | PTER FOUR Coping Disposition, Satisfaction with Information, Perceived |                |
|      | Severity of Illness, and Anxiety among Men Recently Diagnosed with     |                |
|      | Prostate Cancer  |                |
|      | Synopsis   |                |
|      | Introduction   |                |
|      | Background   |                |
|      | Conceptual Framework   |                |
|      | Monitoring and Blunting  |                |
|      | Methods  |                |
|      | Design   |                |
|      | Procedure for Data Collection  |                |
|      | Measurement  |                |
|      | Data Analysis  |                |
|      | Results  |                |
|      | Specific Aim 1   |                |
|      | Specific Aim 2   |                |
|      | Specific Aim 3   |                |
|      | Specific Aim 4   |                |
|      | Specific Aim 5   |                |
|      | Discussion   |                |
|      | Study Strengths and Limitations  |                |
|      | Conclusions/Implications for Research/Practice                         |                |
|      | conclusions, implications for Research, ractice                        | ····· <i>T</i> |
| CHAI | PTER FIVE Conclusions and Discussion                                   |                |
|      |  |                |
| REFE | RENCES   | 55             |
|      | ChapterOne   | 55             |
|      | Chapter Two  |                |
|      | Chapter Three  |                |
|      | Chapter Four   | 63             |
|      |  |                |
| Vita |  | 67             |



# LIST OF TABLES

| Table 2.1. | Key Elements of the Concept Analysis: Health Behavior of Men                  | 18 |
|------------|---|----|
| Table 3.1  | SF-12/UCLA-PCI Descriptives   | 25 |
| Table 3.2  | Total Variance Explained  | 26 |
| Table 3.3  | Rotated Component Matrix  | 28 |
| Table 4.1  | Sample Question from the MBSS   | 44 |
| Table 4.1  | Monitor and Blunter Statistics (N=62)   | 45 |
| Table 4.2. | Demographic Characteristics (N=62)  | 46 |
| Table 4.3. | Satisfaction with Information Sources among High Monitors and<br>Low Monitors | 47 |
| Table 4.4  | Correlation between PSIL and Gleason Score                                    | 48 |
| Table 4.5  | Low and High Monitor participant knowledge of personal Gleason score          | 49 |
| Table 4.6a | Young Monitors (N=32)   | 50 |
| Table 4.6b | Older Monitors (N=30)   | 50 |
| Table 4.7  | Comparison of High and Low Monitors   | 51 |



# LIST OF FIGURES

| Figure 3.1 SF-12/UCLA PCI | Figure 3.1 | SF-12/UCLA PCI |  |  |
|---------------------------|------------|----------------|--|--|
|---------------------------|------------|----------------|--|--|



#### CHAPTER ONE

#### Introduction

World-wide, prostate cancer (PCa) is the second most common cancer in men.<sup>1</sup> It is estimated that 243,740 men in the United States will be newly diagnosed with PCa in 2012.<sup>2</sup> Treatment options include surgery, radiation therapy, surveillance, and hormonal therapy. Presently, there is no opinion as to which treatments are most effective due to lack of clinical trials. Choice of treatment is often based on side effect profiles which can range from mild irritative voiding symptoms to urinary incontinence and/or erectile dysfunction. Quality of life is often sacrificed for a chance at long term survival. Over the past 25 years, the 5 year survival rate for all stages of PCa has increased from 68% to almost 100% with 10-15 year relative survival rates approaching 98% and 91% respectively.<sup>2</sup> Although men with PCa are living longer, some are living with significant side effects including incontinence and sexual dysfunction which can severely impact their quality of life.

Quality of life issues in men with PCa have been studied less than any other form of cancer. <sup>3</sup> Overall, the greater part of research on PCa has focused on medical outcomes, such as PCa treatments, treatment side effects or cancer progression, while psychosocial issues have not been addressed. The few studies available on men's psychological adjustment to cancer as a whole indicate men do not adjust to a cancer diagnosis as well as women. <sup>4, 5</sup> This is concerning, as more men are diagnosed with and die from cancer than women. <sup>6</sup> The purpose of this dissertation was to explore coping styles, psychological impact, informational needs and severity of illness in men diagnosed with PCa.

# **Background and Conceptual Framework**

A prostate cancer diagnosis produces anxiety, psychological distress and denial in men who receive it. The prevalence of psychological distress in this population has been shown to be higher than a similar group of healthy counterparts. <sup>7</sup>Llorente et al., <sup>8</sup> found the rate of suicide among men with PCa was 4.24 times that for men of comparable age who were cancer free. Individuals differ in the way they cope with illness. <sup>9</sup> How



individuals cope has been shown to influence their psychological state, perceived quality of life, <sup>10, 11</sup> likelihood of seeking medical care, <sup>12</sup> and compliance with medical advice. <sup>13</sup>

A relationship exists between gender and health behaviors. In order to understand how men relate to a PCa diagnosis, an analysis of what is presently known about the current state of male health behavior must be included. The beliefs about masculinity and manhood, which are supported by our culture, play a substantial role in constructing how men behave, which have negative consequences for their health. Research has indicated that men are less likely to seek help for medical and psychological illnesses. <sup>14,15,16</sup> Fear of the unknown and anxiety deter men from seeking advice about health issues, <sup>17</sup> and men are less likely to express fear or emotional distress <sup>16</sup>. Charmaz <sup>18</sup> found men's masculinity is greatly affected by illness or disability.

The Cognitive-Social Health Information Processing Model (C-SHIP) focuses on differences in the ways individuals perceive and define stress, and how attentive or pervasive they may be to threat.<sup>19</sup> The conceptual framework utilized for this dissertation and developed by Miller,<sup>19</sup> is a collection of primary theoretical constructs which have emerged from studies in the cognitive, social and health sciences. These constructs include the individual's encoding and self-interpretation of cancer-relevant feedback <sup>20,21,22,23,24,25,26</sup> the individual's affective and emotional responses to cancer threats, <sup>27,24,25,26</sup> and the individual's skills and techniques of self-regulation, coping skills and strategies for dealing with illness. <sup>28</sup> The relationship between these components are suggested by Miller to determine the individual's decision making, adjustment, and behavior in respect to cancer risk and disease.<sup>29,30</sup>

Two types of individuals are identified in the model and are labeled: monitors and blunters. Monitors prefer detailed information, scan for threatening cues and experience anxiety.<sup>31</sup> In contrast, blunters distract themselves and avoid information in order to minimize threat and decrease anxiety.<sup>31</sup> The C-SHIP model as described by Miller <sup>19</sup> is particularly useful in men diagnosed with PCa as decisions regarding PCa are filled with uncertainty. These men have been observed to need and seek information in order to make sense of their illness and to guide them in making treatment decisions. The tendency to monitor, search for, and exaggerate threatening information could cause PCa monitors to experience high levels of anxiety and stress, which may interfere with



2

effective problem solving and coping. PCa blunters, on the other hand, would have a tendency to show less anxiety and greater problem solving ability when compared to monitors. Blunters tend to display avoidant behaviors which could in the long-term lead to detrimental health effects such as rapid cancer progression should the PCa return and follow-up for annual screening be ignored. <sup>32</sup> Monitor and blunter characteristics may lead to signs of depression prevalent in primary care populations. <sup>33</sup> Studies indicate a link between depression, health-seeking behaviors and health status. <sup>34, 35, 36,37,38,39</sup>

This dissertation will focus on the measurement of coping styles utilizing the framework as described by Miller, <sup>19</sup> an analysis of men's health behaviors as a way to show how being male influences health, and a measurement of HRQoL related to PCa treatment, in an attempt to better understand the psychosocial issues related to men and the diagnosis of PCa.

#### **Psychological Distress**

At least two studies have shown that men's psychological adaptation to cancer is poor.<sup>48, 49</sup> Anxiety is the most frequently reported reaction to a diagnosis of PCa cancer and has been reported in men with PCa from a time period beginning with the PSA test and extending through treatment and beyond.<sup>50</sup> Research regarding the psychological impact of a PCa diagnosis has been mixed in that researchers have combined all PCa patients into a single large group. In addition, it is difficult to know exactly what is known about psychosocial issues in men with PCa as previous methods for assessing this information have used methods that have not been designed specifically for men with PCa.

### **Illness Perception**

Illness perceptions are representations or beliefs that patients have about their illness. These beliefs are based on the assumptions that individuals develop their own representation of illness or threat and with an experience or symptom they begin a search for understanding the health threat. <sup>41</sup> As a result, the individual develops a unique perception of illness identity, cause, timeline, consequences, perceived control and emotional reaction to illness.<sup>41</sup> Studies of newly diagnosed hematologic cancer patients, found those who perceived their disease to be more severe had greater emotional distress



<sup>42</sup> and reported higher levels of anxiety and depression. <sup>43, 44</sup> How individuals perceive their illness will likely influence how they are to seek medical care, <sup>45</sup> their quality of life <sup>46</sup> and whether they comply with medical advice. <sup>47</sup> To date, little is known regarding the influence of illness perception on the psychological well-being of men diagnosed with PCa.

## **Information needs**

Patients receiving radiation therapy for breast cancer have been the most frequently studied cancer specific treatment group in relation to cancer and information needs. <sup>56</sup> Cancer patients have been shown to have many informational needs which change in relation to their illness.<sup>53, 54, 55, 56</sup> Information needs vary with age and education. Newspapers, television, friends and other non-medical resources have been found to be primary sources of information for older patients as compared to younger ones. <sup>51</sup> While providing information has been shown to negatively affect coping in some studies <sup>19</sup> positive effects have been identified in the form of faster recovery times, decreased pain<sup>52</sup> and improved mental health and coping.<sup>53,54</sup> Only a few published studies could be located which assessed the informational needs of men with PCa. These studies indicate men desired detailed information about their cancer, its stages and treatment options, <sup>55</sup> survival, self-care and empowerment.<sup>56</sup> In light of the complex nature of cancer patients information needs, and the few studies available on the information needs of men with PCa, it is important to gain knowledge as to how much, what type and when information is appropriate and necessary.

In chapter two of this dissertation, an analysis of health seeking behavior of men is presented. The definitions of gender, norms, attitudes, and masculinity are examined as it relates to health seeking. Social attitudes affecting male health seeking, men's lifestyle, risks for disease and systems barriers affecting men's health are discussed as a way to better understand the impact that gender has on health behavior. Recommendations for clinical practice are also presented.

In chapter three, the results of a study that analyzed the psychometric properties of the SF-12 Health Survey (SF12), and the sexual and urinary domains of the UCLA Prostate Cancer Index (UCLA-PCI), a measure of health related quality of life (HRQL) that measures eight concepts: physical functioning, role limitations due to physical health



problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and mental health are presented. From these eight concepts, two distinct component scores are derived: the physical component and the mental component. <sup>57</sup> The UCLA-PCI is a comprehensive measure of HRQL used to measure urinary and sexual dysfunction of males undergoing treatment for PCa. It consists of five questions related to urinary function, four questions related to bowel function, and six questions related to sexual function. Because urinary and sexual dysfunctions are the two primary side effects of PCa surgery, bowel function was not included in the analysis. The specific aims of the study were to: (1) examine the factor structure of the SF12, mental and physical sub-scales and the urinary and sexual subscales of the UCLA-PCI and (2) evaluate the internal consistency reliability of each dimension identified via factor analysis. Principal components analysis was used to analyze the dimensionality of the subscales. Based on the results, of the Scree plot, four factors were retained and orthogonally rotated using Varimax rotation. Internal consistency reliability testing of the items of the four subscales was conducted using Cronbach's alpha.

In chapter four, the influence of coping styles on anxiety levels, perceived severity of illness, satisfaction with information and the relationship of perceived severity of illness and Gleason score of a sample of men diagnosed with PCa are presented. The specific aims of the study were to: 1) identify the coping styles of monitor and blunter: 2) examine differences in anxiety, depression and stress between the coping styles of monitors and blunters: 3) examine the relationship between monitor and blunter coping styles and perceived severity of illness: 4) examine differences in perceived severity of illness and Gleason score: 5) examine sources of information and satisfaction with information received in a group of men diagnosed with PCa.

Included in chapter five, is a summary of the measurement of coping styles utilizing Miller's framework<sup>19</sup> an analysis of men's health behaviors showing how being male influences health behaviors, and a measurement of HRQL related to PCa treatment. These articles attempt to enlighten the psychosocial issues of men diagnosed with PCa. Finally, recommendations for practice and future research are outlined.

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#### CHAPTER TWO

Health Seeking Behavior in Men: Concept Analysis

#### **Synopsis**

**1. Objective:** This concept analysis examines men's health seeking behavior. The purpose of this paper is to clarify the phenomena of health seeking behavior in men in order to identify attitudes, behaviors and attributes that affect men's health.

**2.** Background: Men and women differ in their health behaviors. The Women's Movement can be credited with identifying important differences.<sup>1</sup> While it is well known that economic status, ethnicity, and access to care influence health behaviors, gender disparity exists regardless of these factors.<sup>2</sup> The World Health Organization<sup>3</sup> (WHO) recognizes that gender differences and gender inequalities can give rise to inequities between men and women in health status and access to health care. Gender warrants analysis and investigation as gender equity has become an important topic in health care reform, both nationally and internationally. In order for health care resources to be equally disbursed similarities and differences among men and women need to be identified.<sup>3</sup> for this reason, WHO has included gender as one of its top health priorities. Health care providers have commonly observed than men underutilize health care services. In fact, this has long been considered the norm. However, it has recently come to the attention of public health entities that significant disparities exist when it comes to the health of men. What is currently known about men and help seeking is limited.<sup>4</sup> It is known that men are in poorer health, have higher mortality rates and lower life expectancies than women in the United States and in most other countries around the world.<sup>2</sup> The lack of awareness of men's health behaviors results in disparities in healthcare delivery, the advancement of disease processes affecting quality of life and poorer outcomes for the health of men. Therefore, it is necessary to define the concepts of health seeking behavior of men in order to recognize and effectively understand how decisions about health are made and how these decisions influence men's health.

**3. Methods:** According to Walker & Avant, <sup>5</sup> steps involved in the process of concept analysis are: 1) describing the uses of the concept, 2) identifying all uses of the concept, 3) determining the defining attributes, antecedents, and consequences and 4) defining the empirical referents of the concept. To begin this analysis, an examination of



6

the definitions of health-seeking, help seeking, and male and gender was performed. Due to the significant influence of gender role in the descriptors of what it means to be male, a gender definition was felt to be necessary in order to understand the concept of being male. Subsequently, an examination of the definitions of these terms was described in the major nursing theories and models. Because much of the literature addressing these concepts was found in the social sciences and psychological literature, a search of terms were included there. Databases used during the literature review included Google Scholar, CINAHL, PubMed, MEDLINE and the Cumulative Index of Nursing and Allied Health Literature. Articles with a focus on health seeking behavior were examined with a concentration on articles dealing with the concept male. Seminal works of Courtenay<sup>6, 7, 8,</sup> <sup>9,10,11,13</sup> were used for a deep exploration into the concept of health seeking behavior in males. Current works in English only were utilized. A recent search of the term in Pub Med listed 7756 hits for health seeking behavior, care seeking behavior, health locus of control, treatment seeking behavior and information seeking behavior. Health care seeking behavior returned 18,889 hits. The purpose of this concept analysis is to explore and identify the essence of the concept of health seeking behavior in men.

**4. Conclusions:** This concept analysis examines men's health seeking behavior utilizing Walker and Avant's concept analysis process.<sup>5</sup> This analysis found men to be in poorer health, having higher mortality rates and lower life expectancies than women in both the U.S. and around the world. Men have strongly endorsed cultural and health-related beliefs, limited social networks, are less likely to seek medical attention, express emotions, and perceive themselves to be less at risk for injury and illness. Healthcare systems were difficult for men to navigate and studies showed men received less advice and had less time with them from physicians. Urology nurses were found to be in a unique position to improve men's health and well-being.

Key words: Health Seeking Behavior, Men, Concept Analysis



#### Introduction

This concept analysis examines men's health seeking behavior. Identifying as many uses as possible of a concept, sorting through those usages and determining which aspects of the concept are most pertinent, is the third step in Walker and Avant's,<sup>5</sup> concept methodology. Dictionaries, thesauruses, and nursing literature were consulted to determine uses and meanings of the words healthcare seeking behavior and male. Methods of Walker and Avant<sup>5</sup> were utilized to identify antecedents, define attributes, consequences, and empirical referents. Concept analysis methodology advances knowledge, understanding and communication in all areas of nursing.

# Definitions and Uses of the Term Health

The word health can be used as a noun. Health denotes a condition of being sound in body, mind, or spirit, freedom from physical disease or pain, the general condition or state of the body, and a toast to someone's health or prosperity.<sup>14</sup> Florence Nightingale, in her *Notes on Nursing: What it is and What it is Not*, <sup>15</sup> defined health as the most important aspect of the human body. The American Nurses Association<sup>16</sup> defines nursing as an agent in the protection, promotion, and optimization of health. The World Health Organization<sup>3</sup> since 1948 has defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Key factors that have been found to influence whether people are healthy or unhealthy include: income and social status, social support networks, education and literacy, employment/working conditions, physical and social environments, personal health practices and coping skills, health child development, biology, genetics, health care services, gender and culture.

After searching the literature for articles with the words health-seeking in the title, it became clear that several other terms were associated with the term health-seeking. These words were help-seeking, care seeking, health care seeking, health locus of control, treatment seeking behavior, ineffective coping and information seeking. Health seeking behavior has become an important subject, as healthcare utilization has become a prominent topic in health care reform both nationally and internationally.



#### **Definitions of the Word Seek/ Seeking**

Seek is the root word for the term seeking. There are 5 distinct listings for the word seeks. It is used as a verb and a noun. When used as a verb, it means to go in search of, look for, to try to discover, to ask for, to try to acquire or gain, to make an attempt. <sup>17</sup> When used a noun, it denotes a series of notes upon a horn calling out to hounds to begin a chase.<sup>18</sup> While all the uses of the term seek as a verb are more congruent with the concept of health seeking, and the use of the term as a noun is not, it was therefore eliminated from the analysis.

The use of the word health seeking in nursing literature is found in the North American Nurses Diagnosis Association (NANDA)<sup>19</sup> definition under the nursing diagnosis of ineffective health maintenance. The NANDA definition and defining characteristics include: an inability to identify, manage or seek out help to maintain health. Defining characteristics include a history of lack of health-seeking behavior; reported or observed lack of equipment, financial, and/or other resources; reported or observed impairment of personal support systems; expressed interest in improving health behaviors; demonstrated lack of knowledge regarding basic health practices; demonstrated lack of adaptive behaviors to internal and external environmental changes; reported or observed inability to take responsibility for meeting basic health practices in any or all functional pattern areas. Related factors of health seeking include: disabled family coping, perceptual-cognitive impairment due to complete or partial lack of gross or fine motor skills; lack of or significant alteration in communication skills (written, verbal, or gestural); unachieved developmental tasks; lack of material resources; dysfunctional grieving; disabling spiritual distress; inability to make deliberate and thoughtful judgments; and ineffective coping. Ackley's Nursing Diagnosis Handbook 8th Edition <sup>20</sup> definition includes personal actions to promote optimal wellness, recovery, and rehabilitation. All of these definitions are congruent with nursing practice. However, for the purpose of this analysis, ineffective coping, and demonstrated lack of knowledge regarding basic health practices will be used to define the concept.



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## **Definitions of the Word Gender**

The word gender is used as both a noun and verb. When used as a noun, there are 4 definitions. A division of nouns and pronouns (and sometimes other parts of speech), such as masculine, feminine, neuter and common; a division between classes or kinds; the mental analog of sex: one's maleness, femaleness, etc., as seen from their own perspective. Gender can be defined as a socio-cultural phenomenon that divides people into various categories such as "male" and "female" with each having associated dress, roles, stereotypes. When used as a verb it means to engender. <sup>21</sup> Professor John Money a professor at Harvard University introduced the term gender which made a distinction between biological sex and gender as a role in 1955. It did not come into widespread use until the 1970's when feminist theory embraced the distinction between biological sex and the social construct of gender. Now, gender includes not just one's status as a man or a woman, but is a matter of personal recognition, social assignment, or legal determination; not only is gender based on one's genitalia but also on the basis of somatic and behavioral criteria that go beyond genital differences.<sup>22</sup> The WHO <sup>23</sup> defines gender as socially constructed roles, behaviors, activities, and attributes that a given society considers appropriate for men and women. The WHO<sup>23</sup> definition will be used to define gender in the context of this paper.

# **Definitions of the Word Male**

The word "male" is used as both a noun and an adjective. It has meaning in Biology, Geography, Geology and Law. When used as an adjective, the word "male" has 11 separate and distinct meanings including: characteristics or behaviors such as a deep masculine, virile voice, or other attributes or conduct deemed by a culture of society to be especially appropriate to or ideally associated with men or boys, <sup>24</sup> Being capable of producing fertilization, but not bearing fruit as in stamens and antheridia, and of the plants, or parts of plants, which bear them. <sup>25</sup> The shield and spear of the Roman god Mars, which is also the alchemical symbol for iron, represents the male sex.<sup>25</sup>

When used as a noun, the word "male" has the following meanings; 1) an animal that produces gametes (spermatozoa) that can fertilize a gamete (ova), <sup>24</sup> 2) a person who belongs to the sex that cannot have babies, 3) the capital of the country Maldives,<sup>24</sup> and



the sex of a person, animal or plant. <sup>25</sup> Synonyms for the word Male, masculine and virile are adjectives that describe men and boys or attributes and conduct that are culturally ascribed to males. In American and Western European culture, these behaviors have traditionally included impatience at indecision which is also a characteristic. <sup>25</sup> It is important to note, that in discussions of men and health, 'men's health' is a term frequently used by the media, academics, health practitioners and the general public and usually implies male specific conditions having to do with problems associated with the prostate or testicles and erectile dysfunction. <sup>26</sup> For the purpose of this paper, men's health will be defined as all social, cultural, biologic and psychological conditions specific and unique to men's health.

## Lenz's Model of Information Seeking Behavior

Dictionary definitions provide insight into meaning of health-seeking. In order to anchor this term to nursing theory and models, the Lenz's model of information seeking <sup>27</sup>was examined. This model focuses on the patient as the active seeker of information and acknowledges the acquisition of health related information outside the formal teaching-learning situation. Lenz noted that individuals obtain health information by two means: active search and passive acquisition. This behavior is initiated when specific events occur which trigger recognition by the individual that information is needed. When an actual or potential health problem exists, the individual seeks information by using either personal sources (friend, someone diagnosed with the same illness-information sought by someone known by the searcher) or impersonal sources (inanimate resources such as publications or someone unknown to the searcher). A combination of both sources is often used in the active search process. <sup>27</sup>

# Men and Healthcare Literature Review

As mentioned previously, current knowledge about why men do or do not seek healthcare is limited. <sup>4</sup> However, the few studies available give insight into what is currently known about men's health seeking behavior. Men's' health will be described in terms of gender/norms/attitudes masculine, social, health behaviors, health risks, systems barriers, and healthcare practices that affect health behaviors.



## **Gender/ Norms/ Attitudes**

Males in North America strongly endorse cultural and health-related beliefs that they are independent, self-reliant, strong, robust, tough. Men feel pressure to adopt these beliefs.<sup>8, 28, 29</sup> Gender role socialization theories hold that men and women acquire gendered behaviors and attitudes from the cultures in which they live. Norms (prescriptions for how men and women should behave) and stereotypes (generalizations about what men and women like) guide attitudes and behavior related to health behaviors.<sup>30, 31</sup> O'Neil <sup>32</sup> identified 4 categories of gender-role conflict: 1) orientation to success, power and competition, 2) restricting emotions, 3) restricting of affectionate behavior between men, 4) and conflicts between work and family. These components were felt to contribute to attitudes which had a negative impact on help seeking in men.<sup>33</sup> <sup>Self</sup>-blame was found to be an important mediator between masculine norms and attitudes toward the health-seeking process.<sup>34</sup>

# **Masculinity and Health Seeking**

Men's masculinity is greatly affected by illness or disability.<sup>35</sup> At present, cultural beliefs men hold about masculinity and manhood play an important role in shaping patterns of behavior which can negatively impact their health. Courtenay <sup>9</sup> lists denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, dismissal of any need of help, a ceaseless interest in sex, and display of aggressive behavior and physical dominance as the prevalent masculine characteristics of males. Pyke <sup>36</sup> found masculine characteristics exhibited by men included being more powerful and less vulnerable than women and having bodies which were more efficient and superior to women's bodies, while Vogel <sup>37</sup> found men associated asking for help and caring for one's health a feminine characteristic. Vogel <sup>37</sup> also pointed out that the most powerful men were those for whom health and safety were irrelevant. He also theorized that men who incorporated messages about dominant masculine behavior might view help seeking as a failure to live up to these incorporated masculinity rules. <sup>37</sup>

# Social Attitudes Affect Men's Health Seeking

Courtney <sup>9</sup> found that men have limited social networks and respond to stress in less healthy ways than women as they use less avoidant coping strategies such as denial



and distraction. <sup>38</sup> Men tend to view their partners and friends as primary resources for health information and assistance with health matters. <sup>39</sup> One study found men get most of their support for health concerns from their female partners, and little from their male friends.<sup>40</sup> Studies on men and distress have found that men deny their physical or emotional distress and attempt to conceal their illnesses or disabilities .<sup>34, 11, 41</sup> Men were also less likely to rely on themselves, more likely to withdraw socially, and less likely to try to talk themselves out of feeling depressed.<sup>8</sup>

# **Health Care Practices**

Tudiver & Talbot <sup>40</sup> found that perceived vulnerability, fear, and denial were important influences as to whether men seek help. Their study, which consisted of family practice patients, found that men initially used an indirect method when seeking help. Men were also found to be more likely to focus on physical problems and less likely to disclose mental and emotional problems. <sup>42</sup> Courtenay <sup>10</sup> found men were less likely to seek help for medical and psychological illnesses, less likely to get regular checkups and to conduct self-examinations, use fewer medications, vitamins, and dietary supplements, sleep less and less well, and stay in bed to recover from illness less time than women. These unhealthy lifestyles and poor health behaviors were found across racial and ethnic groups.<sup>12</sup>

Saltonstall <sup>43</sup> in a study on health practices in everyday life demonstrated that work activities often take precedence over positive health related activities. While corporations expect men to work 12-14 hour days, (limiting access to healthcare) men themselves, expect to be rewarded with money, power, position, and prestige all of which society endorses, accepts and encourages.<sup>9</sup> Data from the CDC indicate twice as many men as women have no regular source of medical care.<sup>44</sup> Men are less willing to seek help when they need it. <sup>6,9,11</sup> report fewer symptoms of physical and mental illness, <sup>45,46</sup> report their health to be better than their friends or peers <sup>47</sup> and are less likely to notice signs and symptoms of illness when they are ill.<sup>48</sup> Men were found to feel they had less control over their personal health and were less likely to feel their personal actions contributed to good health.<sup>49,50</sup> Fear of the unknown and anxiety were found to deter men from seeking advice about health issues.<sup>51</sup> Men are less likely to express fear or emotional distress,<sup>11</sup> except for anger. <sup>52, 11</sup> They were also found to be less likely to



discuss experiences of pain or physical distress, report less pain, less severe pain, have a greater tolerance of pain and higher pain thresholds with shorter pain duration.<sup>53, 54</sup>

# **Health Risks**

Risk of disease and lifestyle are closely correlated in men.<sup>13</sup> Men are less likely to wear seat belts,<sup>55, 56</sup> are less likely than women to perceive themselves as being at risk for illness and injury, <sup>57,58,59,60,61</sup> and perceive less risk associated with the use of cigarettes, alcohol, and other drugs than females. <sup>62, 63, 64</sup> Zuckerman <sup>65</sup> found men underestimated the risks associated with engaging in physically dangerous activities such as dangerous driving.<sup>58, 62, 60</sup>

# Systems Barriers Affecting Men's Health

Men may be reluctant to wait for appointments to see a healthcare provider .<sup>10</sup> Courtenay <sup>10</sup> theorized that identifying with social norms may make men feel that health services are primarily for women and children, and therefore, sitting in a waiting room full of women and children is uncomfortable for them. He also notes that men may lack understanding of such simple tasks as the process of making appointments and negotiating those appointments with a female receptionist. <sup>10</sup> In contrast, women are introduced to healthcare through three avenues: gynecological/pregnancy, primary parent-role with females being responsible for taking children to the doctor for well-care and/or sickness, and through care-taking roles for parents and grandparents. Tudiver & Talbot <sup>40</sup> found that having time, access to care, having to state the reason for a visit and the lack of a male care provider were systems barriers for men. Courtenay <sup>10</sup> also found that men spend less time with physicians than do women and receive less advice from physicians about risk factors for disease.

# Defining Attributes of the Concept of Health Seeking Behavior in Men

#### **Attributes and Antecedents**

After distinguishing all usages of the terms, defining attributes and antecedents are the next steps in concept analysis. This process consists of determining which characteristics are most frequently associated with the concept.<sup>66</sup> To define the attributes and antecedents of the concept of health seeking behavior in men, journal articles



searched were those containing the words help seeking, men and gender in the title. Antecedents are events or incidents that must occur prior to the occurrence of the concept and are risk factors that precede or cause the concept.<sup>5</sup>

# Assumptions

The following assumptions can be made about the health seeking behaviors of men: (i) Men's health-seeking is complex and multidimensional based on biological, social and psychological differences; (ii) men approach healthcare using indirect methods; and (iii) there is a need in our present health care system to recognize and properly address differences in the health seeking behaviors of men and women in order to influence, modify and effectively prevent disease states in men.

#### Consequences

Consequences are considered events or incidents that occur as a result of the occurrence of the concept.<sup>5</sup> The consequences of men and their lack of health seeking behavior can be described as those conditions that are preceded by the concept and are the outcome of the concept. Table 1 lists the Antecedents, Attributes and Consequences of the concept of men and health seeking behavior.

# **Empirical Referents**

The final step in Walker and Avant's <sup>66</sup> method of concept analysis is empirical references. Empirical references present how the concept is to be measured or what the observation of a phenomenon should be in reality. It is the event that demonstrates the existence of the concept. Presently, there is need of collaboration across disciplines in order to investigate men's health to prevent longstanding health threats to men.<sup>67</sup>

Presently, because instruments are not available to assess the concept of healthseeking behavior in males, assessment can be indirectly measured in nursing through instruments that assess gender, psychological, social and health seeking behaviors. Mansfield & Courtenay <sup>68</sup> designed a measure to assess and identify reasons men do not seek professional help for mental and physical health problems. The Barriers to Help Seeking Scale (BHSS) consists of five subscales including: Need for Control, Self-Reliance, Minimizing Problem and Resignation, Concrete Barriers, Distrust of Caregivers, Privacy and Emotional Control. The Gender Role Conflict Scale (GRCS) <sup>32</sup>



assesses male gender-role conflict, which is defined as a "psychological state in which socialized gender roles have negative consequences on the person and others". The GRCS consists of 37 statements and is comprised of four subscales, including Success, Power and Competition; Restrictive Emotionality; Restrictive Affectionate Behavior between Men; and Conflict between Work and Family and is the only scale available to assess help for physical and mental health problems. Attitudes Toward Seeking Professional Psychological Help Scale (ASPPH) 70 is the most widely used measure of attitudes toward seeking professional help which targets the importance of advancing in one's professional life, keeping emotions in check, wielding power over people and situations, and showing discomfort with homosexual behavior between men.<sup>69</sup>

# **Discussion and Indications for Research**

Urology nurses are in a unique position to improve the health and wellbeing of men. According to the CDC <sup>70</sup> data for physician visits by men for conditions such as interstitial cystitis, <sup>71</sup> urinary tract infections, <sup>72</sup> urinary incontinence, <sup>72</sup> benign prostatic hyperplasia, lower urinary tract symptoms, <sup>73</sup> erectile dysfunction and prostate cancer <sup>73</sup> total well over 16.9 million per year. Helgeson <sup>73</sup> found men often find it easier to show emotion and self-disclose to women than to other men, while Henderson <sup>74</sup> found that having a female physician is associated with a greater likelihood of receiving both preventive counseling and increased likelihood of receiving more gender specific screenings for both male and female patients. The Society of Urologic Nurses and Associates, (SUNA) is the professional organization for urology nurses who diagnose and treat urologic conditions, and consists of over 3,000 members the majority of whom are female. <sup>76</sup> Urology nurses are an untapped resource and potential leaders in the investigation of men and their health care issues.

## Conclusions

This concept analysis was undertaken to clarify the meaning of men's health seeking behavior. Unfortunately, there is still much work to be done in the area of men's health. Presently, in the Republic of Ireland, Scotland and England, there is a growing body of research which has assisted in conceptualizing 'health' for groups of men, including gay and isolated groups which serve as the basis for European men's health



services.<sup>26</sup> Additionally, U. S. Public Health Services have recently begun to address men's health practices and practitioners of health and policy to construct and give meaning to this important issue.<sup>70</sup> As a result of these initiatives, gender-based medicine and healthcare are receiving increasing attention in both literature <sup>77,78</sup> and media. <sup>15</sup> Knowledge about gender is important and will benefit men who at present are underserved by healthcare due to a lack of understanding of their health care behaviors. Nurses can be leaders in understanding and investigating the future of men's health.

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| Attributes               | Antecedents  | Consequences   |
|--------------------------|--|--|
| Gender Norms & Attitudes | Smaller social networks  | Physical disease   |
| Masculinity              | Society endorsed norms   | Smoking  |
| Social Attitudes         | Underutilization of health services  | Alcohol Use  |
| Health Care Practices    | Attitudes about sick role/ self - exams  | Reckless/illegal driving   |
| Health Risks             | Denial of Threats of Illness or<br>Injury  | Obesity  |
| Health System Barriers   | <ul> <li>Non-compliance with treatment regimens</li> <li>Knowledge deficit concerning diseases &amp; health</li> </ul> | <ul> <li>Chronic/Fatal disease</li> <li>Physical altercations</li> <li>Work/family conflicts</li> <li>Work hazards</li> <li>Weapons use/criminal activity</li> </ul> |

Table 2.1. Key Elements of the Concept Analysis: Health Behavior of Men

Adapted from Courtney, W. (2003). 30 key determinants of health and well being of U.S. men and boys. *International Journal of Men's Health*, 2 (1).



# CHAPTER THREE

Psychometric Properties of a Combined Instrument to Measure Quality of Life in Men with Prostate Cancer

## Introduction

The purpose of this paper was to analyze the psychometric properties of a combined instrument to measure quality of life in men with prostate cancer. The Short Form Health Survey (SF-12)<sup>1</sup> is a well known and widely used quality of life measure to assess physical and mental health. The UCLA Prostate Cancer Index (UCLA-PCI) is a self-administered, comprehensive measure of health related quality of life (HRQoL) for men with localized prostate cancer, which measures function and bother in the urinary, sexual, and bowel domains.<sup>2</sup> The study of prostate cancer is complex, due to cancer stage, time since diagnosis and variations in treatment. Currently, few validated instruments are available which specifically target quality of life in men with prostate cancer. This study utilizes the SF-12 and the urinary and sexual portions of the UCLA-PCI to assess health-related quality of life (HRQoL) in an observational database of men with prostate cancer, one month following laparoscopic radical prostatectomy.

## Background

World-wide, prostate cancer is the second most common cancer in men.<sup>3</sup> It is estimated that 241,740 men in the United States will be newly diagnosed with prostate cancer in 2012.<sup>4</sup> Health related quality of life (HRQoL) in men with prostate cancer is important as 5 year survival rates over the past 25 years, have increased from 68% to almost 100% for all stages of prostate cancer. In addition, 10-15 year relative survival rates are approaching 98% and 91% respectively.<sup>4</sup> Treatment options for prostate cancer include: radiation therapy, hormonal therapy, surgery, chemotherapy or watchful waiting. Each of these treatment options impact quality of life in various ways. In addition to overall threat of quality of life, two areas of major concern which impact men's physical, mental, and social health have long been and still remain urinary and sexual function.

There is no gold standard for measuring quality of life.<sup>5</sup> Definitions of quality of life vary among investigators, however, most agree that quality of life is a



multidimensional concept that includes some aspects of physical, functional, social and emotional functioning.<sup>6, 7, 8</sup> The quality of life of prostate cancer patients has been studied less than that of other neoplasms, <sup>9</sup> despite the fact that men strongly consider quality of life issues when choosing prostate cancer treatments.<sup>10</sup>

Based on an extensive review of the literature, nineteen instruments were found that have been used to assess quality of life in men with prostate cancer. These instruments include generic approaches to HRQL, cancer-specific, and disease and symptom specific methods. There are no valid, reliable tools to measure quality of life specific to these men. This study attempts to identify whether two valid, reliable instruments, the SF-12 and the urinary and sexual portions of the UCLA-PCI can capture general HRQL using the eight health concepts and identify urinary and sexual dysfunction in men with prostate cancer. In addition to capturing physical well-being, mental status, pain, social and functional concepts, the SF-12 identifies the time frame in which the assessment takes place, making this instrument useful in assessing quality of life throughout the trajectory of prostate cancer diagnosis and treatment.

# Measures

#### SF-12 Health Survey

The SF-12 is a shortened version of the SF-36 health survey. It uses 12 questions to measure health and well being from the perspective of the respondent and takes 2-3 minutes to complete, which makes it convenient in clinical situations, and is useful for disease specific populations. The SF12 is a practical, reliable, and a valid measure of physical and mental health as it covers the same eight domains of the SF-36, i.e. physical functioning, physical, pain, mental health, emotional, social functioning, vitality and overall general health, taken from the 40 concepts included in the Medical Outcomes Study. It includes two summary scores, a Physical Component Summary and a Mental Component Summary. The SF-12 also has the ability to measure a current symptom or symptoms within a specific time period.<sup>2</sup>

# **UCLA Prostate Cancer Index**

The UCLA-PCI is a comprehensive measure of HRQL for men with localized prostate cancer that can be self-administered. It was developed to assess the urinary,



bowel, and sexual function of males experiencing treatment for prostate cancer. It consists of five questions related to urinary function, four questions related to bowel function and six questions related to sexual function. The questionnaire was designed from the patient's perspective, using focus groups and patient surveys to determine what areas were deemed most important. <sup>11</sup> The UCLA-PCI has been validated previously in a similar patient population and was found to be reliable and valid in evaluation of HRQoL issues. Test -retest reliability ranged from .66 to .93 and internal consistency ranged from .65 to .93.<sup>2</sup> For men diagnosed or having completed therapy for prostate cancer, the UCLA-PCI showed adequate test-retest and internal consistency reliability and construct validity by comparing sexual-function in patients with and without cancer.

### Methods

# Sample

The SF-12/UCLA-PCI was administered to a sample of 140 men diagnosed with biopsy confirmed prostate cancer. The subjects completed a written questionnaire during their 1 month postoperative visit after undergoing a prostatectomy at a university medical center. Mean age of the participants was 58.48 (SD=7.69) years with a range of 40-85 years. They were predominantly Caucasian (93%), married (92%) and well educated with 63% having a college education or beyond.

# Procedures

This study was approved by the institutional review board at the study site. Participants were recruited from patients who had positive biopsy results and underwent prostatectomy as their choice of treatment. Eligible and interested men were contacted in person in the urology clinic. Eligible men provided informed consent and Health Information Portability and Accountability Act authorization. Once consent was received, participants were asked to complete the survey instruments approximately one week after undergoing surgery.

## **Data Analysis**

Data for this study were analyzed using SPSS version 20. The SF-12/UCLA-PCI instrument and its 3 components, SF-12, UCLA-PCI Urinary Dysfunction and UCLA-PCI Sexual Dysfunction were analyzed. SF-12 Cronbach's alpha coefficient was



calculated for the SF-12/UCLA-PCI to provide an estimate of internal consistency and reliability. All of the scales were scored by summing the item responses after reversing the scoring of some items to insure that a higher score was always indicative of positive health status. Pearson's correlations were used to examine relationships among the subscales.

#### Results

#### **Reliability Assessment**

A reliability analysis of the SF-12/UCLA-PCI instrument and its three components, SF-12 (12 items), UCLA-PCI Urinary Dysfunction (5 items) and UCLA-PCI Sexual Dysfunction (6 items), was conducted for the sample (*n*=140). Cronbach's α statistics were computed for the instrument and each of the three components. The complete SF-12/UCLA-PCI instrument had a Cronbach's alpha of .89. The SF-12 component had a Cronbach's alpha of .90. This indicates that the SF-12/UCLA-PCI instrument and its SF-12 component have very good internal consistency. A similar reliability analysis was performed on the Urinary Dysfunction Summary (UDS) and Sexual Dysfunction Summary (SDS) scales of the UCLA-PCI. A Cronbach's alpha of .92 was reported for the UCLA-PCI; a Cronbach's alpha 92 was reported for the Urinary Dysfunction portion of the UCLA-PCI. All of these results are consistent with very good to excellent internal consistency reliability.

#### **Principal Component Factor Analysis**

A Principal Component Factor Analysis using the Kaiser criteria of factors with eigenvalues greater than one and Varimax Rotation confirmed that the SF-12/UCLA-PCI was quite adequately represented by four factors representing 66.4% of the variance. Factor loadings were excellent; they ranged from .51 to .93. Questions 17a, 17b, 18, 19, 20 and 21 corresponding to the SDS of the UCLA-PCI loaded on Factor 1 (21.3% Variance). Questions 1, 4a, 4b, 6a, 6b, 6c and 7 corresponding to the Mental Component Summary (MCS) of the SF-12 loaded on Factor 2 (17.6% Variance). Questions 8, 9, 10, 11 and 12, corresponding to the UDS of the UCLA-PCI, loaded on Factor 3 (15.2% Variance). Questions 2a, 2b, 3a, 3b, and 5, corresponding to the Physical Component



Summary (PCS), loaded on Factor 4 (12.2% Variance). Data were standardized and variables were reverse scored as indicated. A principal components analysis with Varimax orthogonal rotation was conducted on the 23 items, N=140. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO=.84.<sup>11</sup> All KMO values for individual items were >.71. Bartlett's test of sphericity chi square (253) =1974.81, p<.001, indicated that correlations between items were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues for each component in the data. Five components had eigenvalues greater than Kaiser's criterion of 1 and in combination explained 68.43% of the variance. Analysis of the scree plot (Figure 3.1) revealed an inflection point that supports the retention of four components that explain 63.77% (Table 3.2) of the variance. The small increase in variance did not justify the increased complexity of the 5 component model so 4 components were used. Factor loadings after rotation shown in Table 3.3 are excellent, they range from .44 to .93 Questions 17 to 21, corresponding to the Sexual Dysfunction Summary (SDS) of the SF-12/UCLA-PCI, loaded onto Factor 1 (20.15% Variance). The Urinary Dysfunction Summary (UDS), questions 8-12, loaded onto factor 3 (14.83% Variance). Questions 1, 4a, 4b, 6a, 6b, 6c and 7 corresponding to the Mental Component Summary portion of the SF-12, loaded onto Factor 2 (17.22% Variance). Questions 2a, 2b, 3a, 3c and 5, corresponding to the Physical Component Summary portion of the SF-12 loaded onto Factor 4 (11.56% Variance). The inter-item Pearson correlation coefficients of the scales of the SDS exceeded .40 (Range: .40-.88) and were statistically significant at the .001 level. Cronbach's alpha was .92 for the SDS. The inter-item correlation matrix of the MCS showed a significant (p<.03 for all) Pearson coefficient range of .17 to .77. Cronbach's alpha was .82 for the MCS. All of the inter-item Pearson correlation coefficients of the scales of the UDS exceeded .45 (Range: .45 - .74) and were statistically significant at the .001 level. Cronbach's alpha was .86 for the UDS. The inter-item Pearson correlation matrix of the PCS showed a highly significant (p<.001 for all) range of .32 to .68. Cronbach's alpha was .82 for the PCS. These results confirm the presence of very good internal consistency within the four subcomponents of the SF-12/UCLA-PCI.

Total SDS, MCS, UDS and PCS scores were obtained by summation of their subscales and standardized. Maximum possible scores were, respectively, 29, 35, 20 and



21. Mean SDS score was 15.34 (SD=7.88). Mean MCS score was 28.85 (SD=4.51). Mean UDS score was 16.14 (SD=4.45). Mean PCS score was 18.29 (SD=3.11). A correlation analysis was then performed. A highly significant (p<.001) and very strong correlation of .62 was found between the MCS and PCS. A strong correlation of .39 (p<.001) was found between the SDS and UDS components. UDS was moderately correlated with PCS and MCS (r=.33, p<.001, r=.18 p=.02). SDS was weakly correlated with MCS (r=.12, p=.09) and PCS (r=.23, p=.004).

# Discussion

Overall results from this study indicate that the SF-12 combined with the urinary incontinence and sexual function domains of the UCLA-PCI is a reliable and valid instrument in assessing HRQL in men who have recently undergone prostatectomy. The internal consistency reliability was very good to excellent with Cronbach's alpha exceeding .81 on all scales in the general and disease specific domains. The moderately weak correlation (.12) between the SF-12 mental subcomponent and the sexual dysfunction component of the UCLA-PCI (p<.08) is not surprising as others <sup>13</sup> found shortcomings in its ability to differentiate among causes of sexual inactivity which, similar to prostate cancer, has few available well tested measures which have been used in general clinical practice.<sup>12</sup> The SF-12 has been well tested in a variety of populations and diseases. The UCLA-PCI has seen more limited usage. The findings from this study add support to the small number of studies found in the literature on the reliability and validity of this instrument in men with prostate cancer. This instrument demonstrated good reliability and validity and the data support its use in assessing HRQoL in men with prostate cancer. Use of this self-administered questionnaire has potential for evaluating the state of health of men with prostate cancer. Lastly, the results support the need for HRQoL measures in the assessment of men with prostate cancer.

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| Item                                    | Mean | Std. Deviation <sup>a</sup> | Question        | Factor |
|---|------|-----------------------------|-----------------|--------|
| Overall Health Status                   | .73  | .18                         | 1 <sup>b</sup>  | MCS    |
| Limitation of Moderate Activity         | .90  | .18                         | 2a              | PCS    |
| Limitation of Climbing Stairs           | .91  | .19                         | 2b              | PCS    |
| Physical health limited activities/work | .83  | .22                         | 3a              | PCS    |
| Physical health limited type of work    | .86  | .20                         | 3b              | PCS    |
| Mental health limited activities/work   | .87  | .19                         | 4a              | MCS    |
| Mental health affected quality of work  | .89  | .18                         | 4b              | MCS    |
| Pain interference with work/activities  | .89  | .17                         | 5 <sup>b</sup>  | PCS    |
| Feelings of calm and peacefulness       | .77  | .16                         | 6a <sup>b</sup> | MCS    |
| Degree of Energy                        | .69  | .20                         | 6b <sup>b</sup> | MCS    |
| Experience Depression                   | .79  | .22                         | 6с              | MCS    |
| Physical/Mental health limit socially   | .90  | .17                         | 7               | MCS    |
| How often leaked urine                  | .64  | .33                         | 8               | UDS    |
| Degree of urinary control               | .82  | .18                         | 9               | UDS    |
| Quantity of daily pads used             | .87  | .23                         | 10              | UDS    |
| Problem with dripping urine             | .75  | .29                         | 11 <sup>b</sup> | UDS    |
| Urinary function problem                | .79  | .25                         | 12 <sup>b</sup> | UDS    |
| Ability to have an erection             | .48  | .29                         | 17a             | SDS    |
| Ability to reach orgasm                 | .55  | .30                         | 17b             | SDS    |
| Quality of erection                     | .65  | .31                         | 18              | SDS    |
| Frequency of erection                   | .48  | .33                         | 19              | SDS    |
| Ability to perform sexually             | .47  | .30                         | 20              | SDS    |
| Overall sexual function                 | .57  | .38                         | 21 <sup>b</sup> | SDS    |

<sup>a.</sup> For each variable, missing values are replaced with the variable mean. <sup>b.</sup>Reversed scale



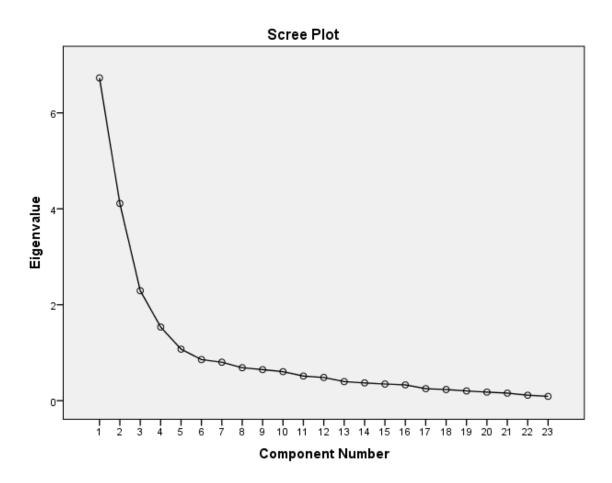
| Component | Initial Eigenvalues |               |              | Extraction | n Sums of Sq | uared Loadings | Rotation Sums of Squared Loadings |          |              |
|-----------|---------------------|---------------|--------------|------------|--------------|----------------|-----------------------------------|----------|--------------|
|           | Total               | % of Variance | Cumulative % | Total      | % of Var     | Cumulative %   | Total                             | % of Var | Cumulative % |
| 1         | 6.73                | 29.26         | 29.26        | 6.73       | 29.26        | 29.26          | 4.64                              | 20.15    | 20.15        |
| 2         | 4.11                | 17.87         | 47.13        | 4.11       | 17.87        | 47.13          | 3.96                              | 17.22    | 37.38        |
| 3         | 2.29                | 9.98          | 57.09        | 2.29       | 9.97         | 57.09          | 3.41                              | 14.83    | 52.21        |
| 4         | 1.54                | 6.68          | 63.77        | 1.54       | 6.68         | 63.77          | 2.66                              | 11.56    | 63.77        |
| 5         | 1.07                | 4.67          | 68.44        |            |              |                |                                   |          |              |
| 6         | .88                 | 3.73          | 72.16        |            |              |                |                                   |          |              |

Table 3.2 Total Variance Explained

Note. Extraction Method: Principal Component Analysis.



Figure 3.1 SF-12/UCLA PCI





|   |     | Comp | onent |     | Factor |
|---|-----|------|-------|-----|--------|
|   | 1   | 2    | 3     | 4   |        |
| Overall Health Status                   |     | .49  |       |     | MCS    |
| Limitation of Moderate Activity         |     |      |       | .84 | PCS    |
| Limitation of Climbing Stairs           |     |      |       | .80 | PCS    |
| Physical health limited activities/work |     | .55  |       | .48 | PCS    |
| Physical health limited type of work    |     | .45  |       | .65 | PCS    |
| Mental health limited activities/work   |     | .82  |       |     | MCS    |
| Mental health affected quality of work  |     | .74  |       |     | MCS    |
| Pain interference with work/activities  |     | .45  |       | .48 | PCS    |
| Feelings of calm and peacefulness       |     | .73  |       |     | MCS    |
| Degree of Energy                        |     | .60  |       |     | MCS    |
| Experience Depression                   |     | .74  |       |     | MCS    |
| Physical/Mental health limit socially   |     | .52  |       |     | MCS    |
| How often leaked urine                  |     |      | .81   |     | UDS    |
| Degree of urinary control               |     |      | .85   |     | UDS    |
| Quantity of daily pads used             |     |      | .69   |     | UDS    |
| Problem with dripping urine             |     |      | .79   |     | UDS    |
| Urinary function problem                |     |      | .78   |     | UDS    |
| Ability to have an erection             | .92 |      |       |     | SDS    |
| Ability to reach orgasm                 | .76 |      |       |     | SDS    |
| Quality of erection                     | .87 |      |       |     | SDS    |
| Frequency of erection                   | .89 |      |       |     | SDS    |
| Ability to perform sexually             | .93 |      |       |     | SDS    |
| Overall sexual function                 | .63 |      |       |     | SDS    |

# Table 3.3 Rotated Component Matrix

Note. Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. a. Rotation converged in 6 iterations.



#### CHAPTER FOUR

Coping Disposition, Satisfaction with Information, Perceived Severity of Illness, and Anxiety among Men Recently Diagnosed with Prostate Cancer

### **Synopsis**

**1. Purpose/Objective:** The purpose of this study was to examine the influence of two coping styles (monitor and blunter) on anxiety levels, perceived severity of illness, satisfaction with information received and the relationship between perceived severity of illness, satisfaction with information received and the relationship between perceived severity of severity of illness and Gleason score in men recently diagnosed with prostate cancer.

**2. Design:** Cross-sectional survey of a convenience sample from a cohort of men who had recently been given the diagnosis of prostate cancer.

3. Setting: Outpatients from a metropolitan university urology clinic

4. Sample: 62 men diagnosed with prostate cancer who selected surgery as treatment

5. Methods: This study was approved by the university institutional review board. Inclusion criteria were: a) males between the ages of 40-70; b) participants who had not received other treatments for prostate cancer; c) participants did not have an additional diagnosis of cancer; d) able to read and write English. Data were collected over a 2 year period. There were 64 potential participants as two did not wish to participate. The *n* for this analysis was 62.

Participants who presented to the urology clinic to discuss treatment for prostate cancer were seen by the surgeon. The surgeon informed patients during the office visit that a research study was being conducted. If the patient was interested in participating in the study, the investigator was contacted to determine whether the patient met study criteria. The investigator then explained the details of the study and obtained informed consent. The participant was then presented with a questionnaire study packet which was completed in the office. After completion, the participants were given a copy of the signed consent.

**6. Results:** Specific aims related to differences in coping styles, between monitor/blunter coping styles were not supported. Depression was more prevalent among younger men diagnosed with prostate cancer. No difference in total satisfaction with information was found. High Monitors (HM) were found to be more satisfied with media as a source of



29

information. A moderate to strong relationship was found between perceived severity of illness (PSIL) and Gleason score for all participants. Knowledge of Gleason score were reported equally by both High Monitors and Low Monitors.

7. Conclusions: The results of this study indicate anxiety exists among participants with depression being more prevalent among younger men versus older men. Monitors were more satisfied with media as a source of information than other information sources which were consistent with research literature on patients with cancer. There was a strong association between Gleason score and PSIL across groups with no differences related to coping style. A majority of the participants knew their Gleason score. This knowledge was attributed to the participants completing the questionnaire immediately after seeing the surgeon at which time a discussion of the Gleason score took place.

**8. Implications for Nursing:** The role of nursing in caring for men with prostate cancer include understanding the implications of information as it relates to anxiety, and tailoring information to decrease anxiety levels. Depression in men with prostate cancer appears to be present but is neither generally assessed nor understood. Until research provides clarification, nurses can assess for depression and offer guidance, support and referral where appropriate.

Key Words: Coping Styles, Prostate Cancer, Anxiety Levels, Severity of Illness



#### Introduction

A diagnosis of prostate cancer (PCa) can produce anxiety, psychological distress and denial in men who receive it.<sup>1</sup> Recent studies indicate the rate of both suicide and cardiovascular events increases significantly within weeks of a PCa diagnosis.<sup>2</sup> Further investigation is needed to examine the psychological impact of a PCa diagnosis.

#### Background

Treatment options for PCa include surgery, radiation therapy, surveillance, and hormonal therapy. Presently, there is no consensus as to which treatments are most effective due to lack of clinical trials. Choice of treatment is often based on side effect profiles which can range from mild irritative voiding symptoms to urinary incontinence and/or erectile dysfunction. Quality of life is often sacrificed for a chance at long term survival. Over the past 25 years, the 5 year survival rate for all stages of PCa has increased from 68% to almost 100% with 10-15 year relative survival rates approaching 98% and 91% respectively.<sup>3</sup> Although men with PCa are living longer, some are living with significant side effects including incontinence and sexual dysfunction which can severely impact quality of life. Overall, the bulk of research on PCa has focused on medical outcomes, such as PCa treatments, treatment side effects or cancer progression, while psychosocial issues have all but been ignored. The few studies available on men's psychological adjustment to cancer as a whole, indicate men do not adjust to a cancer diagnosis as well as women.<sup>3, 4</sup> This is a concern, as there are more men diagnosed with and/or who die from cancer than women.<sup>5</sup>

The purpose of this dissertation is to explore coping styles, psychological impact, informational needs, and severity of illness in men diagnosed with PCa. Specific aims were to 1) identify the coping styles in a group of men diagnosed with prostate cancer 2) examine differences in anxiety, depression and stress between coping styles; 3) examine the relationship between coping styles and perceived severity of illness; 4) examine differences in perceived severity of illness and Gleason score; 5) examine sources of information and satisfaction with information received in a group of 62 men diagnosed with prostate cancer.



31

#### **Conceptual Framework**

The Cognitive-Social Health Information Processing Model (C-SHIP) was developed by Miller<sup>6</sup> on differences in the ways individuals perceive and define stress, and how attentive or pervasive they may be to threat. The conceptual framework utilized for this dissertation developed by Miller<sup>6</sup> and originated from investigations of cognitive, social and health sciences. This framework focuses on ways in which individuals regard or disregard stress. Constructs of the framework include the individual's encoding and self-interpretation of cancer-relevant feedback ,<sup>7,8,9,10,11,12,13</sup> the individual's affective and emotional responses to cancer,<sup>15,11,12,13</sup> and the individual's skills and techniques of self-regulation, coping skills and strategies for dealing with illness.<sup>15</sup> The relationship between these components theorize how individual's make decisions, adjust and behave when there is risk of cancer and disease.<sup>16,17</sup>

#### **Monitoring and Blunting**

Miller identified two main cognitive coping styles, "Monitoring and Blunting." Monitors prefer detailed information, scan for threatening cues and experience anxiety. In contrast, blunters distract themselves and avoid information in order to minimize threat and decrease anxiety.<sup>18</sup> According to Miller<sup>18</sup> monitoring is the main coping style in controllable situations, while blunting becomes the primary coping style in uncontrollable situations. A cancer diagnosis results in more anxiety, fear and uncertainty than any other health problem.<sup>19</sup> Eheman<sup>20</sup> found women with breast cancer were the most active when it comes to information seeking compared to other cancer patients. The monitor-blunter framework is particularly useful to assess men diagnosed with PCa as this group has been observed to desire and seek information in order to make sense of their illness and guide them in making treatment decisions. Few studies exist which have examined coping styles and information seeking in men with PCa. Therefore, using the monitoringblunting framework is appropriate for this study.

#### Methods

#### Design

A cross-sectional survey of a convenience sample from a cohort of men who had been given the diagnosis of prostate cancer within the previous 3months were studied to



examine the associations among coping disposition, satisfaction with information, perceived severity of illness and anxiety.

## **Procedure for Data Collection**

This study was approved by the university institutional review board. Inclusion criteria were: a) males between the ages of 40-70; b) who had not been treated for prostate cancer; c) did not have a diagnosis of another cancer; and d) were able to read and write English. Data were obtained through chart review and the completion of a packet of paper and pencil instruments at the time of an office visit. Participants who presented to the urology clinic to discuss surgical treatment for prostate cancer were seen by a surgeon. The surgeon informed patients during the office visit that a research study was being conducted. If the patient was interested in participating, the investigator was contacted and determined whether the patient met the study criteria. The investigator explained the details of the study and consent was obtained. The patient was presented with the questionnaire study packet and an explanation was given as to the study materials. The patient completed the questionnaire while in the office, which took approximately 10-15 minutes. Once the questionnaire was completed, the researcher received the questionnaire, gave the participant a copy of the signed consent and provided future contact information. Over a two year period 64 men were identified as potential participants. Sixty-two individuals agreed to participate. There was no compensation provided for the study.

### Measurement

## Sociodemographic and Clinical Characteristics:

Study measures were selected based on psychometric properties and appropriateness to assess coping styles, satisfaction for information, perceived severity of illness, and anxiety. All measures and demographic information were assessed at one time point.

*Demographic Information:* Demographic data collected included: age, county of residence, education, marital status, employment status, and race.

## Monitor/Blunter Style Scale:

*Monitor/Blunter Style Scale (short form):* The Miller Behavioral Style Scale (MBSS) is a well-validated self-report scale designed to assess two coping styles,



monitoring and blunting. <sup>21</sup> The MBSS scale is used to predict cognitive-emotional reactions in studies of quality of life, decision-making, adherence, and behavior change.<sup>22</sup> Miller has used the MBSS to investigate how medical decision making, physician recommendations,<sup>23</sup> anxiety and satisfaction with information <sup>24</sup> influence individuals with cancer.

To identify the inclination for participants to be a "monitor or blunter", the Monitor/Blunter Style Scale (MBSS), the abbreviated version of a pencil and paper questionnaire was administered. The MBSS scale asks participants to vividly imagine two hypothetical stress-invoking scenarios, going to the dentist and flying on an airplane. A sample of a scenario is provided in Table 4.0. After each scenario, 8 statements indicate ways in which the participant might cope with the situation presented. Four of the statements are of a monitoring type (e.g., "I would ask the dentist exactly what work was going to be done.") and four are of a blunting type (e.g., "I would take a tranquilizer or have a drink before going"). The participant is asked to select a response to a scenario by placing a check mark before it. The dentist and airplane scenarios were selected because they were scenarios that most participants could identify with and easily believe. Clinic time limitations precluded administration of the full scale.

## Scoring the MBSS

A monitor and blunter score respectively were calculated for each participant by summing the individual monitor and blunter responses for each of the two scenarios. The theoretical range for the Monitor score was 0-8. The theoretical range of the Blunter score was 0-8. The theoretical range of M-B score was -8 to 8.

The Blunter score was subtracted from the monitor score in order to obtain the M-B score for each participant, with a possible range of -8 to 8. The median monitor score of the 62 participants was 4 and the median blunter score was 1; the median M-B score was 3. This suggests that the male participants in this study were more likely to checkmark monitoring items than blunting items. According to Miller, if the M-B score is used to classify a participant as a Monitor or Blunter, then the cut-off point should be 0. If the M-B score is less than or = to 0 then the subject should be classified as a Blunter. If the M-B score is greater than 0, the participant should be classified as a Monitor. Applying Miller's classification system to the group of male prostate cancer participants



in this study resulted in a greater number of participants who exhibited Monitor characteristics than Blunter characteristics with sample sizes of 51 and 11 respectively. An alternate classification proposed by Miller uses only the Monitor scale. Given the unequal group sizes in the study, this alternate classification system was used. In Miller's previous studies, the monitoring subscale was found to be more normally distributed, reliable and predictable than the blunter subscale  $^{25, 26, 27}$  Consistent with these studies, the monitoring subscale when applied to this group of participants resulted in a normal distribution while the blunter scale did not. Therefore, the monitoring subscale alone was used to classify participants by creating a dichotomous variable using a median split. Those participants with scores above the Monitor scale median of 4 were classified as high monitors (LM) (n=30) and those with a Monitor score of 4 or below were classified as low monitors (LM) (n=32). Calculations were based on the HM and LM classification (Table 4.1)

### **Perceived Severity of Illness Scale**

Illness perceptions are representations or beliefs that patients have about their illness. These beliefs are based on the assumption that individuals develop their own representation of illness or threat and with an experience or symptom they begin a search for understanding the health threat. As a result, the individual develops a unique perception of illness identity, cause, timeline, consequences, perceived control and emotional reaction to illness. Studies of newly diagnosed hematologic cancer patients, found those who perceived their disease to be more severe had greater emotional distress and reported higher levels of anxiety and depression.<sup>28,29</sup> How individuals perceive their illness can influence how likely they are to seek medical care, <sup>30</sup> their quality of life <sup>31</sup> and whether they comply with medical advice.<sup>32</sup> To date, little is known regarding the influence of illness perception on the psychological well-being of men diagnosed with PCa.

A visual analogue scale (VAS) was used to determine the severity of illness perceived by the participants. The participants were asked to place a mark on a line indicating how severe they felt their prostate cancer was to them. On the scale, the left endpoint was labeled 0 and given the definition of not severe at all, and the right endpoint was labeled 100 and defined illness as very severe. The VAS was scored by measuring



the total length of the scale between 0 and 100, measuring the length from the 0 to the participants mark and dividing that number by the length of the scale to arrive at the score.

### Depression, Anxiety and Stress

At least two studies have shown that men's psychological adjustment to cancer is poor.<sup>33, 34</sup> Anxiety is the most frequently reported reaction to a diagnosis of PCa and has been reported in men with PCa from a time period beginning with the PSA test and extending through treatment and beyond. Research regarding the psychological impact of a PCa diagnosis has been mixed in that researchers have combined all PCa patients into a single large group. In addition, it is difficult to know exactly what is known about psychosocial issues in men with PCa as previous methods for assessing this information have used methods that have not been designed specifically for men with PCa.

The DASS-21 short form used in this study, is comprised of three seven item selfreport scales for assessing depression, anxiety and stress over the past week (current distress), on a four-point scale which ranges from 0 (did not apply to me at all to 3 (applied to me very much, or most of the time). The total number of the subscale scores were multiplied by two to convert them to full scale scores to allow for interpretation. Scores for each subscale range from 0-42, with a high score indicating greater depression, anxiety, or stress.

## Satisfaction with Sources of Information and Information Received

Patients receiving radiation therapy for breast cancer have been the most frequently studied cancer specific treatment group in relation to cancer and information needs.<sup>35</sup> Cancer patients have been shown to have many information needs<sup>35,36,37,38</sup> which differ according to the nature of their illness.<sup>39</sup> Information needs vary with age and education. Newspapers, television, friends and other non-medical resources have been found to be primary sources of information for older patients as compared to younger ones.<sup>40</sup> While providing information has been shown to negatively affect coping in some studies, <sup>6</sup> positive effects have been identified in the form of faster recovery times, decreased pain <sup>36</sup> and improved mental health and coping.<sup>37, 41</sup> Few published studies could be located which assessed the informational needs of men with PCa. These studies indicate men desired detailed information about their cancer, its stages and



treatment options, <sup>38</sup> survival, self-care and empowerment.<sup>35</sup> In light of the complex nature of cancer patients information needs, and the few studies available on the information needs of men with PCa, it is important to gain knowledge as to how much, what type and when information is appropriate and necessary.

Two qualitative questions were used to assess sources of information and satisfaction with information. The first question asks participants to choose from a list of information sources that they may have utilized to learn more about their prostate cancer. The sources listed were: primary care provider (family doctor, nurse practitioner, physician assistant), urologist, internet, someone else diagnosed with prostate cancer, (PWPC) and media (radio, television, books, magazines). Each source of information was assigned a satisfaction score of 5= very satisfied, 4=somewhat satisfied, 3= neither satisfied nor dissatisfied, 2= somewhat dissatisfied, and 1=very dissatisfied. Scores were obtained by examining the sources of information used (0-5) and satisfaction scores (1-5) and differences were made between High Monitors and Low Monitors as to sources utilized and satisfaction scores obtained.

## PSA and Gleason Score

Participants were asked to provide a PSA and Gleason score if known. If these numbers were not known, then the participants were instructed to leave a blank when reporting. Responses were compared to the PSA and Gleason scores reported in the patient chart to determine whether High Monitors or Low Monitors would know and be able to report this information correctly.

### **Data Analysis**

Demographic data summarized participant characteristics (Table 4.2). Data analysis was conducted using SPSS-20 and an alpha level of 0.5. Participants were sorted into groups based on coping style. The analysis plan based on the specific aims is noted below:

**Specific Aim 1:** To examine differences in anxiety levels between coping styles. Participants were sorted into groups based on coping style. Outcomes were compared between these two coping style groups using Mann-Whitney (MW) or t tests.

**Specific Aim 2:** To examine differences in satisfaction with information between coping styles.



Five sources of information (primary care provider, internet, media, urologist and person diagnosed with prostate cancer) were evaluated. Satisfaction was reported on a 5 element Likert scale of 1- "very satisfied" to 5 "very unsatisfied." Participants were sorted according to coping style; scores were reported for HM and LM groups. Outcomes were compared using Mann-Whitney to determine if a difference in satisfaction with each source existed between the two coping styles. Individual sources of information were summed to obtain a total satisfaction score. A similar MW analysis was used to determine if differences existed between total satisfaction of HM and LM groups (Table 4.3).

**Specific Aim 3:** To examine differences in severity of illness between coping styles.

A Visual Analogue Scale was used to obtain a perceived severity of illness of each participant. Participants were sorted according to coping style. The data for the PSIL are normally distributed. A t-test for two independent samples was used to determine if there was a difference in the PSIL of participants between HM and LM coping groups.

**Specific Aim 4:** To examine differences in the relationship between perceived severity of illness and Gleason score.

Participants were sorted into two groups based on coping style. A Spearman's coefficient between PSIL and Gleason score was computed for the LM group and for the HM group. The significance of the difference between the two correlation coefficients was assessed using the Fisher r to z transformation (Table 4.4).

**Specific Aim 5:** To determine if the HM group were more likely than the LM group to know their Gleason scores.

The number of HM and the number of LM who did not report their Gleason score was calculated. A 2 x 2 Contingency table analysis was used to determine if HM are more likely than LM to know their Gleason scores (Table 4.5).

#### Results

The 62 Caucasian men included in the sample ranged in age from 46 to 70, mean age 61 years. They were typically married (87%), with a college or above education (43%), and half were employed or retired (50%). Approximately 65% were from rural areas.



## **Specific Aim 1**

HM and LM were defined by creating a dichotomous variable using a median split of the monitor scale. (median =4). Those above the median were labeled High Monitors (HM) (n=30) with characteristics typically associated with monitoring (i.e. health threat vigilant, higher risk perception, health related information seeking). Participants whose scores were equal to or below the median monitor score of 4 were labeled Low Monitors (LM) (n=32) with characteristics typically associated with blunters (i.e. health threat avoidant, lower risk perception, distract from health-related information). <sup>33</sup> The specific aim that HM would have greater anxiety than LM was not supported. A Mann-Whitney analysis (z=1.32, p=.19) indicated that significant differences in anxiety were present between the two coping styles. No differences were noted between the mean age and education levels of HM and LM. LM consistently reported higher depression, anxiety and stress scores than HM but this was not statistically significant. No significant relationship was found between age, anxiety and depression. A significant inverse relationship was determined between age and stress with younger men reporting higher depression scores than older men (Spearman's rho= .28, p=.03), (Table 4.6).

### **Specific Aim 2**

The second specific aim, examined differences in satisfaction with information between coping styles. A Mann-Whitney (MW) test showed no difference between the total satisfaction scores reported by HM and LM (z=.71, p=.48). Similar testing showed no difference between the number of information sources consulted by HM and LM (z=11, p=.91). HM consistently reported higher mean satisfaction scores for all sources of information consulted. Media is the only source where the HM satisfaction score was significantly greater than the LM satisfaction score (z=2.3, p=.02). There was a moderate but highly significant positive correlation exhibited between age and primary care providers (rho=.33, p=.01) indicating older men were more likely to be satisfied with information from their primary care provider than younger men. Table 4.7 summarizes all scores for information sources.



39

### **Specific Aim 3**

Kolmogorov-Smirnov normality testing confirmed that the PSIL scores (z=.78, p=.68) are normally distributed. An equal variance two independent sample t-test (t=-.12, df=60, p=.90) demonstrated that there was no difference in HM and LM coping groups. The specific aim that HM would perceive their illness as more severe than LM was not proven.

#### **Specific Aim 4**

A moderate positive correlation (rho=.21, p=.01) was found between PSIL and Gleason score for all participants. The specific aim for the study was that the correlation would be stronger for LM than HM. The Spearman's rho for HM was .32 (p=.08) between PSIL and Gleason. The Spearman's rho for LM was .29 (p=.10). A Fischer r to z transformation analysis of the Spearman's rho coefficient indicated no differences between HM and LM (z=.12, p=.90). The results indicate that for any given Gleason score, LM PSIL is not significantly different from that of HM. This is consistent with the previously reported results that coping style does not affect PSIL.

#### **Specific Aim 5**

One out 30 HM (10.0%) and 3 out of 32 LM (99.38%) did not report a Gleason score by leaving the question, 'what is your Gleason score?' blank. A two by two contingency table analysis utilizing Fisher's exact probability test yielded a p value >.9 indicating equal knowledge of Gleason scores by both HM and LM participants.

## Discussion

The current study was designed to examine the influence of two coping styles HM and LM on anxiety levels, perceived severity of illness, satisfaction with information and the relationship between severity of illness and Gleason score in men diagnosed with but not yet treated for prostate cancer. In general, the small, homogeneous sample used in the study prevented any strong comparisons between HM and LM. These findings did not support the assumptions of Miller <sup>19</sup> that monitors would experience more distress when compared to Blunters in stress inducing situations such as in this study. No significant correlation was seen between anxiety levels and age however, an inverse relationship was seen between age and stress. Younger men reported higher depression scores. Coping



style had no effect on this relationship. This finding is consistent with that of Miller who found elderly women reported lower distress during breast screening exams than did younger women.<sup>6</sup> This may have implications for adherence to medical treatment and compliance in the elderly population.

HM and LM reported no difference in total satisfaction with information received from all sources combined. This was also the case with the number of information sources consulted. HM indicated higher satisfaction scores with all information sources as opposed to LM; this difference was only significant for media (p=.02). These results were consistent with other studies which examined satisfaction with information in breast cancer patients. <sup>42, 43, 44</sup> No comparisons can be made with information received or satisfaction with information in this study population as so few prior investigations have been performed. The expected interaction between HM and LM coping styles and PSIL was not demonstrated. In addition, there was no correlation regarding age, educational level, or information sources. These findings were not consistent with a group of cancer survivors in whom information sources and age were strong predictors of perceived severity of illness.<sup>45</sup>

A moderate to strong relationship (rho=.31, p=.01) was found between PSIL and Gleason score for all participants in the study. However, when comparing this relationship using HM and LM participants, no difference between groups was found. This relationship is consistent with the previously mentioned study results that coping style does not affect PSIL. Constant <sup>30</sup> found a poor correlation between perceived severity of Hepatitis C and the actual severity of liver disease as did others in studies which examined PSIL in subjects with hypertension and chronic respiratory problems.<sup>46,47,48</sup> These studies indicated the perception of a disease usually correlates poorly with its medically defined characteristics. Results from this study are inconsistent with these findings, as our participants perceived their illness to be relative to their Gleason score. This could be attributed to the participants' exposure on the day of the survey to information detailing the strong association of a higher Gleason score with a poorer cancer prognosis.

When examining knowledge of Gleason scores in the HM and LM group, 3 out of 30 HM and 3 out of 32 LM did not report a Gleason score. When comparisons were made

41



between HM and LM, both groups had equal knowledge of both PSA and Gleason scores. A fact that complicates the interpretation of these findings is the condition under which the participants completed the survey instruments. Prior to receiving the survey, the participants were interviewed by a urologist and a urology resident who discussed PSA and Gleason scores with them thus affecting participant response.

### **Study Strengths and Limitations**

Cross-sectional studies performed with convenience samples, such as this one, cannot be generalized to the entire population. Because the study was not randomized, the findings may not be representative of other men with prostate cancer. The small sample size is a limitation that may have influenced the lack of significant findings related to the two coping styles. There were 30 HM and 32 LM in the study. A power analysis would require at least 120 in each group to have an 80% chance of reaching significance on one variable. In addition, ethnic groups were not represented in the study, and therefore, it is not known if these results would be similar or different for men of varying ethnicity, given this cancer diagnosis. The main strengths of the study are: 1) use of the Monitor - Blunting coping style in a sample of men with prostate cancer, 2) an assessment of these patients at a specific point in their disease course (after diagnosis but before treatment), 3) an examination of men's knowledge of Gleason score during this time (pre-treatment) period, 4) an examination of men's satisfaction with information and information sources after diagnosis and before treatment, 5) an assessment of psychological state before treatment using the DASS-21, 6) an assessment of perceived severity of illness prior to treatment.

### **Conclusions/Implications for Research/Practice**

Men with prostate cancer continue to be the least studied of all cancer groups. This study is an attempt to add to the literature on men and prostate cancer. Although there were no significant differences related to coping style, other findings may influence treatment and future research. Regarding coping styles and anxiety, LM were found to have higher anxiety levels, however this was not significantly different from HM at the .05 level (p=.02). However, this does point to anxiety as a potential response to the



diagnosis. Future studies with larger sample sizes might find differences in anxiety related to coping style.

The finding of depression in younger men with prostate cancer is of interest as few studies have examined depression in men with prostate cancer. Unfortunately, literature on depression and prostate cancer is unclear in that timing of assessment and types of treatment are not specified. In addition, it is difficult to know the prevalence of psychosocial issues in men with PCa as prior methods for assessment have not been designed specifically for this population.

HM were more satisfied with media as their source of information. This finding was consistent with other studies which found the most prominent information sources used during the diagnosis and treatment phase of the cancer continuum were printed materials (34.6%) brochures (33.3%) and libraries/unspecified readings (33.3%) as those sources most often consulted.<sup>49</sup> This finding should encourage nurses to write accurate, timely articles to submit to magazines which cater to men as their subscription base; write, edit, and design publications which inform and educate men on prostate cancer issues. Older patients were more satisfied with information received from their primary care physician as opposed to other information sources. Physicians (42.9%) were most often cited within the health care professional's category as reliable and trusted sources of information.<sup>49, 35</sup> A closer look at reliability of information and ease of access to information would be of interest especially in the age group presented in this study.

There was a strong association between Gleason score and PSIL among all participants. Coping style did not influence this association. This finding implies that the men in the study group have been well educated as to the importance of the Gleason score as it relates to prognosis. A second evaluation at a later date could provide additional knowledge as to how well this information was processed and how it may have influenced decision making for treatment.

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## Table 4.1Sample Question from the MBSS

Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Check **all** of the statements that might apply to you.

- I would ask the dentist exactly what work was going to be done.
- \_\_\_\_\_ I would take a tranquilizer or have a drink before going.
- \_\_\_\_\_ I would try to think about pleasant memories.
- I would want the dentist to tell me when I would feel pain.
- \_\_\_\_\_ I would try to sleep.
- \_\_\_\_\_ I would watch all the dentist's movements and listen for the sound of the drill.
  - I would watch the flow of water from my mouth to see if it contained blood.
- \_\_\_\_\_ I would do mental puzzles in my mind.



| Score   | Mean | SD   | Median | Range |
|---------|------|------|--------|-------|
| Monitor | 4.39 | 1.72 | 4.00   | 1-8   |
| Blunter | 1.29 | 1.11 | 1.00   | 0-5   |
| M-B     | 3.10 | 2.02 | 3.00   | -3 -7 |

Table 4.1 Monitor and Blunter Statistics (N=62)



| Characteristics     | N  | (%)    |
|---------------------|----|--------|
| Education           |    |        |
| Grammar School      | 1  | (1.6)  |
| High School         | 11 | (17.7) |
| Vocational          | 10 | (16.1) |
| Some College        | 13 | (21.0) |
| Bachelors Degree    | 10 | (16.1) |
| Masters Degree      | 10 | (16.1) |
| Doctoral Degree     | 2  | (3.2)  |
| Professional        | 5  | (8.1)  |
| Marital Status      |    |        |
| Divorced            | 4  | (6.5)  |
| Living with Another | 1  | (1.6)  |
| Married             | 54 | (87.1) |
| Single              | 2  | (3.2)  |
| Widowed             | 1  | (1.6)  |
| Employment Status   |    |        |
| Unemployed          | 2  | (3.2)  |
| Retired             | 27 | (43.5) |
| Full-time           | 28 | (45.2) |
| Part-time           | 3  | (4.8)  |
| Disabled            | 2  | (3.2)  |
| Geography           |    |        |
| Rural               | 28 | (45.2) |
| Urban               | 34 | (54.8) |
| Gleason Score       |    |        |
| 6                   | 34 | (54.8) |
| 7                   | 23 | (37.1) |
| 8                   | 2  | (3.2)  |
| 9                   | 3  | (4.8)  |

Table 4.2. Demographic Characteristics (N=62)



| Variable                 |       | High Monitor |       |       |      |       |
|--------------------------|-------|--------------|-------|-------|------|-------|
|                          | Mean  | SD           | Range | Mean  | SD   | Range |
| РСР                      | 4.47  | .50          | 3-5   | 4.08  | .98  | 1-5   |
| Urologist                | 4.71  | .52          | 3-5   | 4.52  | .84  | 1-5   |
| Internet                 | 4.09  | .52          | 3-5   | 4.05  | .82  | 1-5   |
| PWPC <sup>a</sup>        | 4.52  | .50          | 3-5   | 4.29  | .93  | 1-5   |
| Media <sup>b</sup>       | 4.02  | .46          | 3-5   | 3.78  | .71  | 1-5   |
| Total Satisfaction Score | 15.40 | 15.4         | 5-24  | 14.50 | 5.94 | 3-25  |

Table 4.3. Satisfaction with Information Sources among High Monitors and Low Monitors

<sup>a</sup> Another person with prostate cancer <sup>b</sup>Books, TV, magazines, radio



|               | Sample<br>Size | Spearman's rho<br>Correlation | Two-tailed<br>p value |
|---------------|----------------|-------------------------------|-----------------------|
| Low Monitors  | 32             | 0.29                          | 0.10                  |
| High Monitors | 30             | 0.32                          | 0.08                  |
| Total         | 62             | 0.31                          | 0.01                  |

## Table 4.4 Correlation between PSIL and Gleason Score

Fisher r-to-z transformation: z=-0.13 (p=0.90)



|               | Unknown<br>Gleason | Known Gleason | Total |
|---------------|--------------------|---------------|-------|
| Low Monitors  | 3                  | 29            | 32    |
| High Monitors | 3                  | 27            | 30    |

 Table 4.5
 Low and High Monitor participant knowledge of personal Gleason score

Fisher's Exact Probability: p>0.99



Table 4.6a Young Monitors (N=32)

| Score   | Mean | SD   | Median | Range |
|---------|------|------|--------|-------|
| MONITOR | 4.50 | 1.61 | 5.00   | 1-7   |
| BLUNTER | 1.09 | 0.96 | 1.00   | 0-3   |
| M-B     | 3.41 | 1.68 | 3.50   | 0-7   |

Table 4.6b Older Monitors (N=30)

| Score   | Mean | SD   | Median | Range |
|---------|------|------|--------|-------|
| MONITOR | 4.27 | 1.86 | 4.00   | 1-8   |
| BLUNTER | 1.50 | 1.23 | 1.00   | 0-5   |
| M-B     | 2.77 | 2.32 | 3.00   | -3 -7 |



| High Monitor (n=32) |   | -52)  | Low Monitor (n=30)  |   |   |  |
|---------------------|---|---|---|---|---|--|
| Mean                | (SD)  | Range   | Mean  | (SD)  | Range   | р  |
| 60.70               | 6.396   | 46-70   | 69.40   | 5.725   | 47-70   | 0.43 *   |
| 4.20                | 1.520   | 1-7   | 4.47  | 2.090   | 2-8   | 0.87 **  |
| 5.40                | 4.900   | 5-24  | 14.50   | 5.940   | 3-25  | $0.52^{*}$   |
| 3.50                | 1.196   | 1-5   | 3.50  | 1.320   | 1-5   | $0.91^{**}$  |
| 6.70                | .942  | 6-9   | 6.40  | 0.528   | 6-8   | 0.22 **  |
| 0.60                | 0.270   | 0.03-1.0  | 0.59  | 0.320   | 0.03-1.0  | 0.98 *   |
| 8.53                | 11.1  | 2.2-63  | 6.83  | 3.470   | 2.3-18  | 0.56 **  |
| 7.05                | 5.320   | 0-20  | 8.39  | 7.950   | 0-32  | $0.80^{**}$  |
| 2.76                | 3.540   | 0-16  | 4.01  | 4.490   | 0-18  | 0.19 **  |
| 10.20               | 7.770   | 0-34  | 11.20   | 9.920   | 0-34  | 0.86 **  |
|                     | 60.70<br>4.20<br>5.40<br>3.50<br>6.70<br>0.60<br>8.53<br>7.05<br>2.76 | 60.70         6.396           4.20         1.520           5.40         4.900           3.50         1.196           6.70         .942           0.60         0.270           8.53         11.1           7.05         5.320           2.76         3.540 | $\begin{array}{c ccccc} 60.70 & 6.396 & 46-70 \\ 4.20 & 1.520 & 1-7 \\ 5.40 & 4.900 & 5-24 \\ 3.50 & 1.196 & 1-5 \\ 6.70 & .942 & 6-9 \\ 0.60 & 0.270 & 0.03-1.0 \\ 8.53 & 11.1 & 2.2-63 \\ 7.05 & 5.320 & 0-20 \\ 2.76 & 3.540 & 0-16 \end{array}$ | $\begin{array}{c ccccccccccccccccccccccccccccccccccc$ | 60.70 $6.396$ $46-70$ $69.40$ $5.725$ $4.20$ $1.520$ $1-7$ $4.47$ $2.090$ $5.40$ $4.900$ $5-24$ $14.50$ $5.940$ $3.50$ $1.196$ $1-5$ $3.50$ $1.320$ $6.70$ $.942$ $6-9$ $6.40$ $0.528$ $0.60$ $0.270$ $0.03-1.0$ $0.59$ $0.320$ $8.53$ $11.1$ $2.2-63$ $6.83$ $3.470$ $7.05$ $5.320$ $0-20$ $8.39$ $7.950$ $2.76$ $3.540$ $0-16$ $4.01$ $4.490$ | 60.70 $6.396$ $46-70$ $69.40$ $5.725$ $47-70$ $4.20$ $1.520$ $1-7$ $4.47$ $2.090$ $2-8$ $5.40$ $4.900$ $5-24$ $14.50$ $5.940$ $3-25$ $3.50$ $1.196$ $1-5$ $3.50$ $1.320$ $1-5$ $6.70$ $.942$ $6-9$ $6.40$ $0.528$ $6-8$ $0.60$ $0.270$ $0.03-1.0$ $0.59$ $0.320$ $0.03-1.0$ $8.53$ $11.1$ $2.2-63$ $6.83$ $3.470$ $2.3-18$ $7.05$ $5.320$ $0-20$ $8.39$ $7.950$ $0-32$ $2.76$ $3.540$ $0-16$ $4.01$ $4.490$ $0-18$ |

Table 4.7 Comparison of High and Low Monitors

<sup>a</sup> Satisfaction with information received <sup>b</sup> Perceived severity of illness- self-rated on a visual analogue scale <sup>c</sup> Assessed with the DASS

\* Equal variance independent sample t-test \*\* Mann-Whitney 2 independent sample test



#### CHAPTER FIVE

#### Conclusions and Discussion

The purpose of this dissertation was to: 1) examine the concept of men's health seeking behavior; 2) analyze the psychometric properties of a combine scale, the SF-12 and the UCLA Prostate Cancer Index (SF12/UCLA-PCI) in men diagnosed with prostate cancer; and 3) examine the influence of two coping styles (Monitor and Blunter) on anxiety levels, perceived severity of illness, satisfaction with information received, and the relationship between perceived severity of illness and Gleason score in men with prostate cancer. In this dissertation three papers are presented.

The first paper describes a concept analysis examining the health seeking behavior of men. This analysis provided insight into gender, norms and social attitudes which contribute to the behaviors of men. Men's health seeking was found to be complex and multidimensional based on social and psychological differences. Men were found to have riskier behaviors, limited access to health care and higher mortality rates than women. Health risks, health care practices and systems barriers for men were examined to demonstrate the need for improvement by healthcare systems. Discernible evidence based on the analysis of men's health seeking provides directions for future research. Attention was called to the opportunities which await nursing as both a resource and potential leader in men's health research.

The psychometric property analysis of a combined instrument the SF-12 and the urinary and sexual portions of the UCLA Prostate Cancer Index is described in Chapter Three. Findings from this methodological study show that the combined scale can address quality of life issues in this population. Use of this self-administered questionnaire has potential for evaluating the state of health of men with prostate cancer. The results support the need for HRQoL measures in the assessment of men with prostate cancer and in determining the need for further support in psychosocial, as well as, functional areas of concern. Current literature has yet to clearly define sexual function/dysfunction in men lending it to opportunities for future investigations.

The relationship of coping styles, anxiety levels, perceived severity of illness, satisfaction with information and the relationship between perceived severity of illness



and Gleason score were presented in Chapter Four. In relation to the Monitor / Blunter Coping styles, no differences were found. Regarding coping styles and anxiety, LM (blunters)were found to have higher anxiety levels, which were not significantly different from HM. However, this did substantiate the fact that anxiety was present in the study group. Recommendations were made as to the need for future studies with would include larger sample sizes. Also of interest were the findings of depression in younger men with prostate cancer as few studies have assessed depression in men with prostate cancer. Implications for future research were presented due to the lack of these studies and their poor experimental design.

HM were more satisfied with media as their source of information. This finding is consistent with the literature. Measuring satisfaction with information during the pretreatment phase of the prostate cancer diagnosis has not been addressed. Findings regarding information could encourage nurses, increase information resources to men with prostate cancer by writing accurate, timely articles to magazines which cater to men as well as, design publications which inform and educate men on issues of prostate cancer. Older patients were more satisfied with information received from their primary care physician as opposed to other information.<sup>72, 73</sup> A closer look at accuracy of information and ease of access to information would be of interest especially in the age group presented in this study.

There was a strong association between Gleason score and PSIL which was universal in the study group. Coping style did not influence this association. This finding suggests that the men in the study group have been well educated as to the significance of the Gleason score and their prognosis. The fact that the majority of the study group knew their Gleason score may be due to the study environment.

Examining psychological issues that men with prostate cancer may experience is overdue. Few studies have been conducted and major limitations of those studies include a lack of specificity related to timing in the disease process and the identification of treatment modalities. While this study demonstrates many of the aspects surrounding a prostate cancer diagnosis, it does not represent prostate cancer as a whole. Future research needs to address patients' psychosocial needs at diagnosis, during treatment and



53

at the end of life. Studies that involve social support available to these individuals may also reveal important issues. The lack of interest in researching men with prostate cancer may be related to age (the disease is found in older men) and/or the sexual and psychological domains involved which are largely unseen and unspoken. Much work needs to be done before meaningful interventions can be proposed that would ease the psychological concerns of these men.

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54



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## Vita

# Date of Birth May 23, 1956

# Place of Birth Charlestown, IN

## **Education:**

| Institution                                    | Degree or<br>Diploma | Dates         | Field(s) of<br>Study |
|--|----------------------|---------------|----------------------|
| University of Arkansas for<br>Medical Sciences | BSN                  | 1983, May     | Nursing              |
| University of Kentucky                         | MSN                  | 1999, May     | Nursing              |
| University of Kentucky                         | PhD                  | 2013, January | Nursing              |

# **Professional Experience:**

| Dates                     | Institution and Location  | Position  |
|---------------------------|---|---|
| May 2005 to present       | University of Kentucky Department of<br>Surgery/ Urology, Lexington, Ky | Certified Urology Nurse<br>Practitioner             |
| Jan. 2000 to<br>May 2005  | St. Joseph Hospital Lexington, Ky                                       | Advanced Practice Nurse<br>Outpatient Surgery       |
| June 1991 to<br>Jan. 2000 | St. Joseph Hospital, Lexington, Ky                                      | Staff Nurse/<br>Ophthalmology Nurse<br>Practitioner |

## **Professional Service**

| 2011      | Society of Urologic Nurses and Associates Committee for Development<br>of Clinical Guidelines: Male catherization   |
|-----------|---|
| 2010      | Society of Urologic Nurses and Associates Committee for Development<br>of National Scopes and Standards of Practice for Urologic Nurses and<br>Advanced Practice Nurses |
| 2009-2011 | Society of Urologic Nurses National Conference Planning Committee   |
| 2007–2011 | Founding President Kentucky Chapter, Society of Urologic Nurses and Associates  |
| 2008      | Student Mentor James W. Stuckert Career Center/ Shadowing   |
| 2009      | Network University of Kentucky  |
| 2009      | MedSurg Nursing Manuscript Review Panel   |
| 2009      | University of Kentucky College of Nursing Adjunct Faculty   |



# Awards and Honors:

| 2008 | Society of Urologic Nurses and Associates, North Central Chapter<br>Member of the Year |
|------|--|
| 2010 | Society of Urologic Nurses and Associates, North Central Chapter<br>Member of the Year |
| 2011 | Recepient of the Patricia Putetti Memorial Lectureship Award                           |
|      | Society of Urologic Nurses and Associates, National Conference                         |

## Membership in Professional Organizations:

| 1998 | American Academy of Nurse Practitioners                    |
|------|--|
| 1998 | Kentucky Coalition of Nurse Practitioners & Nurse Midwives |
| 2007 | American Urological Association                            |
| 2005 | Society of Urologic Nurses and Associates                  |
| 2010 | Sigma Theta Tau Honor Society                              |
| 2011 | Kentucky Urologic Association                              |
|      |  |

## **Poster**

Quillen, R., Hooper, G., Erickson, D., 2012. Intravesical Bupivacaine for Lidocaine Refractory Patients with Painful Bladder Syndrome/Interstitial Cystitis. *Society of Urodynamics & Female Urology*, Annual Meeting

# **Presentations**

Advanced Practice Hands-on Workshop: Basic Pessary Fitting: Society of Urologic Nurses and Associates National Conference, Washington, D.C., Nov. 3, 2012

Hold It Up Sister: A Workshop on Fitting and Managing Pessaries: Society of Urologic Nurses and Associates, National Conference, Washington, D. C., Nov. 5, 2012

Prostate Cancer: Beyond Diagnosis and Treatment-A Look at the Psychosocial Aspects of having Prostate Cancer Man to Man Support Group/American Cancer Society Florence, KY Feb. 2, 2012

Hold It Up Sister: A Workshop on Pessaries and Pelvic Organ Prolapse. National Society of Urologic Nurses Conference, San Antonio, TX October 28, 2011

To PSA or Not to PSA: Is This the Right Question? Moderator for panel discussion on prostate cancer screening. Society of Urologic Nurses and Associates, Boston, MA: October 10, 2010



A Wee Bit on Urology. Midyear Conference of the National Student Nurses Association, Cincinnati, OH: November 7, 2010

Prostate Cancer Forum for Survivors and Spouses of Prostate Cancer American Cancer Society/ Central Baptist Hospital, March 10, 2008

The Practice of Urology: Testing, Technology and Techniques Society of Urologic Nurses and Associates, Kentucky Chapter, Lexington, KY: May 14, 2008

The Lived Experience of Men with Prostate Cancer Man to Man Support Group/ American Cancer Society, April 21, 2007

> Gwendolyn Moffett Hooper Signature

