

**Prostate Cancer:  
Information Needs and Treatment Decision  
Making**

**By  
B. Joyce Davison, R.N., B.N.**

**A Thesis  
Submitted to the Faculty of Graduate Studies  
in Partial Fulfillment of the Requirements  
for the Degree of**

**Master of Nursing**

**Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba**

**(c) June, 1993**



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

395 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395, rue Wellington  
Ottawa (Ontario)  
K1A 0N4

*Your file    Votre référence*

*Our file    Notre référence*

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-86037-5

Canada

Name \_\_\_\_\_

*Dissertation Abstracts International* is arranged by broad, general subject categories. Please select the one subject which most nearly describes the content of your dissertation. Enter the corresponding four-digit code in the spaces provided.

Nursing  
SUBJECT TERM

0569  
SUBJECT CODE

U·M·I

## Subject Categories

### THE HUMANITIES AND SOCIAL SCIENCES

#### COMMUNICATIONS AND THE ARTS

Architecture ..... 0729  
Art History ..... 0377  
Cinema ..... 0900  
Dance ..... 0378  
Fine Arts ..... 0357  
Information Science ..... 0723  
Journalism ..... 0391  
Library Science ..... 0399  
Mass Communications ..... 0708  
Music ..... 0413  
Speech Communication ..... 0459  
Theater ..... 0465

#### EDUCATION

General ..... 0515  
Administration ..... 0514  
Adult and Continuing ..... 0516  
Agricultural ..... 0517  
Art ..... 0273  
Bilingual and Multicultural ..... 0282  
Business ..... 0688  
Community College ..... 0275  
Curriculum and Instruction ..... 0727  
Early Childhood ..... 0518  
Elementary ..... 0524  
Finance ..... 0277  
Guidance and Counseling ..... 0519  
Health ..... 0680  
Higher ..... 0745  
History of ..... 0520  
Home Economics ..... 0278  
Industrial ..... 0521  
Language and Literature ..... 0279  
Mathematics ..... 0280  
Music ..... 0522  
Philosophy of ..... 0998  
Physical ..... 0523

Psychology ..... 0525  
Reading ..... 0535  
Religious ..... 0527  
Sciences ..... 0714  
Secondary ..... 0533  
Social Sciences ..... 0534  
Sociology of ..... 0340  
Special ..... 0529  
Teacher Training ..... 0530  
Technology ..... 0710  
Tests and Measurements ..... 0288  
Vocational ..... 0747

#### LANGUAGE, LITERATURE AND LINGUISTICS

Language ..... 0679  
  General ..... 0289  
  Ancient ..... 0290  
  Linguistics ..... 0291  
  Modern ..... 0291  
Literature ..... 0401  
  General ..... 0294  
  Classical ..... 0295  
  Comparative ..... 0297  
  Medieval ..... 0298  
  Modern ..... 0316  
  African ..... 0591  
  American ..... 0305  
  Asian ..... 0352  
  Canadian (English) ..... 0355  
  Canadian (French) ..... 0593  
  English ..... 0311  
  Germanic ..... 0312  
  Latin American ..... 0315  
  Middle Eastern ..... 0313  
  Romance ..... 0314  
  Slavic and East European ..... 0314

#### PHILOSOPHY, RELIGION AND THEOLOGY

Philosophy ..... 0422  
Religion ..... 0318  
  General ..... 0321  
  Biblical Studies ..... 0319  
  Clergy ..... 0320  
  History of ..... 0322  
  Philosophy of ..... 0469  
Theology ..... 0323

#### SOCIAL SCIENCES

American Studies ..... 0323  
Anthropology ..... 0324  
  Archaeology ..... 0326  
  Cultural ..... 0327  
  Physical ..... 0310  
Business Administration ..... 0272  
  General ..... 0770  
  Accounting ..... 0454  
  Banking ..... 0338  
  Management ..... 0385  
Canadian Studies ..... 0501  
Economics ..... 0503  
  General ..... 0505  
  Agricultural ..... 0508  
  Commerce-Business ..... 0509  
  Finance ..... 0510  
  History ..... 0511  
  Labor ..... 0358  
  Theory ..... 0366  
Folklore ..... 0351  
Geography ..... 0578  
Gerontology ..... 0578  
History ..... 0578  
  General ..... 0578

Ancient ..... 0579  
Medieval ..... 0581  
Modern ..... 0582  
Black ..... 0328  
African ..... 0331  
Asia, Australia and Oceania ..... 0332  
Canadian ..... 0334  
European ..... 0335  
Latin American ..... 0336  
Middle Eastern ..... 0337  
United States ..... 0585  
History of Science ..... 0398  
Law ..... 0615  
Political Science ..... 0616  
  General ..... 0617  
  International Law and Relations ..... 0814  
  Public Administration ..... 0452  
Recreation ..... 0626  
Social Work ..... 0627  
Sociology ..... 0938  
  General ..... 0631  
  Criminology and Penology ..... 0628  
  Demography ..... 0629  
  Ethnic and Racial Studies ..... 0630  
  Individual and Family Studies ..... 0700  
  Industrial and Labor Relations ..... 0344  
  Public and Social Welfare ..... 0709  
  Social Structure and Development ..... 0999  
  Theory and Methods ..... 0453  
Transportation ..... 0453  
Urban and Regional Planning ..... 0453  
Women's Studies ..... 0453

### THE SCIENCES AND ENGINEERING

#### BIOLOGICAL SCIENCES

Agriculture ..... 0473  
  General ..... 0285  
  Agronomy ..... 0475  
  Animal Culture and Nutrition ..... 0476  
  Animal Pathology ..... 0359  
  Food Science and Technology ..... 0478  
  Forestry and Wildlife ..... 0479  
  Plant Culture ..... 0480  
  Plant Pathology ..... 0817  
  Plant Physiology ..... 0777  
  Range Management ..... 0746  
  Wood Technology ..... 0306  
Biology ..... 0287  
  General ..... 0308  
  Anatomy ..... 0309  
  Biostatistics ..... 0379  
  Botany ..... 0329  
  Cell ..... 0353  
  Ecology ..... 0369  
  Entomology ..... 0793  
  Genetics ..... 0410  
  Limnology ..... 0307  
  Microbiology ..... 0317  
  Molecular ..... 0416  
  Neuroscience ..... 0433  
  Oceanography ..... 0821  
  Physiology ..... 0778  
  Radiation ..... 0472  
  Veterinary Science ..... 0786  
  Zoology ..... 0760  
Biophysics ..... 0425  
  General ..... 0419  
  Medical ..... 0572  
EARTH SCIENCES ..... 0573  
  Biogeochemistry ..... 0574  
  Geochemistry ..... 0575

Geodesy ..... 0370  
Geology ..... 0372  
Geophysics ..... 0373  
Hydrology ..... 0388  
Mineralogy ..... 0411  
Paleobotany ..... 0345  
Paleoecology ..... 0426  
Paleontology ..... 0418  
Paleozoology ..... 0985  
Palynology ..... 0427  
Physical Geography ..... 0368  
Physical Oceanography ..... 0415

#### HEALTH AND ENVIRONMENTAL SCIENCES

Environmental Sciences ..... 0768  
Health Sciences ..... 0566  
  General ..... 0300  
  Audiology ..... 0992  
  Chemotherapy ..... 0567  
  Dentistry ..... 0350  
  Education ..... 0769  
  Hospital Management ..... 0758  
  Human Development ..... 0982  
  Immunology ..... 0564  
  Medicine and Surgery ..... 0347  
  Mental Health ..... 0569  
  Nursing ..... 0570  
  Nutrition ..... 0380  
  Obstetrics and Gynecology ..... 0354  
  Occupational Health and Therapy ..... 0381  
  Ophthalmology ..... 0571  
  Pathology ..... 0419  
  Pharmacology ..... 0572  
  Pharmacy ..... 0382  
  Physical Therapy ..... 0573  
  Public Health ..... 0574  
  Radiology ..... 0575  
  Recreation ..... 0460  
  Speech Pathology ..... 0383  
  Toxicology ..... 0386  
Home Economics ..... 0386

#### PHYSICAL SCIENCES

Pure Sciences ..... 0485  
Chemistry ..... 0749  
  General ..... 0486  
  Agricultural ..... 0487  
  Analytical ..... 0488  
  Biochemistry ..... 0488  
  Inorganic ..... 0738  
  Nuclear ..... 0490  
  Organic ..... 0491  
  Pharmaceutical ..... 0494  
  Physical ..... 0495  
  Polymer ..... 0754  
  Radiation ..... 0405  
Mathematics ..... 0605  
Physics ..... 0986  
  General ..... 0606  
  Acoustics ..... 0608  
  Astronomy and Astrophysics ..... 0748  
  Atmospheric Science ..... 0607  
  Atomic ..... 0798  
  Electronics and Electricity ..... 0759  
  Elementary Particles and High Energy ..... 0609  
  Fluid and Plasma ..... 0610  
  Molecular ..... 0752  
  Nuclear ..... 0756  
  Optics ..... 0611  
  Radiation ..... 0463  
  Solid State ..... 0346  
Statistics ..... 0984  
Applied Sciences ..... 0346  
Applied Mechanics ..... 0984  
Computer Science ..... 0984

Engineering ..... 0537  
  General ..... 0538  
  Aerospace ..... 0539  
  Agricultural ..... 0540  
  Automotive ..... 0541  
  Biomedical ..... 0542  
  Chemical ..... 0543  
  Civil ..... 0544  
  Electronics and Electrical ..... 0348  
  Heat and Thermodynamics ..... 0545  
  Hydraulic ..... 0546  
  Industrial ..... 0547  
  Marine ..... 0794  
  Materials Science ..... 0548  
  Mechanical ..... 0743  
  Metallurgy ..... 0551  
  Mining ..... 0552  
  Nuclear ..... 0549  
  Packaging ..... 0765  
  Petroleum ..... 0554  
  Sanitary and Municipal ..... 0790  
  System Science ..... 0428  
Geotechnology ..... 0796  
Operations Research ..... 0795  
Plastics Technology ..... 0994  
Textile Technology ..... 0994

#### PSYCHOLOGY

General ..... 0621  
Behavioral ..... 0384  
Clinical ..... 0622  
Developmental ..... 0620  
Experimental ..... 0623  
Industrial ..... 0624  
Personality ..... 0625  
Physiological ..... 0989  
Psychobiology ..... 0349  
Psychometrics ..... 0632  
Social ..... 0451



PROSTATE CANCER:  
INFORMATION NEEDS AND TREATMENT DECISION MAKING

BY

B. JOYCE DAVISION

A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF NURSING

© 1993

Permission has been granted to the LIBRARY OF THE UNIVERSITY OF MANITOBA to lend or sell copies of this thesis, to the NATIONAL LIBRARY OF CANADA to microfilm this thesis and to lend or sell copies of the film, and UNIVERSITY MICROFILMS to publish an abstract of this thesis.

The author reserves other publications rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's permission.

## Table of Contents

<b>Abstract.....</b>	<b>i</b>
<b>Acknowledgements.....</b>	<b>ii</b>
<b>List of Tables and Figures.....</b>	<b>iii</b>
<b>Chapter One: Introduction.....</b>	<b>1</b>
1.0 Background to the Study.....	1
1.1 Statement of the Problem.....	3
1.2 Purpose of the Study.....	5
1.3 Research Questions.....	5
1.4 Definition of Terms.....	6
1.5 Summary.....	7
<b>Chapter Two: Conceptual Framework.....</b>	<b>8</b>
2.0 Introduction.....	8
2.1 Primary Appraisal.....	9
2.2 Secondary Appraisal.....	11
2.3 Coping.....	12
2.4 Reappraisal.....	14
2.5 Adaptation.....	15
2.6 Summary.....	16
<b>Chapter Three: Literature Review.....</b>	<b>19</b>
3.0 Introduction.....	19
3.1 Seeking Information as a Mode of Coping .....	20
3.2 Identified Information Needs.....	30
3.3 Communication of Information.....	35
3.4 Information and Treatment Decision Making.....	40
3.5 Summary.....	49

<b>Chapter Four: Methodology.....</b>	<b>51</b>
4.0 Research Design.....	51
4.1 Population, Sample, and Sample Selection.....	52
4.2 Procedure.....	52
4.3 Data Collection Instrument.....	53
4.4 Analysis of Results.....	55
4.5 Ethical Considerations.....	57
4.6 Summary.....	58
<b>Chapter Five: Results.....</b>	<b>59</b>
5.0 Introduction.....	59
5.1 Sociodemographic Description of Sample.....	59
5.2 Research Question One.....	61
5.3 Research Question Two.....	65
5.4 Research Question Three.....	66
5.5 Research Question Four.....	68
5.6 Research Question Five.....	69
5.7 Research Question Six.....	69
5.8 Summary.....	71
<b>Chapter Six: Discussion of Results.....</b>	<b>72</b>
6.0 Introduction.....	72
6.1 Information Needs.....	72
6.2 Treatment Decision Making.....	76
6.3 Information Needs and Treatment Decision Making.....	80
6.4 Recommendations.....	81
6.5 Strengths and Limitations of Study.....	84
6.6 Conclusions of Study.....	86

<b>References.....</b>	<b>88</b>
------------------------	-----------

## **Appendices**

A. Lazarus' Conceptual Definitions.....	101
B. Transactional Model of Stress and Coping.....	102
C. Invitation and Explanation of the Study for Participants.....	103
D. Consent Form.....	105
E. Part One: Profile of Information Needs Questionnaire.....	107
F. Likert Scale of Information Needs.....	111
G. Part Two: Control Preference Scale.....	113
H. Part Three: Personal Sociodemographic Profile.....	114
I. Variable Dictionary.....	116
J. Frequency Matrix for All Subjects.....	119
K. Proportion Matrix for All Subjects.....	120
L. Z Score Matrix for All Subjects.....	121

### **Abstract**

This descriptive study used a three part questionnaire to determine if a relationship existed between the role in treatment decision making, and information needs of 57 men newly diagnosed with prostate cancer. The Control Preference Card Sort was used to determine the role preference in treatment decision making, and L. L. Thurstone's Law of Comparative Judgement was used as the main methodological approach to identify the hierarchical profile of information needs.

The majority of men were found to prefer a passive role in treatment decision making. A trend was identified for men who were married, less educated, and more recently diagnosed to prefer a more passive role in decision making.

The profiles of information needs were found to be similar regardless of the role in treatment decision making. Single men rated information on self-care significantly more important than married men.



### **Acknowledgements**

I would like to express my appreciation for the support and knowledge shared with me by the members of my thesis committee. Dr. Lesley Degner, chair of the committee, provided me with the mentorship I required to complete this Master's of Nursing research project, and become proficient in grantsmanship. This study was based on Dr. Degner's previous research in treatment decision making, and information needs. Dr. Elizabeth Hanson's knowledge in oncology nursing and theory assisted me in the interpretation of the results of this study within the theoretical framework. Both of these members challenged my thinking process, and proved to be excellent role models.

Dr. Thomas Morgan shared his medical expertise with me, and challenged my thinking on many treatment and patient information related issues. His commitment to further nursing research, and to the improvement of the care provided to men newly diagnosed with prostate cancer was evidenced by his presence on this committee.

Dr. Jeff Sloan also shared with me his statistical and computer expertise to interpret the data generated from this study. His previous work on the Thurstone Scaling was seen as an essential component of the data analysis.

The Manitoba Health Research Council must also be thanked for the financial support provided to conduct this nursing research study.

In closing, I would like to extend my appreciation for the love and support that my best friend, and husband Rick gave to me over the past two years.

### **List of Tables**

Table One: Sociodemographic Description of Sample.....	60
Table Two: Profiles of Men With $\geq 10$ Circular Triads.....	63
Table Three: Likert Scale- Amount of Information Desired.....	65
Table Four: Comparison of Information Needs Profiles.....	67
Table Five: Preferred and Actual Role Variables.....	70

### **List of Figures**

Figure One: Profile of Information Needs.....	62
---	----

## **Chapter One**

### **Introduction**

#### **1.0 Background to the Study**

In the Western Canadian provinces and the United States, prostate cancer has overtaken lung cancer to become the most common malignancy found in men (Mador, 1991; Statistics Canada, 1992). It is also the second most commonly diagnosed cancer, and the second most common cause of cancer deaths in Canadian men (Statistics Canada, 1992). In Canada, the estimated rate of prostate cancer for 1992 was 10% of all cancers, and 20% of all cancers occurring in men (Statistics Canada, 1992). It is estimated that there will be 12,000 new cases, and 3,700 deaths occurring this year as a result of prostate cancer (Statistics Canada, 1992). The incidence of this disease is increasing yearly, partly as a reflection of the rise in the elderly population (Guthrie & Watson, 1987; Vikram & Vikram, 1988). This fact, combined with the progressive aging of the 'baby boom' population, promises that prostate cancer will replace lung cancer as the most common form of cancer among Canadian men by the end of this decade (Bazinet, 1991; Gorman, 1992). In Manitoba, approximately 19% of the male population is currently 55 years or older, and by the year 2000, this number will increase to 25% (Manitoba Health Services Commission, 1991). Although lung cancer has the highest incidence of mortality among Manitoban men with cancer, Statistics Canada (1992) reported that prostate cancer had overtaken lung cancer to become the most commonly diagnosed cancer among Manitoban men.

Cancer of the prostate is regarded as a disease of older men. Half of the patients with prostate cancer are 70 years and older. In fact, the incidence of prostate cancer among men over 70 is one in 100 (Vikram & Vikrim, 1988). Men less than 45 years of age account for less than 0.6% of all reported cases (Benson, Kaplan, & Olsson, 1987). The average age of incidence in Canada and in Manitoba is 63 years (Statistics Canada,

1992). Statistics Canada (1992) reported there were approximately 570 newly diagnosed cases of prostate cancer in Manitoba in 1992.

Although the specific etiology of prostate cancer remains unknown, higher serum testosterone levels, high fat diets, workplace exposure to certain elements, advancing age, and heredity have been proposed as major determinants of the risk of developing this disease (Ross, Paganini-Hill, & Henderson, 1988; Mador, 1991). The early diagnostic period frequently centers first on the uncertainty of the presence of prostatic cancer, then on the extent of the disease, and alternative treatment approaches. Because of the inability to prevent prostate cancer, early detection offers the most practical method of reducing morbidity and mortality (Bostwick, 1988). Since early prostate cancer seldom produces symptoms, some physicians believe that all men over 40 years of age should have a rectal examination as part of their yearly physical (Huben & Murphy, 1986; Chodak, Keller, & Schoenberg, 1989; Bazinet, 1991; Chesley, 1991; Gorman, 1992). Induration of the prostate on digital rectal examination may be the only clinical evidence of low-stage disease. The Canadian Urological Association recommends that in addition to the rectal exam, a prostate-specific antigen (PSA) test should be done on all men between the ages of 50 and 70 annually. If there is a family history of prostate cancer, the Association recommends that the PSA test should be started annually at the age of 40.

A significant number of patients are also diagnosed when histologic examination of tissue removed for presumed benign prostatic hyperplasia reveals unsuspected carcinoma. In many patients the presenting signs and symptoms of prostate cancer are weight loss, bone pain, and anemia caused by distant metastases (Catalona & Avioli, 1987). Over 70% of the men with prostate cancer have stage B disease or higher at the time of diagnosis (Herr, 1985; Mertens, 1991; Bretton & Fair, 1991; Petros & Catalona, 1992).

Men diagnosed with prostate cancer are faced with many difficult diagnostic and treatment choices, largely as a result of advances in medical technology. Most treatment is aimed at cure, but the optimal treatment for prostate cancer is controversial (Ahmann,

1985a, 1985b; Bretton & Fair, 1991). The extremely variable behavior of prostate cancer has made it very difficult to determine the best treatment for this tumor (Gleason, 1985). Generalizations for treatment choice are made based on the stage of the disease and factors such as the patient's age, expected survival, coexistent medical problems, and desire to retain potency (Huben & Murphy, 1986; Guthrie & Watson, 1987; Gittes, 1991; Trachtenberg, 1991). The most common treatment modalities includes one or more of the following: surgery (transurethral resection, radical prostatectomy); radiation therapy; and hormonal manipulation through orchiectomy or pharmacotherapy (Gittes, 1991). No treatment for prostate cancer is without some risk to sexual function (Bachers, 1985). Survival periods following treatment are also uncertain ranging anywhere from one to five, 10, and 15 years. The medical literature shows that the older the patient and the higher the stage of cancer, the lower the rate of survival (Trachtenberg, 1991; Ramsey, 1992).

### **1.1 Statement of the Problem**

From the onset, cancer of the prostate is marked by uncertainty. The specific etiology remains unknown, the optimal treatment is controversial, and survival rates vary. Technical advances in medicine have also increased the complexity of treatment choices presented to these patients. The majority of oncology units believe health care professionals should provide the necessary information needed by patients to actively participate in treatment decision making (Northouse & Wortmann, 1990), but not all patients want to be involved in the decision making process to the same extent (Cassileth, Zupkis, Smith, & March, 1980; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989; Beisecker & Beisecker, 1990). Although many studies have found that cancer patients desire maximal amounts of information, such information is probably not desired for its usefulness in treatment decision making (Beisecker & Beisecker, 1990).

Information may be sought to reduce the anxiety caused by a diagnosis of cancer (McCorkle & Young, 1978), and/or enhance a sense of autonomy (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). Sutherland and associates (1989), and

Cassileth and associates (1980) found a positive relationship between decision making and identified information needs in cancer patients, with those preferring more active roles in decision making desiring more information. Patients who prefer a more active role in treatment decision making may require different types and amounts of information than do patients who are primarily concerned with coping with the effects of the treatment(s) and disease (Degner & Sloan, 1992).

Previous studies (Weisman & Worden, 1976; Feldman, 1978; Greenleigh Associates, 1979; Jones, 1981; & Derdiarian, 1986, 1987a, 1987b, & 1989) have shown that cancer patients require information in four main categories. In hierarchical order they are: disease (diagnosis, tests, treatments, and prognosis); personal (impact of disease/treatments on physical, emotional, and psychosocial well-being, career and future plans); family (impact of diagnosis on significant others); and social (contractual, leisure, and intimate relationships). Although the older, less educated cancer patients desire less information than their younger cohort (<50 years), the studies show that some are dissatisfied with the kind and/or amount of medical information they receive from physicians and nurses.

Studies have shown that being an older, less educated male with cancer tends to result in a more passive role in decision making (Cassileth, Zupkis, Smith, & March, 1980; Ende, Kazis, Ash, & Moskowitz, 1989; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). A recent study by Degner and Sloan (1992) reported that being a male with cancer of the reproductive system was a significant predictor of preferring a passive role in treatment decision making.

Identifying individuals who are most likely to be positively affected by receiving the information they desire to participate in treatment decision making is currently difficult. Few research studies have included a large enough number of men with prostate cancer in their samples to provide direction for clinical practice. Given the statistical significance of

the incidence, extent of the disease at the time of diagnosis (70% Stage B, or higher), and the uncertainty of treatment outcomes, this research study was warranted.

### **1.2 Purpose of the Study**

The purpose of this descriptive study was:

1. to investigate if a relationship existed between the hierarchical profile of information needs and preferred or assumed role in treatment decision making of men newly diagnosed with prostate cancer;
2. to identify which personal and situational factors were indicative of a preference for certain types of information; and
3. to identify which personal and situational factors were indicative of a preference for a particular role in treatment decision making.

### **1.3 Research Questions**

A breakdown of the general research question ( What relationship exists between the profile of information needs and the preferred role in treatment decision making of men newly diagnosed with prostate cancer?), revealed the following research questions:

1. What is the profile of information needs of men newly diagnosed with prostate cancer ?
2. Are there different profiles of information needs for men who prefer active, collaborative, and passive roles in treatment decision making?
3. Are there different profiles of information needs for men who believe they are assuming active, collaborative, and passive roles in treatment decision making?
4. Do the men differ with respect to their profiles of information needs:
  - a) men who are older (over 70 years), versus those who are younger ( $\leq 70$  years)?
  - b) men who have lower levels of education (less than high school diploma), versus higher levels of education?
  - c) men who have a spouse/partner, versus single?

d) men who are in the early stage of their disease (Stage A or B), versus later stages (Stage C or D) at the time of testing?

e) men who are recently diagnosed (0-13 weeks), versus later from time of diagnosis?

5. Do the men differ with respect to their preferred role in treatment decision making: (a to e as in question 4)?

6. Do the men differ with respect to the role they are assuming in treatment decision making: (a to e as in question 4)?

#### **1.4 Definition of Terms**

The following definitions applied to this study:

**Profile** referred to a description of the arrangement of the information needs in a hierarchial order.

**Newly diagnosed** referred to patients diagnosed with prostate cancer within the last six months (0 to 26 weeks).

**Information needs** referred to a need for knowledge, facts, or understanding that could be gained through communication, education, experience, study, or through explanation, as a way to gain cognitive control over a stressful situation.

**Preferred role in treatment decision making** referred to the involvement the patient wished to have in treatment decisions made regarding the type(s) of medical treatment(s) he received.

**Assumed role in treatment decision making** referred to the role the patient was actually assuming in treatment decisions made regarding the type(s) of medical treatment(s) he received.

**Active role in treatment decision making** referred to the patient making the final decision on the treatment he received, after consideration of the doctor's opinion.

**Collaborative role in treatment decision making** referred to the patient and doctor sharing responsibility for deciding which treatment was best.



**Passive role in treatment decision making** referred to the patient preferring the doctor to make the final treatment decision after considering his opinion, or leaving all treatment decisions up to the doctor.

### **1.5 Summary**

Medical and nursing practitioners in oncology currently believe that patients as consumers of health care services should be informed and have the right to actively participate in treatment decision making. The purpose of this study was to determine: the type of information these men felt was the most important to receive; the role they preferred in treatment decision making; what relationship existed between the profile of information needs and preferred/actual role in treatment decision making; and the effect of situational and personal variables on the profile of information needs, and preferred/assumed role in treatment decision making. The findings from this study were expected to generate knowledge to assist nurses and other health care professionals in clinical practice, provide a basis for further research, and contribute to a higher quality of care for this group of men.

## **Chapter Two**

### **Conceptual Framework**

#### **2.0 Introduction**

Lazarus and his colleagues (Lazarus, 1966; Lazarus, Averill, & Opton, 1970; Lazarus & Launier, 1978) have used cognitive appraisal to analyze the concepts of stress and coping. This psychological process mediates encounters/interactions between the person and environment, and are believed to determine the person's psychological stress reactions, the various emotions experienced, and adaptational outcomes (Lazarus, 1977). This model is transactional because the interaction between the individual and the environment is seen as a continuous two-way process. Lazarus (1984) states that the various forms of stress and emotion are products of the way in which an individual appraises the present and future significance of an actual, imagined, or anticipated encounter to his/her well-being. This theory has three types of cognitive appraisals which serve to assist the individual to mediate stress: primary appraisal, a process of evaluating the significance of an encounter for one's well-being; secondary appraisal, a process of evaluating an encounter with respect to coping resources and options; and reappraisal, a process by which new information is obtained from internal psychological changes and the environment to evaluate how effective specific actions have been. Although the cognitive operations for primary and secondary appraisal are similar, the foci differ. The primary appraisal asks the question 'Am I okay or in trouble?'. The secondary appraisal asks 'What can I do about it?'. These appraisals are evaluative processes by which an individual cognitively interprets the information based on his/her life experiences, values, beliefs, goals, and resources to deal with the stressful encounter, and achieve adaptation.

Lazarus and his colleagues have made several revisions to the original model of stress and coping that was introduced in 1966. The most significant revisions to date were addressed in Lazarus and Folkman (1984). The purpose of this chapter will be to describe this revised model which was used as a conceptual framework to guide this study.

## 2.1 Primary Appraisal

Primary appraisal refers to the cognitive process of evaluating the significance of an encounter for one's well-being. The concept of threat is closely linked to this cognitive process of appraisal because for threat to occur, the individual must evaluate an event as irrelevant, benign-positive, or stressful. An encounter evaluated as irrelevant is one that is considered to have no personal significance and therefore can be ignored. A benign-positive encounter involves a judgement that the event is beneficial or desirable. Stressful appraisals involve judgements of harm, loss, threat, or challenge. The person's current time perspective is important in distinguishing between harm-loss and threat (Coyne & Lazarus, 1980). Harm-loss refers to damage already sustained, whereas threat refers to the same type of damage and an anticipation of what has not yet happened. In harm-loss appraisal, the individual's coping efforts will center on overcoming, tolerating, making restitution for, or reinterpreting the harm in the context of the present. With threat, the focus will be on future attempts at maintaining the status quo, or preventing the harm by heading it off or neutralizing it. These shifts in coping patterns are thought to reflect changes in the individual's appraisal, either because he/she has received new information or because he/she has re-evaluated existing information. Harm/loss and threat appraisals are characterized by negative emotions such as anger, fear, or resentment, whereas challenge appraisals are characterized by pleasurable emotions such as excitement and eagerness (Folkman, 1984).

Although the distinction between challenge and threat is crucial in the study of stress, it involves a number of unsettled issues (Coyne & Lazarus, 1980). Challenge involves a judgement that the demands of an encounter can be met and overcome. Individuals who are challenged would be expected to have a better outcome when faced with a range of stressful events, but many stressful transactions are ambiguous. In this situation, an appraisal of challenge versus threat could be attributed to selective attention without the need for motivational inferences. In other situations, a challenge might

represent self-deception or a distortion of reality. The traditional view is that accurate reality testing is a sign of mental health and successful adaptation, but an examination of the stress/coping literature suggests the matter is not so simple (Lazarus & Launier, 1978).

A primary appraisal, whether harm/loss, challenge, or threat, is affected by personal and situational factors. Personal factors such as beliefs (preexisting notions about reality), and commitments (that which is important and has meaning to the person) are relevant to primary appraisal. Generalized beliefs about the control which an individual has in a situation have an influence on primary appraisal. For example, an individual who has an internal locus of control believes that events are contingent on his behavior, whereas an individual who has an external locus of control believes that events are contingent upon luck, fate, or chance (Rotter, 1966). In an ambiguous or novel situation, or where there is an absence of information, the individual makes inferences based on general experience, personality disposition, and beliefs. The greater the ambiguity, the more influence personal factors have in determining the meaning of the stressful event (Folkman, 1984).

Commitments can be defined at many levels of abstraction. Any encounter that involves a strongly held commitment will be evaluated as significant with respect to whether the individual perceives it as a threat or harm to well-being (Folkman, 1984). Commitments also affect the extent of control an individual believes he has. For example, the more serious the commitments involved in an encounter, the more important it may be for the individual to believe that he or she can control the outcome of the encounter.

Situational factors include the nature of the harm or threat, whether the event is novel or familiar, how likely it is to occur, and how clear or ambiguous the expected outcome is (Folkman, 1984). The more imminent and potent the anticipated stimulus event is to produce harm in relation to the individual's resources, the greater is the likelihood of threat appraisal. If the event is unfamiliar or ambiguous, the intensity of the threat increases because it limits the individual's sense of control or increases his/her sense of helplessness over the danger. Lazarus and Folkman (1984) state that a certain amount of

ambiguity may be beneficial in some situations, based on an individual's psychological structure. Lazarus and Folkman (1984) believe the amount of stress caused by the length of time a stressful event persists can be mediated through coping and reappraisal.

Primary appraisal consists of evaluating whether an individual perceives a situation as threatening or non-threatening. The two main factors affecting the appraisal are factors in the environment (balance between harm and resources, and the imminence and/or ambiguity of the threat), and factors within the individual's psychological structure (motives, beliefs, intellectual resources). Lazarus recognizes that future work is required to develop subtypes for the concepts of harm-loss, threat, and challenge as they are relatively broad (Lazarus & Launier, 1978).

## **2.2 Secondary Appraisal**

After the individual assesses the significance of the stimulus-stressor to well-being, the cognitive appraisal process continues with an examination of coping resources that are available to mediate its impact (Folkman & Lazarus, 1980, 1985; Lazarus & Folkman, 1984). Secondary appraisal occurs when the individual evaluates his/her coping resources, options, and constraints. The evaluative processes in primary and secondary appraisal are highly interrelated. For example, a firm sense of self-efficacy can lead one to appraise an event as benign or irrelevant that would otherwise be threatening. In contrast, if one believes coping resources are depleted, then the event may be perceived as threatening, where it otherwise would not be (Coyne & Lazarus, 1980). It involves balancing competing concerns as the person simultaneously or sequentially evaluates personal and social resources that can be mobilized, the adequacy of alternative coping strategies, and feedback from coping efforts. Information processing is highly selective and influenced by the individual's primary appraisals, emotional state, and personal agendas.

The determinants of secondary appraisal include the person's previous experiences with the situation, generalized beliefs about self and environment, the availability of resources, and assessments of coping resources (Folkman, Schaefer, & Lazarus, 1979).

Coping resources include physical (health, energy, stamina), social (individual's social network, support systems), psychological (beliefs that can be drawn upon to sustain hope, problem-solving skills, self-esteem, morale), and material assets (money, tools, equipment) that an individual has to cope with the demands of the situation (Folkman, Schaefer, & Lazarus, 1979; Antonovsky, 1979; & Schaefer, Coyne, & Lazarus, 1982). Lazarus recognizes the fact that past discussions of secondary appraisal have been relatively incomplete with regard to identifying the various types of secondary appraisal, how they feed back to primary appraisal in shaping the degree of threat, and shape the coping process (Lazarus & Launier, 1978). He also states that the definition of coping may be too broad to be able to measure it empirically.

### **2.3 Coping**

Lazarus and Folkman (1984) postulate that coping involves the interdependent processes of primary and secondary appraisal, both of which mediate between the stimulus and the outcome response (coping effectiveness). Coping refers to cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external demands that are created by the stressful event (Lazarus & Launier, 1978; & Folkman & Lazarus, 1980). Important in this definition is the fact that coping is defined independently of its outcome. It refers to efforts to manage demands regardless of the success of those efforts. The process of coping serves two functions, that of altering the ongoing person-environment relationship (problem orientated), and controlling the stressful emotions (emotion regulation). Problem oriented coping refers to efforts to deal with the sources of stress, whereas emotion regulation refers to coping efforts aimed at reducing emotional distress and maintaining a satisfactory internal state for processing both information and action (Coyne & Lazarus, 1980). Although these two coping functions frequently occur simultaneously, it is possible for the two functions to be in conflict. An example of this is when emotion-focused coping obstructs or delays actions required to protect individuals against illness.

Lazarus and Launier (1978) identified four main coping modes, serving both problem-solving and emotion-regulating functions, capable of being oriented to the self or the environment, and concerned with either past or present (harm/loss) or future (threat or challenge). The four modes are information-seeking, direct action, inhibition of action, and intrapsychic processes.

Information-seeking involves cognitively appraising the stressful event for knowledge needed to make a coping decision or to reappraise the damage or threat. Seeking information provides a basis for action (problem-solving function), and bolstering or rationalizing a past decision (Janis & Mann, 1977). Lazarus (1984) also states that there are other ways of coping with threat than wanting to know all, and that the uncertainty afforded by a lack of detailed information can have utility in certain circumstances.

Direct action refers to anything one does (except cognitively) to handle a stressful encounter. The list of these actions is both diverse and unlimited. These actions can be aimed at the self or the environment, since either is potentially capable of being changed to alter the stressful person-environment relationship. The action can be aimed at overcoming a past-injury, or a future danger.

Inhibition of action refers to the individual holding back action that will do harm. Every type of action is capable of coming into conflict with moral, social, or physical constraints and dangers, and choice is possible only if strong natural impulses to act can be held back in the interest of the other values (Lazarus & Folkman, 1984).

Intrapsychic modes refer to all cognitive processes designed to regulate emotion. It encompasses self-deception mechanisms or defenses such as denial, reaction formation, and projection, avoidance, and efforts to obtain detachment or insulation from a threat to achieve a feeling of control over it. These modes are believed to be mostly palliative, as they make the individual feel better by reducing or minimizing emotional distress. They can be oriented to the past or to the future, and can be focused on the self or on the environment (Lazarus & Folkman, 1984).

There are a number of factors that influence the individual's choice of coping mode. Four such factors are: degree of uncertainty (ambiguity), degree of threat, presence of conflict, and degree of helplessness. A high degree of uncertainty may decrease use of direct action and increase information seeking, whereas failure of these two modes should encourage intrapsychic modes of coping (Lazarus & Folkman, 1984). There are, however, many types of uncertainty. If a threat is appraised as severe, primitive modes of coping may be used such as rage, panic, or confused thinking, even when more realistic and more effective modes of coping might help. Conflict may make a nondamaging solution impossible, since acting on behalf of one impulse, goal, or commitment requires the thwarting of the other. Under such conditions, psychological stress is inevitable, but direct actions are immobilized and the individual is pushed to rely on intrapsychic modes. Helplessness occurs when the harm has already occurred, and inevitable future harms cannot be prevented by action, so they must be accepted, tolerated, or reinterpreted. When helplessness escalates to hopelessness, a condition of total immobilization of action may result.

Coping consists of a constellation of many acts and thoughts engendered by a complex set of demands which are dependent on the simplicity or complexity, and the time frame of the stressful encounter (Lazarus & Folkman, 1984). The measurement of the coping process is therefore complex, as it is difficult to describe what a person is doing and thinking in specific encounters. Most measures of coping currently available are trait-oriented, focus on a limited class of coping modes, and rarely cover the four modes previously mentioned. Lazarus (1984) suggests that to measure coping one must observe the coping pattern used by the individual several times, at diverse moments, across different types of encounters, and over time, in order to make an accurate description.

## **2.4 Reappraisal**

Reappraisal refers to the reevaluation of a situation when new information is available, either from the environment or from within the person. It is a feedback process



that takes two forms. The first involves new information about the changing person-environment relationship and its significance for well-being. The other form, defensive reappraisal, represents cognitive maneuvering to reduce distress rather than to assess accurately the troubled person-environment relationship with a view to changing it. Thus, what was originally appraised as harm-loss or a threat may be reappraised as nonthreatening or desirable (Coyne & Lazarus, 1980). Defensive reappraisal represents the interpretation of cognitive processes and coping.

## **2.5 Adaptation**

Adaptation depends on the cognitive appraisal processes, as well as the success of the coping efforts of the individual. The ultimate goal of both primary and secondary appraisal is adaptation. Lazarus and Folkman (1984) delineate the complex relationship that exists between the three major adaptational outcomes of morale, social functioning, and somatic health. It is important to recognize that good functioning in one sphere may not be predictive of the person functioning well in all areas. Although studies of coping suggest coping styles are related to specific health outcomes, problems exist with measuring the definition of the quality of health (Lazarus & Folkman, 1984).

Social functioning is the way in which the individual fulfills his/her various roles, or the skills necessary for maintaining roles and relationships (Lazarus & Folkman, 1984). The effectiveness with which an individual functions socially is believed to be largely determined by the effectiveness with which he/she appraises and copes with the events of day-to-day living. Effective coping depends on a match between secondary appraisal (coping options and actual coping demands), selected coping strategies, and other personal agendas. Social functioning over the long term is seen as an extension of coping effectiveness in many specific encounters over the life course. Problems exist with the assessment of social functioning. Lazarus suggests that further studies are required to study the stability of social functioning, effects of major life stresses on social functioning, and the influence of personal factors (Lazarus & Folkman, 1984).

The long-term outcome of morale parallels the short-term outcome of emotions generated in a specific encounter (Lazarus & Folkman, 1984). The assessment of morale tends to focus on general negative and positive emotion. Morale over the long-term, depends on appraising encounters as challenging, coping with the negative outcomes to put them in a more positive light, and overall managing of a wide range of demands. Depression that results from learned helplessness is relevant to the issue of morale. Although Lazarus has introduced cognitive mediators to explain individual differences in morale, they are still incomplete because they pay little attention to coping, and do not take into account the meaning of helplessness (Lazarus & Folkman, 1984).

Stress, coping, and emotion are assumed to be causal factors in somatic illness, but the major controversy concerns whether there is generality or specificity in the relationship (Lazarus & Folkman, 1984). Because response based models of stress cannot easily explain individual differences in physiological response patterns and disease outcomes, specificity models (such as this one by Lazarus') are gaining prominence. Some of these latter models have incorporated cognitive appraisal and coping to explain the ways in which personal and situational factors modify the psychological response, and hence emotions and their biological concomitants.

## **2.6 Summary**

Lazarus' Transactional Model of Stress and Coping is a middle-range field theory developed using a deductive approach. It has defined the concepts (Appendix A) and has stated how the concepts relate to one another. See Appendix B for conceptual model. The relationship between cognition and emotion are seen by Lazarus as interdependent, one affecting the other in a continuous process. This dynamic field theory approach assumes that environmental demands, appraisal processes, coping, and emotional reactions are continually changing and altering the pattern of the adaptational encounter (Folkman, Schaefer, & Lazarus, 1979). This model is based on three assumptions: first, each individual has a unique perception of a situation; second, the individual's perception and

evaluation of the situation is influenced by personal and situational factors; and third, the individual's perception of the situation, the individual's response to the situation, and the situation itself, influence each other.

Lazarus' transactional model of stress and coping uses a micro approach that focuses on the interaction between the individual and his/her environment. The individual is seen as being an active participant who is striving to control and master the impact of the stressful encounter. Lazarus assumes that each individual has a unique perception of a situation, even when the situation is shared by several people. He does not deny that some situations and groups of individuals within a situation may share many characteristics, however, he emphasizes that each individual has their own unique perspective of the situation. These perceptions are based on personal and situational factors such as: past experiences with similar situations, one's emotional status at the time of the event, external resources, values and beliefs, current developmental level, educational level, present demands in life, and so on. Lazarus also states that the way in which an individual appraises (evaluates) a situation will affect the coping strategies used.

The way in which individuals appraise a situation, within the context of personal and situational factors, and the effect their coping has on the environment must be recognized as important to the understanding of stress and coping. Such a recognition suggests that this model can describe and predict how an individual will cope with stress (Coyne & Lazarus, 1980). However, the operationalization of these concepts in the model requires further work. Although Lazarus examines the main factors influencing an individual's perceptions of stress, it is highly likely, given the complex nature of stress and the human mind, that there remains a possible multitude of factors that have not yet been explored (Hanson, 1991).

A major criticism of deductive theories is the lack of support until they are tested in research. This explanatory theory has begun to link and describe the relationships between derived concepts. Although this theory is clearly in its infancy stage, its utility will grow

increasingly attractive as health and social science investigators are required by their data to invoke notions of cognitive mediation and bidirectional influences between the individual and his/her environment. Correlational studies (such as this thesis study) are necessary to provide empirical evidence to support, or refute the basic assumptions of this theory.

## Chapter Three

### Literature Review

#### 3.0 Introduction

Lazarus' transactional model of stress and coping has been utilized by oncology nurse researchers (Scott, Oberst, & Bookbinder, 1984; Saunders & McCorkle, 1987; Derdarian, 1986, 1987a, 1987b, 1989; Herth, 1989; Hanson, 1991), and most recently in cardio-vascular nursing (Riemer-Kent, 1991). The concepts of stress and coping are central to the practice of oncology clinicians and researchers, as they actively seek to understand how the patient perceives and responds to such a catastrophic experience as the diagnosis of cancer and its treatment(s). Coping, as a mediation factor, affects disease outcomes through solving problems and regulating emotions (Folkman, Schaefer, & Lazarus, 1979). The way in which an individual copes with stress may be even more important to overall morale, social functioning, and somatic health than the frequency and severity of the stress episodes themselves (Lazarus & Folkman, 1984). This model attends to a variety of coping responses that individuals facing a life crisis might use to alter the emotional responses to the crisis and the crisis itself. Lazarus' view of stress and coping as aligned with the individual's unique appraisal and response to the event, made this model appropriate as a basis for a review of the literature pertaining to the information needs and preferred role in treatment decision making of men newly diagnosed with prostate cancer.

The first section will describe how seeking information is used as a mode of coping, and the impact of person and situation variables on the way in which an individual seeks information. The second section will consist of the information needs previously identified as important to patients diagnosed with cancer. In the third section, the issues concerning the role of health care professionals in the communication of information will be discussed. The fourth section will examine the relationship between information needs and preferred role in treatment decision making, and the impact of situation and person variables on the decision making role. The following literature review will provide a

comprehensive review of the nursing, medical, sociological, and psychological literature. Research studies that have addressed the information needs and preferred role in treatment decision making of the older male cancer patient have been identified, and discussed in detail.

### **3.1 Seeking Information as a Mode of Coping**

The transactional model of stress and coping is based on the assumption that human beings first respond to the stress and uncertainty of an encounter (such as a diagnosis of prostate cancer) by cognitively examining what is happening, and judging the extent of an existing harm and that of a future harm or threat (primary appraisal) to well-being (Folkman & Lazarus, 1985). The cognitive appraisal continues with an examination of coping behaviors (secondary appraisal) to neutralize or resolve the crisis in the environment or in oneself, and regulate emotional stress (Folkman & Lazarus, 1980, 1985; Lazarus & Folkman, 1984). The process is ongoing and dynamic, aimed at survival, growth, and maintenance of the individual's integrity. Coping and appraisal continually influence each other throughout the stressful event.

Reappraisal or evaluation aims to assess the power and availability of resources to counteract the harm or threat of the actual or implied stressful event, the choice of action or inaction, and anticipated outcomes (Folkman & Lazarus, 1980, 1985; Lazarus & Folkman, 1984). Both appraisal and reappraisal occur through interpretation of the incoming data. Therefore, information seeking as a mode of coping may precede and/or co-exist with appraisal and reappraisal, and may have the dual function of mediating appraisal and reappraisal to bring about adaptation/successful coping when an individual is faced with a stressful life crisis such as the diagnosis of prostate cancer.

Lazarus and Launier (1978) have identified that altering the stressful person-environment relationship and controlling the emotional reaction arising from that relationship as the two main functions of coping. Although taking tranquilizers, alcohol, and sedatives are forms of coping which focus on reducing the stress of the person-

environment relationship, these strategies may help the individual cope subsequently with the basic problem (Lazarus, 1974). Coping involves a combination of many acts and thoughts when dealing with a stressful life event (Monat & Lazarus, 1977; Lazarus, 1982). An adaptive coping response is seen as one that contributes to the individual's overall well-being, and includes the individual's physiological, psychological, and social functioning (Monat & Lazarus, 1977). Although information seeking coexists with other modes of coping, Weisman and Worden (1977) found that it was the most predominant coping mode used at peak stress periods associated with a diagnosis of cancer.

The effectiveness of information-seeking as a coping mode is influenced by the way in which an individual appraises a situation, combined with the interaction of person and situation variables (Lazarus, 1977). Some studies have found that men do respond differently than women when faced with a crisis or threat. Weisman and Worden (1976), and Mages and Mendelsohn (1979) found that men were less religious, used more alcohol, and coped more often by use of stoic submission than did women in the period soon after a diagnosis of cancer (Mages & Mendelsohn, 1979). Although women have been reported to be able to maintain self-esteem, men were found to experience declines in the active, assertive, achievement-orientated aspects of their lives, resulting in a decline of self-esteem. These feelings were found to pervade men's work, and their family, social, and sexual lives. The investigators in both studies concluded that personal assessment of cancer is partially a function of gender, with men responding more intensely to threats to self-reliance and being less in touch with their bodies than are women. Derdiarian (1984) reported similar findings concerning the way in which gender affects individual responses to a diagnosis of cancer. Men were reported to attach more importance and perceive more negatively declines in their achievement, dependence, aggressiveness, and sexual performance.

Coping with cancer may also be influenced by age and the stage of the disease. In a study by Weisman and Worden (1977), older cancer patients had more symptoms and

health concerns, and less hope for recovery than the younger patients. There was, however, no relationship found between the patient's age and the amount of emotional distress experienced. The investigators showed that after adjustment for differences of cancer site, older patients who tested with lower ego strength scores on the Minnesota Multiphasic Personality Inventory ceased wanting information about their condition, and tended to avoid the word 'cancer' when referring to their disease. A relationship between the seriousness of the patients' illness and the effectiveness of their coping was found. Those patients with an advanced stage of cancer and more symptoms anticipated less recovery, and experienced greater emotional distress than those who were less seriously ill. Mages and Mendelsohn (1979) also reported that the older adults in their study suffered personal and social losses more rapidly as a result of cancer. They found that compared to younger adults, several older cancer patients retired earlier, disengaged earlier from leisure and social activities, and lost interest in the future.

A study by Folkman and Lazarus (1980) examined the relationship between secondary appraisal and the ways 100 community-residing men and women aged 45 to 64 years coped with the stressful events of daily living during a one year period. Two functions of coping (problem-focused and emotion-focused) were analyzed within the context of the event, who was involved, how it was appraised, age, and gender, as potential influences on coping. Problem-focused coping referred to efforts used to deal with the sources of stress, whereas emotion-focused coping efforts referred to coping efforts aimed at reducing emotional distress to maintain a satisfactory internal state for processing both information and action (Coyne & Lazarus, 1980). A trend was found in which older participants reported more health-related episodes, and fewer family and work episodes than the younger cohort. The authors suggested that as sources of stress begin to change with advancing age, differences in coping might emerge, as a result of more concern about health and less concern about work. This shift in focus would result in an increase in emotion-focused coping, and a decrease in problem-focused coping. The



authors cautioned that more studies were required to determine if there are indeed changes in coping associated with aging. With regard to gender, there was an insignificant difference in the way in which men and women appraised events. Men did use more problem-focused coping than women, but only at work, and in situations requiring acceptance and more information. No gender differences were found in the use of emotion-focused coping within the health-related episodes.

The way in which an individual appraises, and copes with a situation may also be influenced by the emotions caused by other life events occurring simultaneously with the diagnosis of cancer (Lazarus, 1974). Weisman and Worden (1976) reported that a relationship existed between high emotional distress, many concerns, and difficulty coping in patients newly diagnosed with cancer. The presence of many life concerns and emotions were reported to reduce an individual's ability to effectively cope with the diagnosis of cancer. Weisman and Worden (1977) used the term 'existential plight' to refer to a variety of concerns affecting different aspects of life. These concerns were found to be greatest from the time of diagnosis to two to three months into the illness (100 days). Higher emotional stress was found in patients who: were widowed or divorced; lacked or anticipated a lack of support from significant others; had advanced disease; and experienced many symptoms. Weisman and Worden (1977) also reported that 70% of newly diagnosed cancer patients experienced their maximum number of concerns within the first 8 to 10 weeks of their illness. A tendency was found for the frequency of the concerns expressed to diminish after this time frame. Emotional distress, however, was reported by 60% of the newly diagnosed patients at some point beyond the first 10 weeks of the illness. Some of this distress was due to the progression of the cancer, or side-effects of treatment. Multiple regression analysis showed that, at any one assessment, 40-60% of emotional distress was attributed to medical factors, with the remainder apparently due to psychosocial issues. Diagnosis was cited as being a determinant of the amount of emotional distress, with lung cancer patients experiencing the most emotional distress.

However, a more recent study by Drier and McCorkle (1984) reported that the concerns expressed by newly diagnosed patients with lung cancer were not significantly different from 3 to 6 months. Although these results are significant to this literature review, caution must be exercised in making generalizations to men newly diagnosed with prostate cancer, as the types of cancers studied by Weisman and Worden (1976, 1977) included lung, breast, colon, melanoma, and Hodgkin's Disease.

The use of problem-focused coping have been shown to assist in maintaining normal anxiety levels of men diagnosed with genitourinary cancer. Scott, Oberst, and Bookbinder (1984) conducted a study to examine the stress response in 30 men diagnosed with noninvasive bladder cancer who were hospitalized for routine reevaluative cystoscopy. The specific aims of the study were to evaluate the anxiety levels and problem-solving abilities of these men, and to determine the relationship among these variables with concurrent stressors, coping methods, and degree of problem resolution. The participants were interviewed prior to, and six to eight weeks following the cystoscopy. The sample consisted of men between the ages of 36 to 70 years (mean age of 57 years). Ninety-seven percent of the men had greater than a grade 12 education (19 had completed four or more years of college), and 87% were employed. The subjects had been monitored for a period of less than one year to 12 years since diagnosis, and had undergone one to 21 diagnostic procedures (mean = 8) during the course of their disease processes. Anxiety levels were measured using the State-Trait Inventory, problem-solving ability by the Critical Thinking Appraisal (CTA), concurrent stress by the Social Readjustment Rating Scale, and predominant coping strategy by a modified version of the COPE interview (previously used by Weisman and Worden in 1976). The Stress-Coping Model of Lazarus (1981) was used as the theoretical framework.

A strong correlation between the education level and CTA scores was found precystoscopy ( $r=.60$ ,  $p \leq .001$ ), and postcystoscopy ( $r=.57$ ,  $p \leq .05$ ), and education was inversely correlated with state anxiety at the postcystoscopy testing ( $r = .38$ ,  $p \leq .05$ ).

Those men with higher educational levels, higher problem-solving abilities, lower anxiety, and less concurrent stresses in their lives were reported to cope more effectively. No relationships were found between the number of past diagnostic tests or length of time since diagnosis, and the anxiety or critical thinking scores at either testing. Although anxiety levels for the group were within normal limits, one third of these men did experience anxiety levels above the norm on at least one testing occasion. This latter group of men were characterized by low problem-solving ability, and lack of problem resolution. The diagnostic hospitalization was viewed by the men as a break from the real strains of their lives, and not as an event of crisis. The authors suggested the higher anxiety levels after discharge were related to the demands of work. The findings of this study supported a previous study conducted by Oberst and Scott (1983) that reported an increase in state anxiety occurs in men between 30 to 60 days after major surgery for bladder and bowel cancer.

Controversy exists whether control over an impending event helps to mediate a stress reaction, or whether it is actually stress-inducing. Lazarus (1981) stated the relationship between control and adjustment is highly individualized. For example, an individual may seek information, but cognitively choose to use inhibition of action, if the action is capable of coming into conflict with moral, social, or physical constraints. He also states that in addition to appraisal influencing coping, coping may influence the person's reappraisal of what is at stake and what the coping options are (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). In 1986, Folkman and colleagues conducted a study to examine the functional relations among cognitive appraisal and coping processes and their short-term outcomes within the stressful encounter. An intra-individual approach was used to compare the same person with himself or herself across five stressful encounters within a six month period. A random sample of 75 married couples participated in the study. The mean age of the women was 39.6 years, and of the men 41.4 years. The majority of the participants were white Protestants, who were employed, well-educated

(mean= 15.5 years), and middle-income. Results of the study demonstrated that in primary appraisal and coping, subjects used more confrontive coping (aggressive efforts to alter the situation), escape-avoidance (wishful thinking, behavioral efforts such as eating, drinking, smoking, using drugs or other medications), and self-control coping (efforts to regulate one's feelings and actions), accepted more responsibility (acknowledging one's role in the problem), and sought less social support (efforts to seek informational and emotional support), when threat to self-esteem was high, compared to when threat to self-esteem was low. Threats to physical health were associated with more seeking of social support and escape-avoidance. Three strategies tended to be used in high-stake conditions: self-control, escape-avoidance, and seeking social support. In secondary appraisal and coping, subjects used more responsibility and confrontive coping, planned problem-solving (deliberate problem-focused efforts to alter the situation), and positive reappraisal (efforts to create positive meaning by focusing on personal growth), in situations they appraised as changeable, and more distancing (efforts to detach oneself) and escape-avoidance in situations they appraised as having to be accepted. In situations requiring more information before they could act, the subjects sought more social support, and used more self-control and planned problem-solving. Satisfactory coping outcomes were characterized by higher levels of planful problem-solving and positive appraisal, and unsatisfactory outcomes by higher levels of confrontive coping.

The results of this study supports the notion that the mode of coping used to deal with health-related threats may be age related. The younger subjects sought information and used escape-avoidance, if the primary appraisal involved a threat to their physical health. In situations appraised as 'high stake', they were also reported to seek information, use escape-avoidance, and self-control. Contrary to this study, however, Weisman and Worden (1977) reported older, newly diagnosed cancer patients ceased to want information, and used distancing to cope with the illness. A review of the literature

revealed that there was a lack of studies available to carry out a further comparison of the way in which older subjects appraise and cope with health-related issues.

Gerard (1963), McIntosh, (1974), and Molleman and colleagues (1984) reported that seeking information is an effective way to gain control of an uncertain event such as cancer. However, in a more recent study by Brockopp, Hayko, Davenport, and Winscott (1989), a weak correlation was found between the need for information and gaining personal control. The latter study, and that of Dennis (1987), supported Lazarus' conclusion that giving information in an effort to enhance or maintain control may not be appropriate for all patients, and should be highly individualized.

Dennis (1987) conducted a study to identify behavioral, cognitive, and decisional activities that give patients a sense of control during their hospitalization and to characterize the kinds of people who find control in various ways. Bandura's (1977) Social Learning Theory was chosen as the theoretical framework to guide this study, because it states that if people can control or perceive that they are in control of a stressful event, the event will be interpreted as less threatening, underscoring the subjectivity and individuality of control. Two Client Control Q Sets were used to determine what items the patients thought were important for them to get well and/or go home, and what items were important for making their stay more pleasant. Patients then completed the Health Opinion Survey, provided demographic information, and participated in a interview. The major ( $n = 30$ ) and replication ( $n = 30$ ) samples consisted of medical-surgical patients admitted for diagnosis and/or treatment of genitourinary, gastrointestinal, or thyroid disease, or cancer of any origin. The majority of the sample consisted of males (62%), who were well-educated, and between the ages of 24 to 75 years of age (mean age of 45 years).

Q factor analysis of the data resulted in the identification of three dimensions of patient control: knowing and fulfilling the patient role; being involved in making decisions; and directing interpersonal and environmental components. Common to all dimensions were the need for information and cognitive control in the areas of prognosis, diagnostic

tests, surgery, treatments, progress, and effect of illness on life-style/activities. This information was sought as the patient's right to know, to help cope with the uncertainty and stress of the illness, and for making future decisions. Being a medical patient with cancer was shown to be indicative of a desire to be involved in decisions concerning diagnosis and treatments. Dennis concluded that although it is important to identify and support patients who want to be involved in decision making, it is also important to support those who do not wish to do so because they cannot cope with the responsibility. This study failed to identify the kinds of persons who find control in various ways.

Having cancer is a personal experience with different meanings for each individual. Many people believe a diagnosis of cancer is a 'death sentence' (McCorkle, 1980). If the individual perceives the threat as needing attention, he or she will seek medical help. If the threat remains unperceived or perceived as frightening, the person may not take action and deny the existence of the disease (McCorkle, 1980). Elderly persons may also avoid seeking early medical care because they: are uncomfortable communicating with physicians, and believe in false myths about cancer and its treatments (Rimer, 1983); believe physicians may reject more aggressive cancer treatments because of their age (Rimer, 1983; Ouslander, Tymchuk, & Rahbar, 1989); and do not know what questions to ask (Morra, 1985).

The type of information desired by cancer patients has also been shown to be related to the degree of importance attached to the information when faced with a life-threatening illness such as cancer. In 1990, Venkatesh conducted a study to describe the perceived sexual concerns and adjustment of prostate cancer patients undergoing treatment. Seven men were interviewed prior to and after treatment using a semi-structured, open-ended question format. All the participants were married, and aged 45 to 70 (one at 45, four between 60 and 67, and two at 70). Their educational backgrounds included one with a university education, four with some high school, and two with less than high school.

Two of the men were employed, and five were retired. Five men had received radiotherapy, one surgery, and one hormone therapy.

Venkatesh (1990) found that although the men felt that it was necessary to receive information on the sexual effects of the treatment prior to making treatment decisions and during the treatment, they did not actively seek this information. The effect of treatment on usual sexual activity was not considered a priority when faced with a life-threatening disease such as prostate cancer. Sexual dysfunction was accepted as necessary to survive, and something to be dealt with once the threat to their life had diminished. The most significant finding of this study was that the greater the degree of perceived threat to life, the lower the importance ascribed to sexual needs and concerns.

Lazarus' model posits that seeking information is the most basic, frequent, and earliest method used to cope with a stressful event about which information is limited. Information has been conceptualized as a form of cognitive control because it often results in an individual being able to interpret the aversive event so that the threat is lessened. The nature of the information sought may be determined by the harms, threats, and resources perceived as related to a noxious event, and the informational needs or deficits perceived as associated with the stressful encounter. Cohen and Lazarus (1979) have identified four types of information that may be required by patients diagnosed with cancer: the nature of the disease or the medical reasons for initiating particular treatments, the medical procedures to be carried out, the expected side effects, and the strategies patients can use to cope with the upcoming threat. They contend that such information may help patients see how they can assume an active role in treatment decision making, and maintain some control over the stressful situation. The amount and detail of the information, and the preference for a particular role in decision making is seen to be dependent on the individual's perception and evaluation of the situation, personal and situational factors, and the continuous interaction between the individual and his/her environment.

### 3.2 Identified Information Needs

Several studies have been conducted to identify the information needs of cancer patients. Some authors report that the needs may be universal, while others believe that they must be individually determined. However, a review of the literature has shown that although the patients may rank order information needs differently, there are similar needs that can be used as a framework for cancer patient education programs. For example, a review of previous retrospective studies (Feldman, 1976; Weisman & Wordon, 1977; Greenleigh Associates, 1979; Jones, 1981; Deridarian, 1986) has indicated that the information desired by cancer patients falls into four major categories (in hierarchical order): disease, personal, family, and social. Following diagnosis, the informational needs that patients perceived as necessary for effective coping with each of these categories were: **disease-related** -- diagnosis, tests, treatments, and prognosis; **personal-related**-- impact of the disease and/or the treatments on their physical well-being and ability to function, their psychological well-being and emotional stability, their job/career, and their plans/goals for the future; **family-related**--impact on spouse/significant other, children, parents, and siblings; and **social-related**--contractual, leisure, and intimate relationships. The authors of these studies found the patients perceived they received inadequate information in all four categories.

Reynolds et al. (1981) asked 67 cancer patients what information they desired from their oncologist. The sample consisted of mixed cancer diagnoses. The patients stated they wished to obtain full information on each of the following categories (in order of importance): investigations, treatments, and side-effects; symptoms; diagnosis; parts of body affected; and prognosis. Similar information needs were identified in a study by Newall, Gadd, and Priestman (1987), who conducted a study to compare attitudes of cancer patients at two teaching hospitals in the USA and the UK. When the 46 USA participants were asked which aspects of their disease they wanted to know about, they identified the following items (in rank order): how the disease began; course of the disease;



side-effects of treatment; likelihood of cure, useful life-span, pain, self-help measures; duration of treatment; treatment plan; and diagnosis. An analysis of the information needs of the UK participants ( $n = 50$ ) and the USA participants showed that there were significant differences in their identified information profiles. The Americans showed a greater desire for information on all aspects of their disease, and sought information from all sources available. Although both groups sought information from their physicians, the UK patients claimed to have gained most of their general knowledge about cancer from their relatives and friends. Both studies reported that the patients felt they were well-informed about their disease and treatments, and were satisfied with the amount of information they received.

In 1985, Morra reported on a study to determine if the information needs of cancer patients differed from those of their family and friends. She analyzed telephone calls made by cancer patients ( $n = 1087$ ) and their family/friends ( $n = 1460$ ) over an 18 month period to the Cancer Information Service in Connecticut. Patient information needs were found to be related to diagnosis, treatment, coping, referrals, and site information. Most of the referral questions (75%) were from patients looking for second opinions. When the data from the two groups were compared, patients were reported to seek information early on in the process, beginning with symptoms and diagnostic tests, and continued fairly steadily through to coping with the disease process. Relatives and friends seemed to enter the picture later on, and were more concerned with information about treatment. This study showed that the length of time since diagnosis may have little effect on the information needs of cancer patients. The results of this study were further supported by Derdarian (1986, 1987a, 1987b).

Research to identify the informational needs of recently diagnosed cancer patients conducted by A. K. Derdarian (1986, 1987a, 1987b) using the Derdarian Informational Needs Assessment Instrument (DINA) identified the information requirements of this patient group pertained to the four major categories as previously found by Feldman (1976), Wiseman & Worden (1976), Greenleigh Associates (1979), and Jones (1981).

Both the 1986 and 1987 samples consisted of 60 (males =31, females =29) recently diagnosed (1-17/18 days) cancer patients with mixed diagnoses and prognoses. Both samples also had 20% (n =12) older adults that were 56 to 70 years of age. Although the 1986 study indicated few differences in the informational needs among the patients related to age, gender, and stage of cancer, the 1987 study reported that men in general attached more importance to information needed about tests, physical well-being, and spouse. The older adults tended to need less information on relationships with spouse, parents, and career/job than the younger subjects. Patients with local and regional disease were also found to need more information than those with disseminated disease. Since no other differences were found when the patients were stratified according to gender, stage of life, marital status, education, time lag since first symptoms, and having read about cancer, the author concluded that the results of the study would be useful to provide a baseline to predict the informational needs of these patients in the future course of their treatment. In the 1986 study, Derdarian concluded that although more research is needed, the information needs of recently diagnosed cancer patients may be universal.

Adams (1991) wrote an article, based on an extensive literature review, that described another approach to identify the information needs of patients and their families believed to be critical to coping with and adapting to the impact of cancer and its treatment. She focused on the informational/educational needs of cancer patients during the five phases of their disease. The length of time since diagnosis was seen as the major determinant on the informational needs of cancer patients, with the first (diagnostic) phase requiring the most extensive need for information. In this phase, information on the health care setting, tests, and diagnosis, were cited as the most important. The major categories of disease, personal, family, and social, as identified by Derdarian (1986, 1987a, 1987b) were also listed. In the treatment phase, the patients' informational needs identified were: knowing the reason for the proposed treatment; outcomes of the treatment; prognosis;

continuing care requirements; potential side effects of treatments; and suggested coping mechanisms.

In the third phase, rehabilitation and continuing care, she stated patient education should focus on available community support services and pain management options. In the fourth phase, cancer survivorship/remission, health care providers were seen as taking an active role in providing the patient with information on survivorship education, by addressing the concerns about recurrence and living with treatment-related problems such as changes in body image, as well as by making referrals to other community resources as required. In addition, she stated patients should be taught self-monitoring for signs and symptoms of recurrence.

In the advanced phase, the educational needs were seen to shift from the patient to the family with provision of practical information about feeding, administration of medications, community resources, and recognition of medical emergencies. If the disease was in the palliative phase, the most important information for families was found to pertain to the patient's condition (the dying process), comfort measures, and community hospice programs. The provision of this information was seen as necessary for the patients and families to participate in the decision making process. The author was cognizant of the fact that future studies were required to provide the scientific foundation to prove that these were in fact the information needs of the five phases of the disease.

Individualized information for cancer patients and their spouses receiving the intervention has been shown to increase the acquisition of knowledge, increase the satisfaction with the information obtained, and, to some extent, increase coping with the situation. Because cancer's physical and personal implications have a more immediate impact on the patient soon after diagnosis, information in this phase is seen as the more important and more frequently requested (McCorkle, 1980; Derdarian, 1989).

In 1989, Derdarian conducted a study to determine if interventions consisting of information, referral, counselling, and follow-up individualized to patient and spouse had

an effect on their satisfaction and coping. Both the control and experimental sample consisted of 30 male cancer patients and their spouses selected from a clinic in a major cancer centre in the United States. There were no statistically significant differences between the two groups. The mean age of the participants was 41 years, their educational backgrounds ranged from 12 to 19 years, time since diagnosis was 3 to 10 days, and there were 30 patients with Stage I-II cancer and 31 patients with Stage III-IV cancer. The patients and their spouses were randomly assigned to the control or experimental group, and asked to independently complete two sets of instruments. The Patient-Information Needs Assessment and Spouse-Informational Assessment were completed prior to teaching, and the Patient-Satisfaction and Spouse-Satisfaction Assessments were completed 5 to 10 days after the initial visit. The control group received routine information, referral, counseling, and follow-up care. The experimental group received formal, individualized intervention, and one or two follow-up phone calls to check the adequacy of the information.

Both the groups requested and attached the most importance to information pertaining to the disease, personal, family, and social categories. Patients and spouses in the experimental group showed increased knowledge, increased satisfaction with the information obtained, and to some extent increased ability to cope with the disease. The author of this study concluded that these findings provide support for Lazarus' theory that states individuals facing a major threat seek information as a way of coping, and that information-seeking can help patients and spouses cope more effectively.

The provision of information has also been shown to to reduce the disruption of usual life activities, increase coping abilities with treatments, reduce the negative emotional responses following surgery, and provide an overall increase in the cancer patient's quality of life (Leventhal & Johnson, 1983; Johnson, 1984; Johnson, Nail, Lauver, King, & Keys, 1988). However, concrete objective information, has been found to be superior to other types of information with respect to the speed with which patients resumed their usual

activities (Israel & Mood, 1982; Rainy, 1985). The positive effects of concrete objective information on coping are believed to occur because patients' have an accurate cognitive representation of the upcoming experience that is composed of concrete and objective elements of the experience, thus, they have fewer unknowns about the experience, and their attention can focus on the concrete of the experience (Johnson, Nail, Lauver, King, & Keys, 1988).

Johnson and associates (1988) studied 84 men with Stage A, B, and C prostatic carcinoma receiving radiation therapy for primary treatment, without previous or concurrent cancer, and without history of radiation therapy, to determine if additional information would lead to less disruption of activities, and less mood disturbances during and following radiation therapy. The majority of the sample were married (83%), and had at least a high school education (84%). The mean age of the participants was 67.9 years. Coping was measured by the Sickness Impact Profile, and emotional response by the Profile of Mood States. These two questionnaires were completed during the first, third, and last week of treatment, and at the first and third month after treatment ended. The subjects in the experimental group ( $n = 42$ ) who received the additional detailed information reported significantly less disruption in activities than did the subjects in the control group. Emotional disturbances were reported to be low in both groups. The authors suggested giving detailed information increases the patients' ability to cope during and after radiation therapy, because such concrete information supports an unambiguous cognitive representation of the experience, increases the predictability of the experience, and focuses attention on the concrete objective aspects of the experience.

### **3.3 Communication of Information**

Traditionally, physicians have been exclusively entitled to impart medical information relative to proposed treatments, informed consent, and curative activities. In contrast to this, nurses have been limited to explanations of nursing care and reexplanations of information already given to the patient by other members of the health care team

(Trandel-Koreenchuk & Trandel-Koreenchuk, 1986). Thorne (1988) found that cancer patients reported physicians as the major source of information relating to the disease and treatment, while nurses tended to communicate information about the treatment and illness experience, and give advice. The majority (90.5%) of the patients in this study rated such advice as unhelpful. Today, the distinction between what is medical and nonmedical information is less than clear. Although the current nursing ideology is that it is the nurse's obligation to provide patients with the information necessary to make treatment choices, make adjustments in their lives, and reduce the anxiety caused by illness, little is known about the disclosure practices of nurses.

Communication involving information sharing between the patient and physician is an essential reciprocal process. Both participants have crucial information that the other requires to make a treatment decision. Some patients need information about the disease and its consequences, even though they have read about cancer since their diagnosis (Weisman & Worden, 1976; Mages & Mendelsohn, 1979). Studies (Beisecker, 1988; Beisecker & Beisecker, 1990) have shown that although older cancer patients, on the average, exhibit relatively low rates of information-seeking behavior when interacting with physicians, the physician is the preferred source of information (Cassileth, Volckmar, & Goodman, 1980; Frank-Stromberg & Wright, 1984; Beisecker & Beisecker, 1990). With regard to gender, Thorne (1988) reported that male cancer patients rarely identified nurses as a source of information, while women often did. Venkatesh (1990) also found that men with prostate cancer did not regard nurses as a source of sexual information.

The exchange of information between a patient and physician is critical to help persons understand and cope with what is happening to them, and know what treatment options are available and recommended. When information is not exchanged, information control occurs, which may result in patients being unable to participate in the treatment decision making process (McCorkle, 1980; Trandel-Koreenchuk & Trandel-Koreenchuk, 1986). Factors that have been identified as increasing satisfaction with care, and

encouraging an exchange of information and participation in decision making between older patients and physicians include: a longer interaction (Lloyd, Parker, Ludlam, & McGuire, 1984; Derdarian, 1989; Beisecker & Beisecker, 1990); information pertinent to individual's needs, time to consider decisions, and inclusion of family (Weiss, 1986); providing detailed information (written, verbal, and audio) (Reynolds, Sanson-Fisher, Poole, Harker, & Byrne, 1981); showing concern (Thorne, 1988); and using first name to address patient, providing privacy for physical examination, examining patient's trunk, and discussing test results with patient (Blanchard, Labreque, Ruckdeschel, & Blanchard, 1988).

A review of the literature on consumer and health care information-seeking activities, and instruments developed to measure this concept shows that the type and amount of information desired by consumers varies with the individual. A review of this literature by Bagley-Burnett (1988) reported that the information-seeking activities of an individual will be determined by: the amount of information that an individual has; experience with the health care system; amount of time spent identifying health care resources; time spent in actual decision process; sociodemographic variables; perceived risks, benefits, and costs of searching for information; and need factors related to the critical nature of the problem.

Although the literature has shown that cancer patients in every age group want maximal amounts of information, not all patients want to be involved in the treatment decision making to the same extent (Cassileth, Zupkis, Smith, & March, 1980; Sutherland, Llewellyn-Thomas, Lockwood, Trichler, & Till, 1989; Beisecker & Beisecker, 1990). Several studies have shown that although the majority of the older male cancer patients do want information relating to their illness, both good and bad (Cassileth, Volckmar, & Goodman, 1980; Blanchard, LaBreque, Ruckdeschel, & Blanchard, 1988; Sutherland, Llewellyn-Thomas, Lockwood, Trichler, & Till, 1989; Ende, Kazis, Ash, & Moskowitz, 1989), such information is probably not desired for its usefulness in treatment decision

making (Beisecker & Beisecker, 1990; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). A study by Dennis (1987) reported that such information may be used as a coping strategy to reduce the uncertainty and stress caused by a diagnosis of cancer, and for making future decisions. Cassileth (1980) reported that patients who preferred to have as much information as possible, and who were more actively involved in their own care were more hopeful than persons who did not want to participate. However, Jones (1981) reported that some patients do not want to be given all the information as they prefer the uncertainty of not knowing, and McIntosh (1976) reported that many patients choose not to know all the information as it provides them with more hope.

A disparity currently exists between the information needs of cancer patients, and the information needs of these patients as perceived by health care professionals. Staff have been shown to overemphasize or misconstrue certain patient information needs. Nehemis, Gerber, and Charter (1984) conducted a study to determine if staff did misconstrue the importance of common changes or losses experienced by cancer patients. The study included 26 male patients with advanced cancer, 5 oncologists, and 10 nursing staff members from a large Veteran's Affairs Medical Center. The patients had a mean age of 18 to 73 years (mean age of 59.54 years), and had a variety of cancer diagnoses. Seven of the patients had prostate cancer. The questionnaire consisted of 14 areas of life changes or losses cited in the research and clinical literature as significant for cancer patients. Relevant demographic and medical information was obtained from the interview and from medical records. The patients were asked to rank from 1 to 14 (14 highest), each area according to which represented the greatest personal loss or change for them as an individual. The oncologists and nursing staff were asked to rank the same list from 1 to 14, as they believed it applied to the cancer patients.

A comparative analysis of the results showed a significant difference between the staff members and the patients. Although the staff member overrated the importance of pain and physical appearance, and undervalued changes in simple daily activities such as



routine household chores and leisure activities, they did correctly identify the lower ranking patients accorded to diminished sexual activity. Using the mean ranks as the measure of variability, the cancer patients rank ordered the following as most important to them: change in relationship with family; changes in physical appearance (e.g. weight loss, hair loss); effects of medical/surgical treatment; inability to complete routine household chores; lessened ability to care for self as before (e.g. bathing); disruption of leisure activities/hobbies; seeing friends less often; decreased enjoyment of food; decreased sexual activity; lessened financial security; inability to be employed as before; pain caused by the cancer; inability to plan for the future; not feeling up to par much of the time; and not being able to get around as before (lack of energy, tiring easily). Since the mean scores for the patients showed much less variability (ranging from 5.3 to 9.9), the authors concluded that patients with advanced cancer do not single out any item or cluster of items as having an overriding importance in their lives, and that these patients need to be evaluated by staff on an individual basis.

Oberst (1984) looked at cancer patients' perceptions of the completeness and quality of information given to them. Outpatients receiving chemotherapy were asked to rank each of the randomly ordered information items for importance and amount of information they believed they had on the item. The questionnaire used a Likert scale of 1 to 5, with 5 being the highest rank. The items which the patients felt were the most important for them to receive information on were diagnosis and treatment related. The patients were reported to feel they had incomplete information on both these subjects.

Providing detailed information combined with direct questioning has been shown to result in patients being able to recall more of the facts, but not all patients with cancer wish to be told all aspects of their illness (Reynolds, Sanson-Fisher, Poole, Harker, & Byrne, 1981). Reynolds et al. reported that asking patients the areas in which information is desired may be a more effective means of determining what information they wish to receive rather than providing detailed information to all patients. Although one group in

their study received less than two-thirds of the information they wanted, the patients did not express dissatisfaction. They concluded that even if patients are not given the amount of information they desire from their physicians, they may be reluctant to express dissatisfaction as they may believe it may affect their future care.

### **3.4 Information and Treatment Decision Making**

The psychological research confirms that situations of uncertainty are stressful for people, especially when they feel they have lost control of the situation (Lazarus, 1966; Lazarus & Folkman, 1984). It follows then, that one of the roles of health care professionals is to empower patients and their families so that they may maximize their abilities, and make some difference in the course of their lives and illness trajectories in spite of the ongoing uncertainties (Corbin & Strauss, 1988). Cancer patients are faced with a complexity of choices from the earliest point of choosing diagnostic approaches and initial treatment strategies. For those at risk of developing cancer, there may be choices about preventative changes in lifestyle, or undergoing anxiety-producing diagnostic procedures. Although these life events suggest an opportunity for cancer patients to exercise their autonomy and individual preferences, there are also emotional and psychological processes involved in clarifying values and preferences in making decisions. Studies (Lazarus, 1966; Tversky & Kahnemann, 1974; Simon, 1976; Janis & Mann, 1977; Nisbett & Ross, 1980; Lazarus & Folkman, 1984) confirm that decision making under conditions of uncertainty is a highly subjective process, dependent on the influence of numerous cognitive and emotional biases. Thus, helping cancer patients to make decisions can be viewed as a means to empower patients in situations of uncertainty, and as a way to support their coping efforts.

Recently, much attention has been focused on the need for health care professionals to provide patients with the information they require to make informed treatment decisions (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). Medical consumerism fosters the client assuming more bargaining power in the relationship

with the medical provider, by actively listening to what the provider has to say, and making his/her own decisions. This current belief is based on the assumption that most people desire some degree of control over treatment decisions, resulting in a positive influence on their survival and quality of life (Degner & Russell, 1988). However, there is no empirical evidence to support that such interventions are effective for all individuals, and recent studies have suggested that a more individualized approach may be more effective (Degner & Beaton, 1987; Forrow, Wartman, & Brock, 1988; Degner & Sloan, 1992). These latter studies support Lazarus' view of stress and coping as aligned with the individual's unique appraisal and response to an uncertain life event.

The new emphasis on increased patient involvement in care is largely due to the current ethical, legal, and social concerns of a more consumerist conscious society. Ethically, the provision of information is necessary in a society that supports patient autonomy and self-determination. Legally, informed consent as the ethical basis of patient care serves to place respect for a patient's self-determination at the center of the physician-patient relationship, and it recognizes that an active role in treatment decision making is often the best guarantee that these decisions will promote well-being (Forrow, Wartman, & Brock, 1988). Socially, patients as health consumers are advocating for a more equal relationship with the health care professionals. Although the patients' desire for information and the use of such information for the purpose of decision making has been studied by many researchers, it is still not understood if the provision of information leads to more patient involvement in the decision making process, or if it is appropriate for all individuals.

Past research has produced conflicting findings regarding the type and degree of participation that patients prefer to have in medical decision making. Although advocacy of shared decision making by patients and clinicians is supported in theory, many clinicians doubt whether patients actually want to participate in medical decision making. Some studies do suggest that the general public, as well as patients with cancer, may prefer a

collaborative role in medical treatment decision making. For example, a random sample survey of 200 subjects surveyed by Vertinsky, Thompson, and Uyeno (1974) concluded that although the majority of respondents did not wish to take the entire responsibility for medical decision making, they also did not wish to be entirely passive in the patient/physician relationship. A similar study by Haug and Lavin (1981) which surveyed 466 members of the general public and 86 physicians, found that a substantial proportion of the public wished to assume a consumerist position, and take some responsibility for medical decision making. In 1980, Cassileth, Zupkis, Sutton-Smith, and March conducted a survey of 300 cancer patients to determine information and decision making preferences. Two-thirds of the patients indicated a preference for participating in medical decisions. Further evidence that patients may prefer a pattern of shared decision making was provided by a study conducted by Strull, Lo, and Charles (1984).

Strull, Lo, and Charles (1984) explored patients' preferences for information, discussion, and decision making authority, and the clinicians' estimate of their patients' preferences about these aspects of medical care. Ninety female and 120 male hypertensive patients (mean age of 59 years) from a community hospital, free-standing health maintenance organization, and Veterans Administration outpatient clinic completed questionnaires. Forty-one physicians and nine nurse practitioners/clinical pharmacists also completed a questionnaire pertaining to one or more of the 210 patients. Clinicians were reported to underestimate the amount of illness-related information and discussion about therapy, and overestimate the patients' preference for involvement in treatment decision making. Despite these discrepancies, 89% of patients reported a high degree of satisfaction with their medical care, and 84% of patients indicated that they were very/extremely satisfied with the way decisions were made about their treatments. The centre with the oldest, least educated, and lowest income patients (mean age of 64 years, 94% males), showed the lowest percentage (39%) of those wishing to participate in decision making. The authors concluded that better assessment of individual preferences for information,

discussion , and decision making may result in enhanced patient participation. These conclusions were supported by a study conducted by Greenfield and associates (1985).

Greenfield and associates (1985) studied a group of patients to determine if giving more information would increase patient involvement in decision making and increase their satisfaction with the care provided. The majority of the participants were older, less educated, males with ulcer disease. The study found that providing the experimental group with detailed information, and encouragement to participate in decision making, resulted in these patients: being more involved in the physician-patient interaction; asking their physicians more pertinent questions; reporting fewer physical and role limitations; being more active in decision making; and being more knowledgeable about their disease. No differences were found between the groups concerning their level of satisfaction with the care provided.

Studies that have examined the preferred role of cancer patients in decision making report that older cancer patients (50 years and older) prefer the physician to make treatment decisions (Cassileth, Zupkis, Smith, & March, 1980; White, Muss, Michielutte, Cooper, Jackson, Richards, Stuart, & Spurr, 1984; Beisecker, 1988; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Ende et al., 1989; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989; Degner & Sloan, 1992). It was apparent from these studies that not all patients wish to assume an active role in treatment decision making. In fact, Blanchard and associates (1988) reported those patients who were passive in decision making were slightly more satisfied with their care than those who perceived they were active participants. Providing patients with adequate knowledge and information has been reported as a means for most patients to learn to participate in making choices about their treatments (Degner & Beaton, 1987). This finding was supported by Cassileth et al. (1989) who reported that if patients with cancer of the prostate are given the information and the time to make decisions, they do assume an active role.

Cassileth, Zukis, Smith, and March (1980) conducted a study to examine: the medical and demographic characteristics of patients who prefer an active versus a passive role in treatment decision making; the relationship between hopefulness and participation preferences; and what patients perceive as necessary information. A total of 256 cancer patients (40.2% males, 38.7% aged 60 years and older, 11 months post-diagnosis) seen in a university hospital outpatient department, participated in the study. The subjects completed the Information Styles Questionnaire and the Beck Hopelessness Scale. The results of this study demonstrated that there was a strong association between preference for information and participation in decision making related to the factors of age and education. The younger, more educated patients preferred to actively participate in decision making and desired detailed information, while the older, less educated patients were found to prefer the physician to make treatment decisions and to avoid detailed treatment-related information. Patients who preferred an active role, detailed information, and whose prognosis was more positive were reported to have the highest degree of hope. The authors stated that this study also demonstrated that providing detailed information to patients should not cause depression, as previously thought.

Due to conflicting findings of previous studies on consumerism among the younger and older patients, Beisecker (1988) decided to re-examine the relationship between age, and the desire for information and input into medical decision making. The sample (n=106) consisted of 42 males and 64 females with a wide range of medical problems. There were 21 patients 60 years and older in the sample. The study found that age showed no effect on patient consumerist behavior with doctors. Although patients of all ages were passive when interacting with doctors, older patients were less likely to believe they had a right to make medical decisions or to challenge a physician's authority. All patients were found to desire information, but the older patients were less likely than younger patients to believe they had a right to medical information. The author offered two explanations for this finding. The first explanation was that the older patient came of age during the time

when the doctor was considered a traditional power figure and someone to be revered and obeyed. The second explanation is developmental in nature, suggesting the older patient is tired of assuming decision making responsibility and prefers to rely on the expertise of others to make the right decision.

Blanchard and associates (1988) examined 439 interactions between hospitalized adult cancer patients and oncologists to investigate patient preferences for a participatory role in decision making and preference for information. The sample consisted of 54% older males (mean age of 54.58 years). Approximately 2% of the sample had prostate cancer. Although the majority of the patients (92%) preferred all the information to be given to them, only 69% wished to participate in decisions regarding their medical care and/or treatment. Those who did not prefer an active role were described as being older males.

The findings of Blanchard and associates (1988) were further supported by a study by Ende and associates (1989) conducted to determine the characteristics of patients who prefer an active role in decision making, and to identify if their preferences were affected by varying disease severity. The sample ( $n = 312$ ) was composed of 38% males, 65% of the subjects were 51 years and older, with the majority being white, married, low income, and less educated (68% grade 12 or less). Although the patients in this study wanted to be informed, they preferred the physician to be the principal decision maker. Older, less educated patients were reported to have less of a desire for information, and prefer a passive role in treatment decision making, compared to the younger patients. The authors suggested that even though the majority of the patients in this study preferred the physician to make the final decisions, they still had a desire to understand and be involved in the decision making process. Furthermore, such actions do not necessarily mean they are surrendering their autonomy, but rather they are granting permission to the physician to take charge of certain decisions they prefer not to make.

These results match the findings of other investigators such as Sutherland and associates (1989), who conducted a study to compare two methods of determining how actively cancer patients sought information about their health status, their preferences in decision making with their actual experience, and their desire for information with the actual role they assumed in decision making. The sample consisted of 52 (17 males and 35 females) newly diagnosed, post-surgical cancer patients with mixed diagnosis, seen at an outpatient facility in the province of Ontario. The mean age of the sample was 48 years (s.d.  $\pm$  13.8). Five men in the sample had prostate cancer. The majority of the patients (90%) were receiving radiation therapy, and the remaining 10% were receiving chemotherapy. The patients were asked to complete the Health Opinion Survey, Information Seeking Questionnaire, and a questionnaire designed by the authors to measure patient preferences in treatment decision making.

This study found that 77% of the patients reported they had participated in treatment decision making to the extent they desired, while the remainder would have preferred a greater input. An interesting feature of the data was that 63% of the patients felt the physician should be the primary decision maker, 27% felt it should be collaborative process, and 10% felt that they should be active or take a major role. Although the majority of the patients actively sought detailed information, understood the information, and were satisfied with the information they received, the majority preferred the physician to be the primary decision maker. The results indicated that patients' preferences for information may be related to factors other than their desire to participate in treatment decision making. The authors of this study suggest that cancer patients may actively seek information as a means to achieve psychological autonomy.

Degner and Sloan (1992) studied the preference for treatment decision making in 436 newly diagnosed cancer patients (mean age of 59 years, 52% males). Preferences were elicited using a card sort that had two sets of five cards. Each card described a different role in decision making. The first set of roles focused on the patient/physician



relationship in treatment decision making, whereas the second set focused on who the subject would want to make treatment decisions if he/she was unable to participate. Patients completed the card sorts one at a time, comparing each card with every other card in subsets of two until their preference was determined. The majority of patients (59%) stated that they desired the physician to make all the treatment decisions. If they were unable to make decisions, 90% of the patients stated they wanted the doctor to dominate the decision making process. Older and less educated patients were found to prefer less control than the younger, more educated patients. Being an older male with cancer of the reproductive system was identified as a significant predictor of preferring a passive role in decision-making. Secondary analysis showed that of the 60 men with prostate cancer in this study, 82% ( $n = 49$ ) preferred a passive role in decision making, 12% a collaborative role ( $n = 7$ ), and 7% an active role ( $n = 4$ ). This gender effect was not evident in patients with other types of cancer.

Information is not always effectively communicated to the cancer patient, and it has been suggested detailed medical information may be of little value to those who do not have the educational background to interpret it (Cassileth, Zupkis, Smith, & March, 1980; Mackillop & Johnson, 1986; Mackillop, Stewart, Ginsburg, & Stewart, 1988). This may have an impact on the preferred role in decision making, because studies (Cassileth, Volckmar, & Goodman, 1980; White, et al., 1984; Beisecker, 1988; Blanchard, LaBreque, Ruckdeschel, & Blanchard, 1988; Degner & Sloan, 1992) have shown that the older, less educated cancer patients prefer physicians to make treatment decisions.

Some studies have also shown that single (Blanchard, LaBreque, Ruckdeschel, & Blanchard, 1988), and divorced/separated (Ende, Kazis, Ash, & Moskowitz, 1989) cancer patients assume a more active role in decision making. Beisecker (1988) reported that although the older male patients did not want to participate in decision making, they often brought their wives/companions to medical appointments. The spouses of older cancer

patients were reported to ask the doctor more questions than the spouses of younger cancer patients.

Past research has produced conflicting findings regarding the impact of stage of disease on the preference for information and preferred role in treatment decision making. Cassileth, Zupkis, Sutton-Smith, and March (1980) reported that a relationship did exist between those cancer patients who prefer an active role in treatment decision making and detailed information, and those cancer patients whose prognosis was positive. However, Blanchard and associates (1988), reported that cancer patients who preferred an active role in decision making had a poor prognosis. Ende and associates (1989) reported the desire of medical patients to make decisions decreased as the severity of the illness increased. The clinical hypothesis that sicker cancer patients prefer less control in treatment decision making was not supported in the study conducted by Degner and Sloan (1992).

Cassileth and associates (1989) investigated the effect of giving detailed information and treatment choices to a group of prostate cancer patients ( $n = 147$ ) with Stage D metastatic disease. The patients were asked to discuss the information they received and make the treatment decision with their wives/families at home. The patients and their spouses were asked to complete separate questionnaires following the decision, and then again 3 to 6 months later. The follow-up questionnaires showed that 93% of the patients, and 91% of the wives indicated they were satisfied with the treatment choice they made. This study demonstrates that if this group is given the information, they can play an active role in decision making, and remain comfortable and satisfied with their choices. Similar findings were reported by Derdarian (1989), as discussed earlier.

Some investigators have suggested that as patients become more experienced or accustomed to physician interactions, and once the initial blow of the diagnosis has subsided, they may become more involved in treatment decision making (Degner & Sloan, 1992). However, Cassileth and associates (1980) found that even 11 months post

diagnosis did not change the preference of older, less educated cancer patients to prefer the physician to make treatment decisions and to avoid detailed treatment-related information.

Although the majority of studies suggest that cancer patients prefer the physician to make treatment decisions, several studies suggest that those patients who assume a more active role experience significant benefits over their more passive counterparts. Findings in studies on cancer patients have identified benefits such as: increased satisfaction in treatment decisions; increased satisfaction with care received; less anxiety and depression pre- and post-operatively; and a higher degree of hope (Cassileth, Zupkis, Smith, & March, 1980; Morris & Royle, 1988; Cassileth et al., 1989). Findings in non-cancer patients have identified benefits such as: less stress; decreased levels of symptom distress and illness concern; and increased functional status, coping, control over illness, self-efficacy, understanding of and commitment to the treatment plan, and satisfaction with their physician (Schulman, 1979; Greenfield, Kaplan, & Ware, 1985; Brody, Miller, Lerman, Blum, & Smith, 1988; Morris & Royle, 1988). However, Blanchard and associates (1988) found that the older male cancer patients were satisfied with the care they received, even though they did not participate in treatment decisions.

### **3.5 Summary**

A review of the literature supports Lazarus' assumption that the amount of information that a cancer patient seeks is individual, and is dependent upon the effect of the personal and situational factors of gender, age, education, marital status, stage of disease, and length of time since diagnosis. The information needs that appear to be universal to all cancer patients are related to the subcategories of disease, personal, family, and social concerns. One researcher reported that men attached less importance to the social category. The majority of cancer patients were reported to want information; however, the older, married, less educated, sicker male with cancer, was shown to be less active in seeking information, less likely to believe he had the right to the information, and desired less detailed information. The effect of stage of disease was not clearly determined due to

conflicting reports of past research. Newly diagnosed patients were reported to have the most extensive information needs. Although the physician was reported to be the preferred source of this information, older patients were found to be uncomfortable communicating with doctors.

Personal factors such as being an older, less educated male with prostate cancer was reported to result in a more passive role in decision making. However, several studies have shown that if older men with prostate cancer are given the information, and the time to make decisions, they assume a more active role in treatment decision making, and remain satisfied with the treatment choices that are made. Due to the disparity of the results from past research studies, it was not possible to identify (with any certainty), the impact of marital status, stage of cancer, and length of time since diagnosis on the role men prefer in treatment decision making.

There were no studies in the literature that had examined the relationship that exists between profiles of informational needs of patients and the role they preferred to assume in treatment decision making. It was the purpose of this study to identify what relationship, if any, existed between these variables, and to readdress the effect of the personal factors (age, education, and marital status) and the situational factors (stage of disease and length of time since diagnosis) on the information needs and preferred/assumed role in treatment decision making, of men newly diagnosed (0-6 months) with prostate cancer.

## **Chapter Four**

### **Methodology**

#### **4.0 Research Design**

This cross-sectional descriptive study used a correlational design. This design was utilized for several reasons. First, in a correlational design the researcher examines specific variables based on the conceptual framework, and measures the variables as they exist with no manipulation (Brink & Wood, 1989). The literature review, and the Stress-Coping conceptual framework (Lazarus, 1966) supported the belief that certain personal and situational factors of the population under study would be related to the information needs profile and preferred/actual role in treatment decision making. Second, cross-sectional data allowed the researcher to identify the present profile of information needs, and preferred/assumed role in treatment decision making. Third, such data allowed the investigator to determine the relationship between the variables, information needs, and preferred/assumed role in treatment decision making, without knowing which variables were important until data analysis was complete. Fourth, cross-sectional data collection and correlational analysis assisted the researcher to develop a description of this patient population. Fifth, this correlational design was used to determine if empirical evidence could be provided to support this conceptual model.

A correlational design using a structured questionnaire was appropriate because the aim of the investigation was to delineate the characteristics of a particular population. The subjects in this study completed a three part questionnaire to obtain data on the personal and situational factors, develop a profile of their information needs, and determine their preferred/assumed role in treatment decision making. The investigator also used the patients' medical records to confirm sociodemographic data relating to the stage of disease, length of time since diagnosis, and past and/or current treatments.

#### **4.1 Population, Sample, and Sample Selection**

The research results of this study are generalizable to the target population of Manitoban men newly diagnosed with prostate cancer who were treated by one of the urologists who practice at one urology clinic in the province of Manitoba. The cross-sectional sample for this investigation represented approximately 10% ( $n = 57$ ) of the patients diagnosed with prostate cancer in Manitoba annually. The study sample, however, was a convenience sample of patients newly diagnosed (0 to 6 months) with prostate cancer. Approximately 220 newly diagnosed prostate cancer patients are treated by the two urologists at this clinic annually. The data was collected over a six month period, from July 9, 1992, to January 8, 1993.

The selection criteria included newly diagnosed (0-6 months) prostate cancer patients who: were currently being treated by one of the urologists at the urology clinic; could read, speak, and write English; were aware of their diagnosis; and were orientated to time, place, and person.

#### **4.2 Procedure**

The physicians and their nurses provided the researcher with the names of potential subjects who met the criteria. Sample recruitment occurred once the research project had received formal ethical approval from the Faculty of Nursing at the University of Manitoba, and the Ethical Review Committee at the clinic. The question of permission for access to medical information, however, rested with the potential subjects.

All the patient interviews were conducted in an examination room at the urology clinic either before or after the subject's scheduled appointment. A quiet, private environment was provided for completion of the questionnaire.

Informed written consent was obtained from all subjects who agreed to participate in this study, once they have received complete disclosure as to the purpose of the investigation and following assurances of confidentiality (Appendix C). The consent form (Appendix D) was signed and witnessed when the researcher and subject met for the data

collection. A copy of the consent form was given to each subject who agreed to participate in the study.

Each subject who gave informed consent was asked to complete the three part questionnaire. The researcher was present to assist in the completion of questionnaire. The researcher maintained an atmosphere of professional objectivity, and refrained from leading the subjects when asked a question.

The subjects were asked to complete the research questionnaire without their spouse/family being present to control for the possible confounding variable of outside influence. When the interview was over, the participants were thanked for their participation, and they were encouraged to contact the researcher if they had any questions and/or concerns. At this time the researcher also ascertained which participants wished to have the study results mailed to them. The medical record data was retrieved following completion of the questionnaire. Additional qualitative data was documented by the researcher on the last page of the questionnaire following the interview.

The estimated time to complete the questionnaire was between 30 to 60 minutes. All the subjects were able to complete the research questionnaire, so it was not necessary to make secondary arrangements. Any questions that the subjects asked were documented and answered by the researcher, physician, and/or clinic nurse.

#### **4.3 Data Collection Instrument**

The research data was obtained by means of a three part questionnaire.

**1. Part One- The Information Needs Questionnaire** (Appendix E) was developed by another Master's of Nursing student (Barbara Bilodeau), and was previously used to study a group of women with breast cancer. This part of the questionnaire was adapted, based on previous research and clinical experience, to reflect the nine categories of information found to be important to men with prostate cancer. The nine categories used were: advance of disease; likelihood of cure; effect on social activities; effect on family/close friends; self-care needs; effect of treatment(s) on usual sexual activity; types of

treatments available (advantages and disadvantages of each); risk of family members developing disease; and side effects of treatment(s).

Using Thurstone's Law of Comparative judgement as the scaling model, the nine categories of information were arranged in subsets of two using the Ross matrix of optimal ordering (Ross, 1974). The subjects were asked to select out of each pair the one information need that was more important to him at the time of testing. Ross's method ensured that the maximum spacing for the maximum number of items was obtained to avoid selection bias.

A Likert scale of the same nine information items (Appendix F) was also used to provide the researcher with a tool to measure the amount of information the participant desired about a particular information item at the time of the interview.

**2. Part Two- The Control Preferences Scale** (Appendix G) was used, with permission from Dr. L. Degner who developed the measurement instrument. This instrument consisted of five cards containing statements about different potential roles in treatment decision making, ranging from selecting one's own treatment, through a collaborative role with the physician, to leaving all decisions to the physician. The subjects were then asked to pick their preferred role in treatment decision making if they were given the amount of information they had identified on Part One of the questionnaire. The cards were presented in random order, and the subjects asked to compare subsets of two until their preference was obtained. Once the preference was recorded, the subjects were asked to reconsider the cards and select the one that best represented the role they were currently assuming in treatment decision making.

**3. Part Three- The Personal Sociodemographic Profile (PSP),** developed by the researcher (Appendix H), was used to gather data on the personal factors (age, marital status, education, employment status, and ethnicity) and the situational factors (stage of cancer, current and/or past treatments, and length of time since diagnosis). Data on the length of time since diagnosis, stage of disease, and past and/or current treatments,



was obtained from the patient's medical record. The last page of the questionnaire was completed by the researcher after the interview.

The questionnaire was pilot tested with six patients who were similar to the population of interest, to ascertain whether there were any difficulties with the instructions and/or items in the questionnaire. Data obtained from the pilot test were not included in the results of this study for various reasons, such as: some of the interviews were conducted at another site, participants had missed a page, and the researcher had made clerical errors.

#### **4.4 Analysis of Results**

Once the quantitative and qualitative data was collected, the focus shifted to data analysis.

**Research question 1- What is the profile of information needs of men newly diagnosed with prostate cancer?** Thurstone Case V model scaling techniques as per McKenna, Hunt, and McEwen (1981) was applied directly to produce a dimension representing the profile of information needs for men newly diagnosed with prostate cancer. Adequacy of fit was assessed via Mosteller's test (Mosteller, 1951a, 1951b) which also assessed the unidimensionality assumption. Relative weights were produced via Torgerson's algorithm (Torgerson, 1958). The ceiling effect of the Likert scale was self evident from summary statistics. Concurrent validity with the Thurstone scale results was tested via Kendall's coefficient of concordance and comparable measures of association.

The Likert scale results identified the amount of information the participants wanted at the time of the interview. This scale served as a comparative measure for the Thurstone scaling variable, acting as a criterion validity check and providing an opportunity to investigate the strengths and weaknesses of the two scaling methods.

The internal consistency of the subjects' ratings of the nine information needs was also judged by computing the number of circular triads present in the results of each subject. The subjects who made  $\geq 10$  circular triads in their comparative judgements were identified, and a description of their sociodemographic profiles studied.

**Research question 2- Are there different profiles of information needs for men who prefer active, collaborative, or passive roles in treatment decision making?** Differences in the profiles of information needs were compared using the Thurstone scales by least squares estimation and simple chi-square testing. This method, originally proposed by Mosteller (1951a, 1951b) and detailed in Torgerson (1958), was applied. Ramsey and Case (1970) also proposed a data transformation to make use of maximum likelihood methods and produce a linear model for paired comparisons data. This allowed for analysis of variance techniques to be used to look for such differences.

The Control Preference Card Sort was used to classify patients into the active, collaborative, or passive role (see Appendix G). Once classified, patients were then compared in terms of their profiles for informational needs by way of the methods mentioned previously, i.e. chi-square and ANOVA procedures.

**Research question 3- Are there different profiles of information needs for men who believe they are assuming active, collaborative, and passive roles in treatment decision making?** Since the only difference between the role preferred and the role assumed is a matter of perception, the analytic techniques for the assumed roles data was the same as that for the preferred role data.

**Research question 4- Do the men differ with respect to their profiles of information needs:**

a) men who are older (over 70 years) versus those who are younger ( $\leq 70$  years)?

b) men who have lower levels of education (less than high school diploma) versus higher levels of education?

c) men who have a spouse/partner versus single?

d) men who are in the early stage of their disease (Stage A or B) versus later stages (Stage C or D) at time of testing?

**e) men who are recently diagnosed (0-13 weeks), versus later from time since diagnosis?**

Such comparisons of Thurstone scales was achieved by least squares estimation and simple chi-square testing as originally proposed by Mosteller (1951a, 1951b), and detailed in Torgerson (1958). Ramsay also proposed a data transformation to make use of maximum likelihood methods and produce a linear model for paired comparison data. This allowed for analysis of variance techniques to be used directly on Thurstone scaling data for the purpose of comparing subgroups, and was used to look for such differences.

**Research question 5- Do the men differ with respect to their preferred role in treatment decision making: (a to e as in question 4)?**

The Control Preference Cart Sort was used to classify patients into the active, collaborative, and passive role (as previously discussed). Once classified, patient preferences were then compared to the factors (differences) using least squares estimation and simple chi-square testing. This allowed for analysis of variance to be used to compare subgroups and look for differences.

**Research question 6- Do the men differ with respect to the actual role they are assuming in treatment decision making: (a to e as in question 4)?**

Since the only difference between the role preferred and the role assumed was a matter of perception, the analytical techniques for this question were the same as for research question 5.

#### **4.5 Ethical Considerations**

It was recognized that there was a slight degree of risk that newly diagnosed patients would experience psychological discomfort discussing their illness. Previous research had shown that answering questions about information needs and roles in treatment decision making would provide patients with the opportunity to examine their own thoughts and feelings, and provide them with the opportunity to participate in research that would give meaning to their experience of cancer.

All consenting subjects were assured of confidentiality. The subjects were given an identification number so that their names were not part of the data collection forms. However, a master list of chart numbers and identification numbers were kept so charts could be used to check the raw data. This information was kept in a locked filing cabinet in the researcher's home.

The data collection forms and coding sheet will not be destroyed for a minimum of ten years. At that time they will be destroyed by means of a paper shredder.

Written consent was sought for the study including permission to access medical information. Each subject was informed that participation in the study was entirely voluntary and that they had the right to withdraw from the study at any time. There was no experimental manipulation of the participating subjects and no harmful effects occurred as a result of this study. In addition, there were no obvious benefits to participating in this study. However, subjects were given the opportunity to tell the researcher what their current informational needs were, and how they preferred to be involved in treatment decision making. This allowed the participants the opportunity to help future patients diagnosed with prostate cancer.

#### **4.6 Summary**

The survey questionnaire was completed by 57 patients newly diagnosed with prostate cancer from the practices of two urologists, at a Winnipeg clinic. The quantitative data was numerically coded (Appendix I), and analyzed using descriptive and inferential statistics. The Statistical Analysis System (SAS) was used to analyze the data with the assistance of Dr. Jeff Sloan, Nursing Faculty Statistician. The ethical considerations, as outlined in this chapter, were followed. The next chapter will present the results of the data analysis.

## Chapter Five

### Results

#### 5.0 Introduction

The results of this descriptive study will be presented in this chapter. First, the sociodemographic characteristics of the sample are described. Findings with respect to each of the research questions are then presented. The chapter concludes with a summary of the most important findings.

#### 5.1 Sociodemographic Description of Sample

Data on the personal and situational factors were collected to provide a detailed description of the 57 men who participated in this study. The average age of the men in this sample was 71 years ( $\pm$  s.d. 6.78), and the average length of time since diagnosis was 9.42 weeks ( $\pm$  s.d. 9.23). The majority of the men in this sample were married ( $n = 42$ , 73.7%), retired ( $n = 48$ , 84.2%), and had Stage B disease ( $n = 38$ , 66.7%).

Approximately half of the men had less than a high school diploma education ( $n = 31$ , 54.4%), and approximately half ( $n=29$ , 50.9%) had not been treated for their disease. Surgery ( $n = 18$ , 31.5%) was the most frequent treatment received by the group of men who had already received treatment. See Table One for a summary of the personal and situational factors.

Forty-six (80.7%) of the subjects were born in Canada, and 11 (19.3%) were born elsewhere. English was the first language of 54 (94.7%) of the participants, and Ukranian the first language of 3 (5.3%). The majority of the men (47.4%) were of British ethnic origin.

**Table One: Sociodemographic Description of Sample (n= 57)**

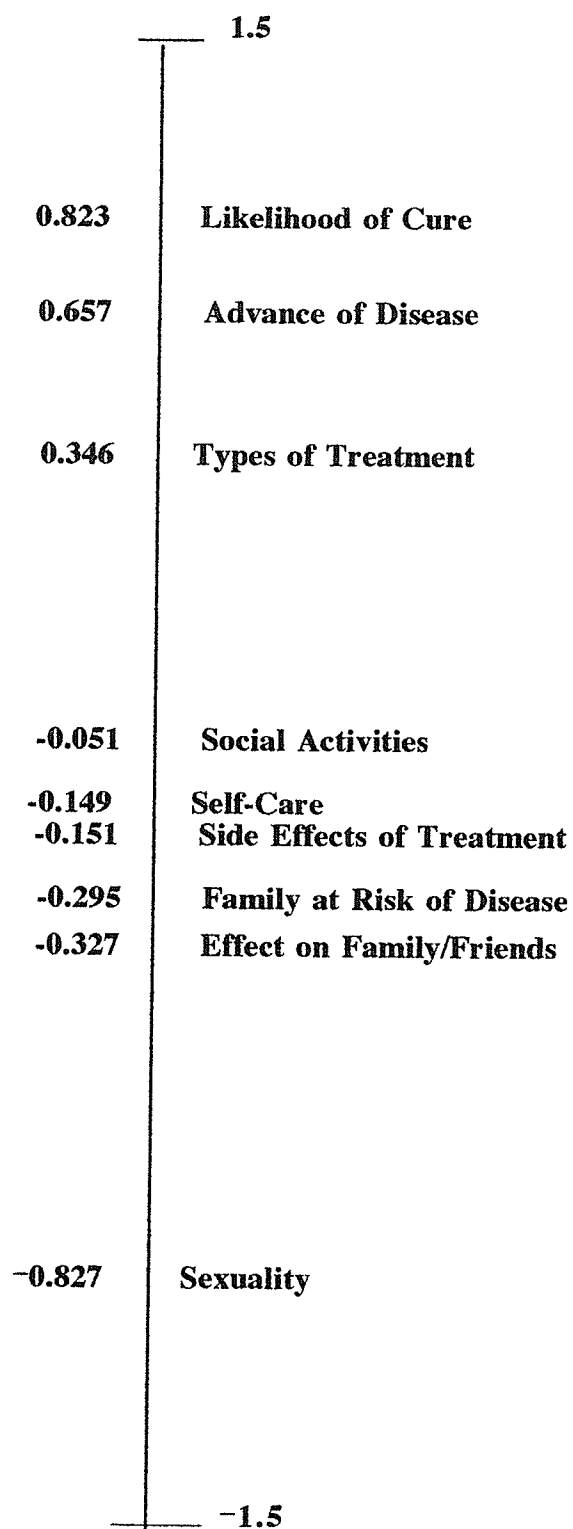
<b>Factors</b>	<b>number (%)</b>
<b>Personal Factors</b>	
Age	
≤ 70 Years	26 (45.6)
> 70 Years	31 (54.4)
Education	
≤ Grade 8	17 (29.8)
Some high school	14 (24.6)
High school diploma	10 (17.5)
> High school	16 (28.1)
Marital Status	
Married	42 (73.7)
Single	15 (26.3)
Employment Status	
Retired	48 (84.2)
Full-time/part-time	9 (15.8)
<b>Situational Factors</b>	
Length of Time Since Diagnosis	
0 -13 weeks	37 (64.9)
14-26 weeks	20 (45.1)
Clinical Stage of Cancer	
Stage A	4 (7.0)
Stage B	38 (66.7)
Stage C	4 (7.0)
Stage D	7 (12.3)
Unknown	4 (7.0)
Treatment	
No Treatment	29 (50.9)
Surgery	18 (31.5)
Surgery/Hormone	4 (7.0)
Hormone	3 (5.3)
Radiotherapy	2 (3.5)
Surgery/Radiotherapy	1 (1.8)

## 5.2 Research Question One

What is the profile of information needs of men newly diagnosed with prostate cancer? The frequency, proportion, and normal deviate matrices for the total sample of newly diagnosed men with prostate cancer can be found in Appendices J, K, and L. The relative scale values or means for each of the nine patient information needs are identified in the last row on the normal deviate matrix (Appendix L).

The rank ordering of the nine information needs for the sample ( $n = 57$ ) can be found in Figure 1. The likelihood of cure, advance of disease, and types of treatment were identified as the three most important information needs. Information related to social activities, self-care needs, side-effects of treatment, risk of disease to family members, and effect of disease on family and close friends were fairly evenly distributed in the middle of the scale. The effect of treatment on usual sexual activity was rated as the least important.

Circular triads were analyzed to determine the internal consistency of the participants in selecting the information need they considered to be the more important. The maximum number of circular triads for a set of nine items is 84. The range of triads shown by any one subject was 0 to 24, with a median of 4, and mean of 5.5. Six of the subjects had no circular triads which showed they were completely consistent in their judgements of which information need they considered the most important. Eleven subjects (19.3%) made 10 or more circular triads in their paired comparative judgements. Table Two provides a description of the profiles of the men who made 10 or more circular triads in their comparative judgements.

**Figure One: Profile of Information Needs****n= 57**



**Table Two: Profiles of Men With  $\geq 10$  Circular Triads**

Patient#	#Triads	Time Since Diagnosis/wks.	Age	Stage	Marital Status	Educ	Prefrole/Actrole
4	24	11	75	B	M	some H.S.	passive/passive
48	19	24	67	C	M	H.S. Dip.	active/passive
13	18	1	71	?	M	< 8th grade	passive/passive
51	16	2	73	B	M	< 8th grade	collab/collab
9	15	5	60	B	M	H.S. Dip.	passive/collab
6	14	17	63	B	M	< 8th grade	passive/active
36	14	22	66	B	M	some H.S.	passive/passive
50	11	7	60	B	M	some H.S.	passive/passive
21	10	23	83	?	M	< 8th grade	active/active
32	10	7	70	D	M	< 8th grade	passive/passive
45	10	1	64	B	M	> H.S.	passive/passive

Total n=11

The number of circular triads that occurred for an individual subject among the same trio of information needs ranged from 1 to 11, with a sample mean of 3.98, and a median of 4. Three of the subjects had 11, 10, and 9 circular triads respectively. The subject with the most circular triads (11) included the information needs of advance of disease, likelihood of cure, and types of treatments. The subject with 10 circular triads included the information needs of effect of treatment on social activities, self-care, and side-effects of treatment. The subject with 9 circular triads included the information needs of likelihood of cure, effect of treatment on social activities, and self-care. The three most common information needs revealed in these circular triads were likelihood of cure, effect of treatment on social activities, and self-care.

The test for Kendall Zeta, for the entire sample, showed a mean value of 0.974. The subjects were consistent in their comparative judgements about which information need was considered the more important. The group of men who were assuming an active role in decision making (test for Kendall Zeta 0.994), and the group of men who preferred a collaborative role in decision making (test for Kendall Zeta 0.992) were found to be the most consistent in their paired comparisons. In contrast, the groups of men who preferred (test for Kendall Zeta 0.967), and were assuming (test for Kendall Zeta 0.964) a passive role in treatment decision making were the least consistent in their individual judgements of their paired comparisons.

The coefficient of agreement shows the extent to which the subjects are in agreement with reference to their comparative judgements. Kendall's Coefficient of Agreement for the total sample was 0.248 ( $\chi^2 = 556.387$ , 37.987 df,  $p = 0.000$ ). The subjects were found to be moderately consistent in their comparative judgements about which information needs were most important to them.

The Likert scale was used to determine how much information the men wanted at the time of the interview. The majority of the men (> 50%) wanted a fair bit to almost everything on eight of the information needs (see Table Three). Approximately 51% of the men wanted a little bit to almost nothing on the effect of treatment on usual sexual activity. This scale showed the majority of men newly diagnosed with prostate cancer do want more information concerning their disease process.

**Table Three: Likert Scale- Amount of Information Desired**

<b>Information Need</b>	<b>Fair Bit/Almost Everthing (Freq/%)</b>	<b>Little Bit/Almost Nothing (Freq/%)</b>
Types of Treatment	44/77.2	13/22.8
Likelihood of Cure	43/75.5	14/24.5
Side-effects of Treatment	42/73.6	15/26.4
Social Activities	42/73.6	15/26.4
Advance of Disease	40/70.1	17/29.9
Effect Family/Friends	35/61.4	22/38.6
Risk of Disease to Family	34/59.6	23/40.4
Self-Care	33/57.9	24/42.1
Sexuality	28/49.1	29/50.9

**N= 57**

**Cumulative Percentages= 100%**

### **5.3 Research Question Two**

Are there different profiles of information needs for men who prefer active, collaborative, and passive roles in treatment decision making? Eleven (19.3%) of the men newly diagnosed with prostate cancer preferred an active role, and 13 (22.8%) preferred a collaborative role. The majority (n = 33, 57.9%) stated they preferred a passive role in treatment decision making.

All the men rated information on the likelihood of cure, advance of disease, and types of treatment as the most important, and information on the effect of treatment on usual sexual activity as the least important. The other five information items were again clustered in the middle of the scale. Information on the side-effects of treatment, and the effect of treatment on social activities were rated similarly in importance by the three groups.

The men who preferred an active role in treatment decision making rated information on the effect of treatment on usual sexual activity more important than the men in the other two groups. The men in the collaborative group rated information on the risk of disease to family, and effect of disease on family/friends as less important, and information on self-care more important, than the men in the other two groups.

#### **5.4 Research Question Three**

Are there different profiles of information needs for men who believe they are assuming active, collaborative, and passive roles in treatment decision making? Ten (17.6%) of the men newly diagnosed with prostate cancer believed they were playing active roles, 13 (22.8%) a collaborative role, and 34 (59.6%) a passive role in treatment decision making.

The likelihood of cure, advance of disease, and types of treatment were identified as the three most important information needs. The effect of treatment on usual sexual activity was again ranked as the least important information need. However, the men in the active group rated it higher in importance than the other two groups. The other five information needs were again clustered in the middle of the scale. The men in the collaborative group were found to rank information on self-care higher than the men in the other two groups.

The men who were assuming active and collaborative roles in treatment decision making were grouped together, and their information profiles compared with the passive group. The men who were assuming a more active role in treatment decision making rated information on the side-effects of treatment slightly more important than the men in the passive group. A difference was identified in the rank ordering of three information needs by the active/collaborative group and the passive group; however, the differences in mean Z scores was minimal. These two profiles of information needs were very similar to the overall sample profile. See Table Four for a comparison of the information profiles.

**Table Four: Comparison of Information Needs Profiles**

<b>Sample Profile n= 57</b>	<b>Passive n= 34</b>	<b>Active &amp; Collaborative n= 23</b>
Likelihood of cure	X	X
Advance of disease	X	X
Types of treatment	X	X
Social activities	X	Side-effects of treatment
Self-care	X	Social activities
Side-effects of treatment	X	Self-care
Risk of disease to family	X	X
Effect on family/friends	X	X
Sexuality	X	X

**\* X means the same ranking**

The differences in the information profiles of the preferred and actual roles can be attributed to the fact that there were 7 subjects whose actual and preferred roles were different. Two men preferred a collaborative role, but were assuming a passive role; one subject preferred a passive role and was assuming an active role; two subjects preferred a passive role and were assuming a collaborative role; and two subjects preferred an active role and were assuming a passive role.

Kendall's Coefficient of Agreement showed there was agreement among the subjects in their paired comparative judgements. The Chi-square test statistic showed the p-value for the passive group, and the collaborative group was the same ( $p = 0.000$ ), and for the active group it was 0.00002. The combined group (active and collaborative) also had a p-value of 0.000.

### 5.5 Research Question Four

Do the men differ with respect to their profiles of information needs:

- a) men who are older ( $> 70$  years), versus those who are younger ( $\leq 70$  years)?
- b) men who have lower levels of education ( $<$  high school diploma), versus higher levels of education?
- c) men who have a spouse/partner, versus those who are single?
- d) men who are in the early stage of disease (Stage A or B), versus later stages (Stage C or D) at the time of testing?
- e) men who are recently diagnosed (0-13 weeks), versus later from time of diagnosis (14-26 weeks)?

A different profile of information needs was identified for the men who were single. The single men ranked information on the advance of the disease, likelihood of cure, and self-care to be the most important. The difference in the relevance attached to the information need of self-care between the married, and single men was statistically significant ( $p < 0.000$ ).

Differences in the relevance of some information needs were observed in the mean Z scores ( $> 300$ ), however, they were not statistically significant. The following trends were identified: Men who were-

1. married, more educated, and had early clinical stage disease rated information on the types of treatment higher;
2. younger rated information on the risk of disease to family higher;
3. single and less educated rated information on self-care higher;
4. older rated information on the side-effects of treatment higher;
5. married rated information on the effect of disease on family and friends higher;
6. diagnosed with early stage disease rated information on the effect of treatment on usual sexual activity higher.

### **5.6 Research Question Five**

Do the men differ with respect to their preferred role in treatment decision making: (a to e as in question 4)? The frequency distribution of the sample variables showed that there was a trend for men who were less educated, married, and more recently diagnosed (0-13 weeks) to prefer a passive role in treatment decision making. See Table Five for the frequency distribution of the variables.

An examination of the differences in the preferred role variables (a-e) was conducted using chi-square analysis. No significant differences were found.

### **5.7 Research Question Six**

Do the men differ with respect to the actual role they are assuming in treatment decision making? The frequency distribution of the variables showed there was a trend for men who were married, less educated, and more recently diagnosed men to assume a passive role in treatment decision making. See Table Five for the frequency distribution of the variables.

An examination of the differences in the assumed role variables (a-e) was conducted using Chi-square analysis. No significant differences were found.

**Table Five: Preferred and Actual Role Variables**

<b>n=57</b>	<b>Preferred Role</b>		<b>Actual Role</b>	
<b>Age</b>	<b>≤ 70</b>	<b>&gt; 70</b>	<b>≤ 70</b>	<b>&gt; 70</b>
Active	5	6	4	6
Collaborative	7	6	7	6
Passive	14	19	15	19
Total	26	31	26	31
<b>Education</b>	<b>≤ H.S. Dip</b>	<b>&gt; H.S. Dip</b>	<b>≤ H.S. Dip</b>	<b>&gt; H.S. Dip</b>
Active	4	7	5	5
Collaborative	6	7	5	8
Passive	21	12	21	13
Total	31	26	31	26
<b>Marital Status</b>	<b>M</b>	<b>Single</b>	<b>M</b>	<b>Single</b>
Active	6	5	6	4
Collaborative	10	3	10	3
Passive	26	7	26	8
Total	42	15	42	15
<b>Stage of Disease</b>	<b>Early</b>	<b>Late</b>	<b>Early</b>	<b>Late</b>
Active	7	4	8	2
Collaborative	10	3	10	3
Passive	25	8	24	10
Total	42	15	42	15
<b>Time</b>	<b>0-13 wks</b>	<b>14-26 wks</b>	<b>0-13 wks</b>	<b>14-26 wks</b>
Active	4	7	4	6
Collaborative	9	4	9	4
Passive	24	9	24	10
Total	37	20	37	20



## 5.8 Summary

The study sample was representative of the target population of men newly diagnosed with prostate cancer in the province of Manitoba, however, the findings can only be generalized to men newly diagnosed with prostate cancer who are: demographically similar to this sample; treated at this Winnipeg clinic; and treated by one of the urologists who practice in this clinic. The majority of the participants were found to prefer and to assume a passive role in treatment decision making. Overall, there were no statistically significant differences found in the Thurstone profiles of information needs between the preferred and assumed role in treatment decision making. The three most important information needs identified were advance of disease, likelihood of cure, and types of treatment. The information needs of the effect of treatment on social activity, self-care, side-effects of treatment, risk of disease to family, and effect of disease on family/friends were clustered in the middle of the Thurstone scale. All the men, regardless of the role preferred or assumed, rated information on the effect of treatment on usual sexual activity to be the least important. The Likert scale showed the majority of men wanted more information relating to their disease.

One difference was observed in the profiles of information needs with regard to the personal and situational factors. Single men ranked information on self-care significantly higher than married men. Although other differences were observed, they were not statistically significant.

There were no statistically significant differences found between the preferred or assumed role in treatment decision making, and the personal and situational factors. However, men who were less educated, married, and more recently diagnosed seemed to prefer or assume a passive role in treatment decision making.

## **Chapter Six**

### **Discussion of Results**

#### **6.0 Introduction**

The final chapter of this thesis discusses the results in relation to previous research findings, and Lazarus' conceptual model. The findings are discussed under the headings of information needs, treatment decision making, and information needs and treatment decision making. The effect of personal and situational factors are included in each section. Recommendations for nursing practice and future research are provided, the strengths and limitations of the study identified, and then the conclusions of the study presented.

The sample in this study was representative of the population of men newly diagnosed with prostate cancer in the province of Manitoba with regard to the variables of education, marital status, stage of disease, and treatment for stage of disease. However, the mean age of the men in this sample was 71 years, which is higher than the mean age of 63 years reported by Statistics Canada (1992). The mean age of incidence of prostate cancer increased by five years between 1991 and 1992. Due to the delayed process of reporting incidences, the 1993 statistics are expected to reflect a mean age of incidence similar to this study.

#### **6.1 Information Needs**

The types of information needs identified by this group of men newly diagnosed with prostate cancer was found to be similar to the information needs of cancer patients identified in previous research studies. These studies reported the information desired by cancer patients falls into four major categories (in hierarchial order) related to the general categories of disease, personal, family, and social (Feldman, 1976; Wiseman & Worden, 1976; Greenleigh Associates, 1979; Jones, 1981; Derdarian, 1986, 1987a, 1987b). The hierarchial order of the information needs of this sample was related to the general categories of disease (likelihood of cure, advance of disease, and types of treatment), social (affect of treatment on social activities), personal (self-care, and side-effects of treatment),

and family (risk of disease to family, and affect of disease on family/friends). The effect of treatment on usual sexual activity (a social-related information need) was rated as the least important information need. This finding suggests that although the information needs of recently diagnosed cancer patients may be universal, the rank ordering of these needs may be different for older men with prostate cancer.

Lazarus' conceptual model states that information-seeking involves cognitively appraising the stressful event for knowledge needed to make a coping decision, or to reappraise the damage or threat to self (Cohen & Lazarus, 1979). The three most important information needs identified by this group of men newly diagnosed with prostate cancer were likelihood of cure, advance of disease, and types of treatment. These three needs were consistent with the conceptual model, because the men required this information to assess the imminent threat of the disease to their survival. Previous retrospective studies also reported the most immediate concern of newly diagnosed cancer patients was physical survival (Feldman, 1976; Greenleigh Associates, 1979; Jones, 1981; Weisman & Worden, 1976). The next five information needs were clustered in the middle. This finding is also consistent with Lazarus' model as the need for this information, although important, was not seen as essential for survival.

Information on the effect of treatment on usual sexual activity was ranked as the least important by the men in this study. However, when the men were asked how much information they wanted about the effect of treatment on their usual sexual activity, approximately 50% indicated they wanted a fair bit to almost everything. This finding indicates that although the men in this study may have ranked this information item as the least important, approximately half of the men did want to receive this information. This finding provides support for the results of a study conducted by Venkatesh (1990), who stated information on the effect of treatment on usual sexual activity was required, once the initial blow of the diagnosis and treatment were over.

In addition to the nine information needs listed in the Thurstone scale, three men indicated they wanted to receive concrete objective information on the environment in which the treatment would take place (size and location of treatment room, appearance of equipment), length of time required for the procedure, and the sequence of events. These three men were in the process of deciding whether to have surgery or radiation therapy. Johnson and colleagues (1988) reported that concrete objective information has a positive effect on coping because it provides the patient with an accurate cognitive representation of the impending experience. These researchers also concluded that when patients know what to expect, their confidence in their ability to cope with the experience may be increased, and that such interventions could increase the patient's ability to cope not only during, but after treatment.

Three circular triads, among the same trio of information needs, were identified in the analysis section. The reasons for the inconsistencies in the comparative judgements will now be discussed. The information needs in the first circular triad (advance of disease, likelihood of cure, and types of treatment), and the second circular triad (effect of treatment on social activities, self-care, and side-effects of treatment), were ranked fairly equal in importance in the profile of information needs. This shows that the subjects found it difficult to make consistent choices with regard to the information items in these two circular triads. The third circular triad consisted of the information needs of likelihood of cure, self-care, and effect of treatment on social activities. Although the likelihood of cure and self-care were ranked fairly equal in importance, the likelihood of cure was ranked as the most important in the overall sample profile of information needs.

Previous studies (Weisman & Worden, 1976; Cassileth, Zupkis, & Sutton-Smith, 1980) reported older cancer patients did not want detailed information on their disease process, however, the Likert scale showed the majority of subjects in this study did want a fair bit to almost everything on each of the information needs. Although the men in this study did not express dissatisfaction with the information provided to them by their

physician, they still wanted more. One explanation for this finding is the men indicated they wanted more information because they believed this was a socially acceptable positive response. Additional explanations of this finding may be that these men were unsure of what they knew, were not receiving the type of information they wanted, were not being given the information at a level they could understand, and/or were not able to comprehend the information because they were overwhelmed by the stress of the diagnosis. Another explanation may be similar to the one reported by Reynolds and associates (1981) who suggested that even if recently diagnosed cancer patients are not given the amount of information they desire, they are often reluctant to express dissatisfaction as they believe it may affect their medical care in the future.

The profile of the Likert scale of information needs differed from the Thurstone scale of information needs. One explanation for this finding is the two scales were used to measure two different dimensions. The Thurstone scale asked the participants to rank the information needs with respect to their importance, and the Likert scale asked the subjects to identify the amount of information they desired at the time of testing. The Likert scale was not able to produce the ceiling effect which was evident in the Thurstone scale results. It is believed that if the objective of a study is to determine the importance a subject attaches to a particular item, the Thurstone scale methodology is more valid and reliable.

The most significant difference in the Thurstone profile of information needs, with regard to the personal and situational factors, was found in the marital status variable. Single men rated information on self-care statistically more important than the men who were married ( $p < 0.000$ ). The statistical significance of this finding could be challenged, because the majority of the men in this sample were married. A larger sample is required to determine if marital status is predictive of the need for information on self-care.

Other trends were identified in the analysis chapter with regard to the profiles of information needs and the personal and situational factors, but there were no previous research studies found to support the trends identified. These trends included: married,

more educated men who had early stage disease rated information on the types of treatment higher; younger men rated information on the risk of disease to family higher; single men who were less educated rated information on self-care higher; older men rated information on the side-effects of treatment higher; married men rated the effect of disease on family and friends higher; and men with early stage disease rated information on the effect of treatment on usual sexual activity higher. Although the differences noted were not statistically significant, they were believed to be clinically relevant.

## **6.2 Treatment Decision Making**

The majority of the men (57.9%) in this study preferred or assumed a passive role in treatment decision making. This finding supports previous studies that have reported older cancer patients do prefer the physician to make treatment decisions (Cassileth, Zupkis, Smith, & March, 1980; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989; Degner & Sloan, 1992). When they were asked why they choose this role, the majority of them stated that "the doctor is the specialist, and he knows what is best for me", or "I don't know what treatment is best for me, so the doctor has to decide".

Fifty of the 57 men reported congruence between their preferred and assumed role in treatment decision making. Of the patients who reported a lack of congruence, four of the seven men reported assuming a less active role than they preferred, and three assumed a more active role than they preferred. The questionnaires were reviewed to determine why these subjects differed in their roles in treatment decision making, however, no explanation could be found related to the study variables. Only one of the men who preferred an active role, but assumed a passive role identified lack of information at the time of diagnosis as a reason for his role selection. This finding indicates that the majority (87.7%) of the men had the opportunity to participate in decision making about their treatment to the extent that they desired.

In a study conducted by Degner and Sloan (1992), 428 newly diagnosed cancer patients were surveyed to determine their preferred role in treatment decision making. The sample consisted of almost an equal number of males ( $n = 226$ ) and females ( $n = 210$ ), with a mean age of 59 years ( $SD \pm 13.9$ ). The length of time since diagnosis was 10.7 weeks ( $SD \pm 5.97$ ). The preferred roles of the subjects reported by Degner and Sloan, with regard to the variable of age, were as follows: subjects  $< 50$  years- active 21%, collaborative 37%, and passive 42%; and subjects  $> 50$  years- active 10%, collaborative 27%, and passive 64%. The preference role frequencies of the men in this pilot study were found to be similar to the older group of patients in Degner and Sloan's study. Both this study, and the study conducted by Degner and Sloan (1992) used the same five cards to measure role preference. These findings showed the majority of older participants preferred a passive role in decision making. This finding suggests that being an older, newly diagnosed cancer patient may be predictive of a preference for a passive role in treatment decision making.

Degner and Sloan (1992) also reported that being a male with cancer of the reproductive system was indicative of a preference for a passive role in clinical treatment decision making. The men in this study were found to prefer a more active role in decision making than the men newly diagnosed with prostate cancer in the study conducted by Degner and Sloan. An analysis of the data from Degner and Sloan's (1992) study showed that of the 60 men in their study newly diagnosed (0-6 months) with prostate cancer, 49 (82%) preferred a passive role, 7 (12%) preferred a collaborative role, and 4 (7%) preferred an active role in treatment decision making. This pilot study showed that 33 (57.9%) preferred a passive role, 13 (22.8%) a collaborative role, and 11 (19.3%) an active role.

One explanation for this difference may be that the patients treated by the two urologists in this study were well informed, and encouraged to participate in deciding which treatment was best for them. The practices of these physicians may have been

responsible for the higher number of subjects in this study who were found to be more actively involved in the treatment decision making process. This last statement is supported by the fact that there was a high congruence (87.7%) between preferred and assumed roles. Still another explanation is that age (> 50 years) rather than the presence of a reproductive cancer is more predictive of a passive role in decision making. This assumption is further supported by a study conducted by Sutherland and associates (1989).

Sutherland and associates (1989) measured the preferences in decision making of 52 cancer patients receiving either radiation or chemotherapy at the Princess Margaret Hospital in Toronto. All patients were at an early phase in the course of their disease. The majority of the participants in this study were female ( $n = 35$ ), and five of the 17 males had prostate cancer. The mean age of the subjects was 48.5 years ( $SD \pm 13.8$ ). A set of five statements similar to the ones used in this study was used to classify patients into the active, collaborative, or passive role. The majority (63.5%) of these patients preferred a passive role in treatment decision making, 26.9% a collaborative role, and 9.6% an active role. The frequencies of these role preferences were similar to the men in this study. This finding may suggest that the preference for a passive role in treatment decision making is more prevalent among newly diagnosed cancer patients regardless of the type of cancer.

There are several possible explanations for the men in this study preferring or assuming a passive role in treatment decision making. One explanation previously reported by Beisecker (1988) was that the older patients may be less likely to believe they have the right to participate in treatment decisions or to challenge the authority of physicians. A second explanation is many of the patients may not want to assume the responsibility for decisions that may ultimately lead to unfavorable outcomes. Some other reasons for these men to prefer the more traditional authoritarian model of the patient-physician relationship may be that these older men: do not know what questions to ask; believe the physician is the specialist, so he/she knows what is best; do not believe the physician has the time to help them make decisions, because they are busy treating sicker patients; do not believe



they have a right to participate in treatment decisions as this would challenge the authority of the physician, and perhaps effect their future care; and are uncomfortable communicating with physicians.

Lazarus states that the preference for a particular role in decision making is dependent on the individual's perception and evaluation of the situation, personal and situational factors, and the continuous interaction between the individual and his/her environment. There was a trend identified for men newly diagnosed with prostate cancer, who were less educated, to prefer and assume a passive role in treatment decision making. This finding was supported by previous research studies (Cassileth, Volckmar, & Goodman, 1980; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Degner & Sloan, 1992) that reported older, less educated cancer patients prefer the physician to make treatment decisions.

There was also a trend for the men in this study, who were married, to prefer or assume a passive role in treatment decision making. This trend was supported by Blanchard and associates (1988), who reported that married, older male cancer patients assumed a less active role in decision making. One explanation for this is that the wives have assumed the role of 'broker of health care' on the patient's behalf. Beisecker (1988) also reported that although older male patients did not want to participate in treatment decision making, they often brought their wives or companions to medical appointments. The wives in this latter study were reported to make more consumerist comments than their husbands in the patient-physician interaction. The majority of the men in this study, also brought their wives to medical appointments, however the role these wives assumed in the decision making process was not measured. Since the majority of the men in this sample were married, the impact of marital status could not be further investigated.

A trend was also identified for the more recently diagnosed (0-13 weeks) men in this study to prefer or assume a passive role in treatment decision making. Twenty of the men in this study were interviewed between 0 to one week following diagnosis. It is

believed that this more recently diagnosed group of patients would assume a more active role in decision making once the initial threat of the diagnosis had subsided and their health was restored. However, this is also the time period where most treatment decisions are made. This finding has significant implications on clinical oncology nursing practice. These implications will be discussed later in this chapter.

### **6.3 Information Needs and Treatment Decision Making**

There was no relationship found between the profiles of information needs and the preferred or assumed role in treatment decision making. This finding suggests that regardless of the role preferred or assumed in the decision making process, the information needs of this group of men are similar. It is suggested that a larger sample is required to identify if there are any significant differences in the types of information desired related to role preference.

The majority of the men in this study preferred the physician to make the final treatment decision, but according to the Likert scale, they still had a desire to have more information on each of the nine categories of information. This finding suggests that the desire for information may be related to factors other than the desire for behavioural involvement in decision making. Several studies have reported older male cancer patients do want information relating to their illness, both good and bad (Cassileth, Volckmar, & March, 1980; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989), but such information is probably not desired for its usefulness in treatment decision making (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989).

The majority of the men in this study wanted to be given the information to understand and be involved in decisions even though they preferred not to make the final treatment decision themselves. Of the 33 men who preferred a passive role, 21 of these men preferred the physician to make the final treatment decision after seriously considering their opinion about which treatment was best for them. One explanation of this finding is

that these men may desire this information to satisfy an aspect of psychological autonomy that does not include their participation in treatment decision making. The information may be viewed as a way to exercise their right to self determination, or provide them with a sense of autonomy or empowerment. Empowerment in this context involves the patient determining the amount of information to be received, and the degree to which participation will occur in the decision making process. The identification of strategies that would provide empowering information to this group of men, and the effect of these strategies on the treatment decision making process certainly deserves further study with this group of older male cancer patients.

#### **6.4 Recommendations**

##### **Nursing Practice**

The relevance of this study to nursing practice is apparent. Nurses work in a variety of settings which provide care for men with prostate cancer during the treatment phase. However, treatment decisions are usually made within the first few weeks following diagnosis. This is the time frame that these men and their families require the information and support to be involved in the treatment decision making process. The majority of these men are diagnosed, given information, and treatment decisions made without the input of nurses. There is a role for clinical nurse specialists in the community urology clinics. Nurses have a professional responsibility to act as advocates to ensure clients are provided with the information that will enable them to satisfy their rights to health care (Canadian Nurses Association, 1991).

Nurses as members of the health care team have the responsibility to work with colleagues and other health care professionals to secure an excellent standard of care for clients. It is suggested that a collaborative physician-nurse role be established in these community clinic settings to meet the health care needs of this group of older male cancer patients. Nurses have the knowledge and skills to provide the information these men and their families require to make informed treatment decisions. Nurses also have the

capabilities required to assess these individuals' coping styles, information-seeking activities, and preferred role in treatment decision making. The information from these nursing assessments could be used to design interventions capable of enhancing the delivery of care to this group of older men, and to assist them in coping with their disease process.

The type and amount of information these men want was identified in this study. These findings could be integrated into patient teaching sessions offered by nurses at the time of diagnosis as well as through the treatment phase. For example, at the time of diagnosis the three most important information needs are likelihood of cure, advance of disease, and types of treatments available. The effect of treatment on usual social activities was also considered important. Although there is a need for the other information items, these types of information could be offered at other teaching sessions.

This study found that married men rated information on self-care lower than single men. Since married men may not consider this information as important, they may not ask for any information concerning their self-care needs either prior to or following treatment. This finding is important to nursing practice, because it demonstrates the need for wives to be included in teaching sessions.

The ability to make choices represents one of the most fundamental human rights, one that is basic to each individual's sense of competence. The Code of Ethics for Nursing states that all clients should be aided in becoming active participants in their care to the maximum extent that circumstances permit, and that nurses have the obligation to assist clients maintain or regain some degree of autonomy (Canadian Nurses Association, 1991). Helping these men and their families receive the type and amount of information they require to participate in treatment decisions in the diagnostic phase can be viewed as central to the practice of nursing.

Approximately 60% of the men in this study preferred or assumed a passive role in treatment decision making. However, there were approximately 40% who did want to be

involved in the treatment decision making. It is therefore imperative that nurses and physicians identify the patient's preferred role in treatment decision making early in the illness trajectory period. One way of doing this would be to administer the role preference card sort at the time of diagnosis. This would provide these patients with the opportunity to become aware of the different roles they may assume in treatment decision making, and allow the physician and nurse to support them in their preferred role.

Nurses working in these community urology clinics could also assume a role in the coordination of health care services offered to these men. For example, the nurse's role could include pre and post-operative teaching, coordination of medical appointments, arrangement of home care services, arranging contact with a cancer support group, follow-up care, and emotional support. This type of comprehensive care would provide a higher, more cost-effective level of health care to this group of men.

### **Clinical Research**

The need for further research studies includes:

1. replication of this study with a larger patient population (minimum 550 newly diagnosed subjects) to determine if the trends identified are statistically significant;
2. compare the results of the research study identified in #1 with the one currently being conducted with women diagnosed with breast cancer to determine if the differences in information needs and role in treatment decision making are gender-related;
3. replicate this study with a younger group of men with cancer of the reproductive system (for example, testicular cancer), to determine if the preference for men to choose a passive role in treatment decision making is age-related; and
4. conduct a study to identify the type of interventions that would provide empowering information to men newly diagnosed with prostate cancer, and to determine if these interventions would have an effect on the preferred role in treatment decision making.

### **6.5 Strengths and Limitations of Study**

Flexibility, precision and control are some key terms that are used when describing survey research. This type of methodology can be explicitly described, making it easier to analyze and replicate (Brink & Wood, 1989). Brink and Wood (1989) state that the value of a correlational survey is directly related to the validity and reliability of the tool being used and the accurate measurement of the variables. Part one of the questionnaire was tested for reliability and validity, before data collection was started. Part two of the questionnaire was used previously by Dr. Degner with large samples of cancer patients, and had been found to be both valid, and reliable. Precise quantitative analysis also provided strength to the results of this study. Another strength of this study was that it was conducted at one site where two urologists practice. Although the patients were treated by two different urologists, the practices of both physicians (in information disclosure, and participation of patients in treatment decision making) were similar. This increased the internal validity of the results of this study. Another strength of the study was that the questionnaire for this study was relatively short, and considered satisfactory for this patient population.

This research design, however, was not without its limitations. The proposed non-probability sample posed threats to external validity. The researcher was cognizant of the variables over which there was an element of control, thus bolstering the representativeness of the research findings for the quantitative data (Brink & Wood, 1989). The sample size was not large enough to determine if the trends identified were statistically significant. However, the purpose of this pilot study was to identify trends, and assist Dr. Degner to determine the size of sample that would be required for a larger study.

It is believed that previous contact with the health care system, and having past experience with cancer may have had an effect on the information needs identified. Some of the subjects had gone through the process of diagnosis and treatment with another family

member, and/or friend diagnosed with cancer. Since this variable was not included in the data collection, it is unknown what affect this variable had on the data set.

The Thurstone Scale methodology may have had an effect on the information profiles, as some of the men thought they could not select an item more than once, and some thought it was a test to see if they were being consistent in their choices. Although the instructions for item selection was thoroughly explained at the beginning of the interview, the effect of this limitation is not known. Perhaps this is why 11 subjects made 10 or more circular triads in their paired comparative judgements. However, Kendall's Coefficient of Agreement showed the subjects were consistent in their comparative judgements about which information needs were the most important to them.

Some of the men had difficulty selecting the card that represented the role they preferred and assumed in treatment decision making. Perhaps the card sort methodology requires adjustment for measuring the role preferences of older male cancer patients. One way of doing this would be to use three cards, which describe the qualifiers of each role in more detail. Although this limitation was observed, the role preferences identified in this study were remarkably similar to the older (>50 years) newly diagnosed cancer population preferences reported by Degner and Sloan (1992).

Another limitation identified was that the educational level of the questionnaire may have been too high. Approximately half of the subjects had less than a high school diploma, however, there were no statistically significant differences found related to education, and Kendall's Coefficient of Agreement showed there was agreement among the paired comparisons of the Thurstone Scale of information needs.

The information needs were identified by the researcher via an extensive review of the literature. This may have reflected a bias on the part of the researcher, but when the subjects were asked to identify other information needs, they stated that the ones selected were accurate. Three men did indicate that they would like more information on the site of treatment, type of equipment used, and so on, but it is believed that this information would

be part of the information given when discussing the types of treatment available, and/or the side-effects of treatment.

The presence of the researcher while the questionnaire was being completed may have influenced the results of the study, but it is believed the effect was minimal. The researcher provided the subjects with as much privacy as possible during the completion of part one of the questionnaire, and answered questions in an objective manner.

Twenty of the subjects were interviewed at the time of, or one week after being told they had prostate cancer. Although this was an advantage, the men may have been too overwhelmed by their recent diagnosis to answer the questionnaire accurately. The researcher found this was not the case, as the men were very willing to complete the questionnaire and share the experience they were faced with. All of the subjects were also interviewed following a discussion with their physician on the treatment options. Many of the newly diagnosed men may have believed the treatment decision had already been made by the time they completed the questionnaire. It is believed that the answers may have been different if the interview had been conducted prior to the treatment consultation appointment with the physician.

## **6.6 Conclusions of Study**

Lazarus states that giving information in an effort to enhance or maintain control may not be appropriate for all patients, and should be highly individualized. He does not deny that some situations and groups of individuals within a situation may share many characteristics, however, he emphasizes that each individual has their own unique perspective of the situation. The results of this study suggests the profile of information needs of men recently diagnosed with prostate cancer are similar regardless of the decision making role preferred or assumed. However a larger sample is required to determine if there is a significant relationship between the profile of information needs, role in treatment decision making, and the personal and situational variables.



This correlational study did not provide the empirical evidence to support the assumption of Lazarus' conceptual framework that personal and situational variables do have an affect on the coping process. However it is believed that when the study is replicated with a larger sample the trends identified will be shown to be statistically significant.

In summary, the majority of the men in this study wanted to be informed, they preferred their physician to make the treatment decision, and the majority of the men had participated in the decision making process to the extent they desired. These results suggest the importance of empowering these men by providing them with the information they want, in the ways that they want it, and supporting them in their preferred role in treatment decision making. Such interventions would assist these older men to reduce the stress attributed to the diagnosis of prostate cancer, increase their autonomy in treatment decision making, and assist them in coping with their disease process. Nurses do have a role in the community urology clinic working collaboratively with physicians to enhance the delivery of care to this newly diagnosed group of older male cancer patients.

## References

- Adams, M. (1991). Information and education across the phases of cancer care. Seminars in Oncology Nursing, 7 (2), 105-111.
- Ahmann, F. R. (1985a). Dilemmas in managing prostate carcinoma (part I): Localized disease. Geriatrics, 40 (7), 34-42.
- Ahmann, F. R. (1985b). Dilemmas in managing prostate carcinoma (part II): Metastatic disease. Geriatrics, 40 (9), 61-71.
- Bachers, E. S. (1985). Sexual dysfunction after treatment for genitourinary cancers. Seminars in Oncology Nursing, 1 (1), 18-24.
- Bagley-Burnett, C. (1988). Measuring information-seeking behaviors. In M. Frank-Stromberg (Ed. ), Instruments for clinical nursing research (pp. 151-169). Norwalk: Appleton & Lange.
- Bandura, A. (1977). Social learning theory. Englewood Cliffs, NJ: Prentice-Hall.
- Bazinet, M. (1991). Prostate cancer- Canadian perspectives. Cancer of the Prostate: A Desk Reference for Primary Physicians, 3-6.
- Beisecker, A. E. (1988). Aging and the desire for information and input in medical decisions: Patient consumerism in medical encounters. The Gerontologist, 28 (3), 330-335.
- Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. Medical Care, 28, 19-28.
- Benson, M. C., Kaplan, S. A., & Olsson, C. A. (1986). Prostate cancer in men less than 45 years old: Influence of stage, grade and therapy. The Journal of Urology, 137, 888-890.
- Blanchard, C. G., LaBrecque, M. S., Ruckdeschel, J. C., & Blanchard, E. B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. Social Science Medicine, 27 (11), 1139-1145.

- Bostwick, D. G. (1988). Premalignant lesions of the prostate. Seminars in Diagnostic Pathology, 5(3), 240-253.
- Bretton, P. R., & Fair, W. R. (1991, July/August). Options for managing localized carcinoma of the prostate. Contemporary Urology, 12-16.
- Brockopp, D. Y., Hayko, D., Davenport, W., & Winscott, C. (1989). Personal control and the needs for hope and information among adults diagnosed with cancer. Cancer Nursing, 12(2), 112-116.
- Brody, D. S., Miller, S. M., Lerman, C. E., Blum, M. J., & Smith, D. G. (1988). Patient perception of involvement in medical care: Relationship to illness attitudes and outcomes. Journal of General Internal Medicine, 4, 506-511.
- Brink, P. J., & Wood, M. J. (1989). Correlational designs. In P. J. Brink & M. J. Wood (Eds.), Advanced design in nursing research (pp. 104-118). Newbury Park: Sage Publications.
- Canadian Nurses Association. (1991, November). Code of ethics for nursing. Ottawa, Ontario: Canadian Nurses Association.
- Cassileth, B. R., Volckmar, D., & Goodman, R. L. (1980). The effect of experience on radiation therapy patients' desire for information. International Journal of Radiation Oncology, Biology, and Physics, 6, 439-496.
- Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. Annals of Internal Medicine, 92, 832-836.
- Cassileth, B. R., Soloway, M. S., Vogelzang, N. J., Schellhammer, P. S., Seidmon, W. J., Hait, H. I., & Kennealey, G. T. (1989, Supplement 5). Patients' choice of treatment in stage D prostate cancer. Urology, 33, 57-62.
- Catalona, W. J., & Avoli, L. V. (1987). Diagnosis, staging, and surgical treatment of prostatic carcinoma. Archives of Internal Medicine, 147, 361-363.

- Chesley, A. E. (1991). Prostate cancer- The importance of a digital rectal examination. Cancer of the Prostate: A Desk Reference for Primary Physicians, 7-11.
- Chodak, G. W., Keller, P., & Schoenberg, H. W. (1989). Assessment of screening for prostate cancer using digital rectal examination. Journal of Urology, 141, 1136-1138.
- Clark, M. (1984a). Stress and coping: Constructs in nursing. Journal of Advanced Nursing, 9, 3-13.
- Clark, M. (1984b). The constructs 'stress' and 'coping' as a rationale for nursing activities. Journal of Advanced Nursing, 9, 267-275.
- Cohen, F., & Lazarus, R.S. (1979). Coping with stress of illness. In G. C. Stone, F. Cohen, & N. E. Adler (Ed. ), Health Psychology (pp. 217-224). San Francisco: Jossey-Bass Publishers.
- Corbin, J. M., & Strauss, A. (1988). Unending work and care. San Francisco: Jossey-Bass.
- Coyne, J. C., & Lazarus, R. S. (1980). Cognitive style, stress perception, and coping. In Handbook on Stress and Anxiety (pp. 144-158). San Francisco: Jossey-Bass Publishers.
- Degner, L. F., & Beaton, J. I. (1987). Life-death decisions in health care. New York: Hemisphere Publishing.
- Degner, L. F., & Aquino-Russell, C. (1988). Preferences for treatment control among adults with cancer. Research in Nursing and Health, 11, 367-374.
- Degner, L. F., & Sloan, J. A. (1992). Decision making during serious illness: What role do patients really want to play? Journal of Clinical Epidemiology, 45 (9), 941-950.
- Dennis, K. E. (1987). Dimensions of client control. Nursing Research, 36, 151-155.

- Derdiarian, A. K. (1984). An investigation of variables and boundaries of cancer nursing: A pioneering approach using the Behavioral Systems Model for nursing. Proceedings, 3rd International Conference on Cancer Nursing (pp. 92-102). Melbourne: Australia.
- Derdiarian, A. K. (1986). Informational needs of recently diagnosed cancer patients. Nursing Research, 35(5), 276-281.
- Derdiarian, A. K. (1987a). Informational needs of recently diagnosed cancer patients: A theoretical framework. Part 1. Cancer Nursing, 10(2), 107-115.
- Derdiarian, A. K. (1987b). Informational needs of recently diagnosed cancer patients: Part 2 method and description. Cancer Nursing, 10(3), 156-163.
- Derdiarian, A. K. (1989). Effects of information on recently diagnosed cancer patients' and spouses' satisfaction with care. Cancer Nursing, 12(5), 285-292.
- Dodd, M. J., & Ahmed, N. (1987). Preference for type of information in cancer patients receiving radiation therapy. Cancer Nursing, 10(5), 244-251.
- Driever, M. J., & McCorkle, R. (1984). Patient concerns at 3 and 6 months postdiagnosis. Cancer Nursing, 235-241.
- Ende, J., Kazis, L., Ash, A., & Moskowitz, M. A. (1989). Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. Journal of General Internal Medicine, 4, 23-30.
- Feldman, F. L. (1976). Work and cancer health histories-a study of the experiences of recovered patients (Report). San Francisco: California Division, American Cancer Society, 36-52.
- Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. Journal of Personality and Social Psychology, 46(4), 839-852.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior, 21, 219-239.

- Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. Journal of Personality and Social Psychology, 48 (1), 150-170.
- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. Journal of Personality and Social Psychology, 50 (5), 992-1003.
- Folkman, S., Schaefer, C., & Lazarus, R. S. (1979). Cognitive processes as mediators of stress and coping. In V. Hamilton and D. M. Warburton (Eds. ), Human stress and cognition: An information processing approach (pp. 265-318). New York: John Wiley Publications.
- Forrow, L., Wartman, S. A., & Brock, D. W. (1988). Science, ethics, and the making of clinical decisions. Journal of the American Medical Association, 259 (21), 3161-3167.
- Frank-Stromberg, M., & Wright, P. (1984, April). Ambulatory cancer patients' perception of the physical and psychological changes in their lives since the diagnosis of cancer. Cancer Nursing, 117-130.
- Gerard, H. B. (1963). Emotional uncertainty and social comparison. Journal of Abnormal Social Psychology, 66, 568-573.
- Gittes, R. F. (1991). Carcinoma of the prostate: Review article. The New England Journal of Medicine, 324 (4), 236-245.
- Gleason, D. F. (1985). A typical hyperplasia, benign hyperplasia, and well-differentiated adenocarcinoma of the prostate. The American Journal of Surgical Pathology, 9 (3), 53-67.
- Gorman, C. (1992, October 5). The private pain of prostate cancer. Time.
- Greenfield, S., Kaplan, S., & Ware, J. E. (1985). Expanding patient involvement in care: Effect on patient outcomes. Annals of Internal Medicine, 102, 520-528.

- Greenleigh Associates. (1979, November). Report on the social, economic, and psychological needs of cancer patients in California: Major findings and implications (Report). San Francisco: California Division, American Cancer Society, 40-116.
- Guthrie, T. H., & Watson, P. (1987). Prostate cancer. American Family Physician, 36 (4), 217-224.
- Hanson, E. (1991). An exploration of the taken for granted world of the cancer nurse in relation to stress and the person with cancer. Unpublished doctoral dissertation, University of Lancaster, England.
- Haug, M. R., & Lavin, B. (1981). Practitioner or patient: Who's in charge? Journal of Health and Social Behavior, 22, 212-229.
- Herth, K. A. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. Oncology Nursing Forum, 16 (1), 67-72.
- Herr, H. W. (1987). Malignant tumors of the genitourinary tract: Prostate cancer. In R.E. Rakel (ed.), Conn's Current Therapy. Philadelphia: Saunders, pp.566-570.
- Hinkle, L. E. (1974). The concept of "stress" on the biological and social sciences. International Journal of Psychiatry in Medicine, 5 (4), 335-357.
- Holroyd, K. A., & Lazarus, R. S. (1982). Stress, coping, and somatic adaptation. In L. Goldberger and S. Breznitz (Eds.), Handbook of stress: Theoretical and clinical aspects (pp. 21-35). New York: The Free Press.
- Huben, R. P., & Murphy, G. P. (1986). Prostate cancer: An update. Cancer Journal for Clinicians, 36 (5), 274-292.
- Israel, M. J., & Mood, D. W. (1982). Three media presentations for patients receiving radiation therapy. Cancer Nursing, 5, 57-63.
- Janis, I., & Mann, L. (1977). Decision making: A psychological analysis of conflict, choice, and commitment. New York: Free Press.

- Johnson, J. E. (1984). Coping with elective surgery. In H. H. Werley & J. J. Fitzpatrick (Eds. ). Annual review of nursing research: Volume 2, (pp. 107-132). New York: Springer-Verlag.
- Johnson, J. E., Nail, L. M., Lauver, D., King, K. B., & Keys, H. (1988). Reducing the negative impact of radiation therapy on functional status. Cancer, *61*, 46-51.
- Jones, J. S. (1981). Telling the right patient. British Medical Journal, *283*, 291-292.
- Lazarus, R. S. (1966). Psychological stress and the coping process. New York: McGraw-Hill.
- Lazarus, R. S. (1974). Psychological stress and coping in adaptation and illness. International Journal of Psychiatry in Medicine, *5*(4), 321-333.
- Lazarus, R. S. (1977). Cognitive and coping processes in emotion. In A. Monat and R. S. Lazarus (Eds. ), Stress and coping an anthology (pp. ). New York: Columbia University Press.
- Lazarus, R. S. (1981). The stress and coping paradigm. In C. Eisdorfer, D. Cohen, A. Kleinman, and P. Maxim (Eds. ), Model for clinical psychopathology (pp. 177-214). New York: Spectrum.
- Lazarus, R. S. (1982). Stress and coping as factors in health and illness. In J. Cohen, J. W. Cullen, & L. M. Martin (Eds. ), Psychosocial aspects of cancer (pp. ). New York: Raven Press.
- Lazarus, R. S., Averill, J. R., & Opton, E. M. (1970). Toward a cognitive theory of emotion. In M. Arnold (Eds. ), Feelings and emotions. New York: Academic Press.
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer Press.
- Lazarus, R. S., & Launier, R. (1978). Stress-related transactions between person and environment. In Perspectives in international psychology (pp. 287-319). New York: Plenum Press.



- Leventhal, H., & Johnson, J. E. (1983). Laboratory and field experimentation: Development of a theory of self-regulation. In P. J. Woodridge, M. H. Schmitt, J. H. Skopper, & R. C. Leonard (Eds. ), Behavioral science and nursing theory (pp. 189-262). St. Louis: C. V. Mosby.
- Lloyd, G. G., Parker, A. C., Ludlam, C. A., & McGuire, R. J. (1984). Emotional impact of diagnosis and early treatment of lymphomas. Journal of Psychosomatic Research, 28(2), 157-162.
- Lyon, B. L., & Werner, J. S. (1987). Stress. Annual Review of Nursing Research, 5, 3-22.
- MacKillop, W. J., & Johnston, P. A. (1986). Ethical problems in clinical research: The need for empirical studies of the clinical trials process. Journal of Chronic Disease, 39, 177.
- Mackillop, W. J., Stewart, W. E., Ginsburg, A. D., & Stewart, S. S. (1988). Cancer patients' perceptions of their disease and its treatments. British Journal of Cancer, 58, 355-358.
- Mador, D. R. (1991). Prostate cancer: Epidemiology, diagnosis, and staging. Oncore, 1(3), 4-5.
- Mages, N. L., & Mendelsohn, G. A. (1979). Effects of cancer on patients' lives: A personological approach. In G. C. Stone, F. Cohen, & N. E. Adler (Eds. ), Health psychology (pp. 255-301). San Francisco: Jossey-Bass.
- Manitoba Health Services Commission. (1991). Annual Report.
- McCorkle, R. (1980). An ethical dilemma: Information control in cancer care. Bioethics Quarterly, 2(3), 148-158.
- McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. Cancer Nursing, 1, 373-378.

- McIntosh, J. (1974). Processes of communication, information seeking and control association with cancer: A selective review of the literature. Social Science and Medicine, 8, 167-187.
- McKenna, S. P., Hunt, S. M., & McEwen, J. (1981). Weighting the seriousness of perceived health problems using Thurstone's method of paired comparisons. International Journal of Epidemiology, 10, 93-97.
- Mertens, W. (1991). Systemic treatment of prostate cancer. Oncore, 1 (3), 10-12.
- Molleman, E., Krabbendam, P. J., Annyas, A. A., Koops, H. S., Sleijfer, D. T., & Vermey, A. (1984). The significance of the doctor-patient relationship in coping with cancer. Social Science and Medicine, 18, 475-480.
- Morra, M. E. (1985, Supplement 1). Making choices: The consumer's perspective. Cancer Nursing, 8, 54-59.
- Morris, J., & Royle, G. T. (1988). Offering patients a choice of surgery for early breast cancer: A reduction in anxiety and depression in patients and their husbands. Social Science and Medicine, 26, 583-585.
- Mosteller, F. (1951a). Remarks on the method of paired comparisons: 1. The least squares solution assuming equal standard deviations and equal correlations. Psychometrika, 16, 3-9.
- Mosteller, F. (1951b). Remarks of the method of paired comparisons: 3. A test of significance for paired comparisons when equal standard deviations and equal correlations are assumed. Psychometrika, 16, 207-218.
- Nehemkis, A. M., Gerber, K. E., & Charter, R. A. (1984). The cancer ward: Patient perceptions-staff misconceptions. Psychotherapy Psychosom., 41, 42-47.
- Newall, D. J., Gadd, E. M., & Priestman, T. J. (1987). Presentation of information to cancer patients: A comparison of two centres in the UK and USA. British Journal of Medical Psychology, 60, 127-131.

- Nisbett, R., & Ross, L. (1980). Human inference: Strategies and shortcomings in social adjustment. Englewood Cliffs, NJ: Prentice-Hall.
- Northouse, L. L., & Wortmann, C. B. (1990). Models of helping and coping in cancer care. Patient Education and Counseling, 15, 49-64.
- Oberst, M. T. (1984). Patient's perceptions of care management of quality and satisfaction. Cancer (Supplement), 53, 2366-2373.
- Ouslander, J. G., Tymchuk, A. J., & Rahbar, B. (1989). Health care decisions among elderly long-term care residents and their potential proxies. Health Care Decisions, 149, 1367-1375.
- Petros, J. A., & Catalona, W. J. (1992). Lower incidence of unsuspected lymph node metastases in 521 consecutive patients with clinically localized prostate cancer. The Journal of Urology, 147 (6), 1574-1575.
- Rainey, L. C. (1985). Effects of preparatory patient education for radiation oncology patients. Cancer, 56, 1056-1061.
- Ramsay, J. O., & Case, B. (1970). Attitude measurement and the linear model. Psychological Bulletin, 74, 185-192.
- Ramsey, E. (1992, June). Recommendations for prostate cancer screening. Proceedings of the 47th Annual Meeting of the Canadian Urological Association (pp. 1-2). Markham, Ontario: Science and Medicine Canada.
- Reimer-Kent, J. M. (1991). The characteristics of patients who waited an indeterminate period of time for coronary artery bypass graft surgery. Unpublished master's thesis, University of Manitoba, Winnipeg, Manitoba.
- Reynolds, P. M., Sanson-Fisher, R. W., Poole, A. D., Harker, J., & Byrne, M. J. (1981). Cancer and communication: Information-giving in an oncology clinic. British Medical Journal, 282, 1449-1451.
- Rimer, B., Jones, W., Wilson, C., Bennett, D., & Engstrom, P. (1983). Planning a cancer control program for older citizens. The Gerontologist, 23 (4), 384-389.

- Ross, R. T. (1974). Optimal orders in the method of paired comparisons. In G. M. Maranell (Ed.), Scaling: A sourcebook for behavioral scientists (pp. 106-109). Chicago: Aldine Publishing Company.
- Ross, R. K., Paganini-Hill, A., & Henderson, B. E. (1988). Epidemiology of prostatic cancer. In Skinner, D. G., Lieskovsky, G. (Ed.) , Diagnosis and management of genitourinary cancer. Philadelphia: W. B. Saunders Company.
- Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs: General and Applied, 80 (1, Whole No. 609).
- Saunders, J. M., & McCorkle, R. (1987). Social support and coping with lung cancer. Western Journal of Nursing Research, 9 (1), 29-42.
- Schulman, B. A. (1979). Active patient orientation and outcomes in hypertensive treatment. Medical Care, 17, 267-280.
- Science and Medicine Canada. (1992, March). Introduction. In Drs. L. Sullican and J. Trachtenberg (Co-Chairs), Proceedings of Issues and Controversies in Prostate Cancer. Symposium conducted at University of British Columbia, Vancouver, British Columbia, Canada.
- Scott, D. W., Oberst, M. T., & Bookbinder, M. I. (1984). Stress-coping response to genitourinary carcinoma in men. Nursing Research, 33 (6), 325-329.
- Seyle, H. (1979). The stress concept and some of its implications. In V. Hamilton and D. M. Warburton (Eds. ), Human stress and cognition: An information processing approach (pp. 11-32). Chichester: John-Wiley & Sons.
- Simon, H. A. (1976). Administrative behavior: A study of decision-making processes in administrative organizations (3rd ed.). New York: Free Press.
- Statistics Canada, Health & Welfare Canada, Provincial Cancer Registries, National Cancer Institute of Canada. (1992). Canadian Cancer Statistics. Toronto, Canada.

- Sutherland, H. J., Llewellyn-Thomas, H. A., Lockwood, G. A., Tritchler, D. L., & Till, J. E. (1989). Cancer patients: Their desire for information and participation in treatment decisions. Journal of the Royal Society of Medicine, 82, 260-263.
- Thorne, S. E. (1988). Helpful and unhelpful communications in cancer care: The patient perspective. Oncology Nursing Forum, 15 (2), 167-172.
- Torgerson, W. S. (1958). Theory and methods of scaling. New York: John Wiley.
- Trachtenberg, J. (1991). A stage-by-stage approach to the treatment of prostate cancer. Cancer of the Prostate: A Desk Reference for Primary Care Physicians, 12-15.
- Trandel-Korenychuk, D. M., & Trandel-Korenychuk, K. M. (1986). Disclosure of information in nursing. Legal Forum, 10 (3), 69-73.
- Tversky, A., & Kahnemann, D. (1974). Judgement under uncertainty: Heuristics and biases. Science, 185, 1124-1131.
- Venkatesh, P. S. (1990). Perceived sexual concerns and sexual adjustment of patients undergoing prostatic cancer therapy. Unpublished master's thesis, University of Manitoba, Winnipeg.
- Vertinsky, I. B., Thompson, W. A., & Uyeno, D. (1974). Measuring consumer desire for participation in clinical decision making. Health Services Research, 9, 121-134.
- Vikram, B., & Vikram, R. K. (1988). Prevention of impotence in patients with prostate cancer. Medical Aspects of Human Sexuality, 22 (3), 29-33.
- Weisman, A. L., & Worden, W. J. (1977). The existential plight in cancer: Significance of the first 100 days. International Journal of Psychiatry in Medicine, 11, 365-372.
- Weisman, A. L., & Worden, W. J. (1976). Coping and vulnerability in cancer patients. In Report of Project Omega, Department of Psychiatry, Harvard Medical School. Boston, MA: Massachusetts General Hospital.
- Weiss, S. J. (1986). Consensual norms regarding patient involvement. Social Science and Medicine, 22 (4), 489-496.

White, D. R., Muss, H. B., Michielutte, R., Cooper, M. K., Jackson, D. V., Richards, F., Stuart, J. J., & Spurr, C. L. (1984). Informed consent: Patient information forms in chemotherapy trials. American Journal of Clinical Oncology, 17, 183-190.

## **Appendix A**

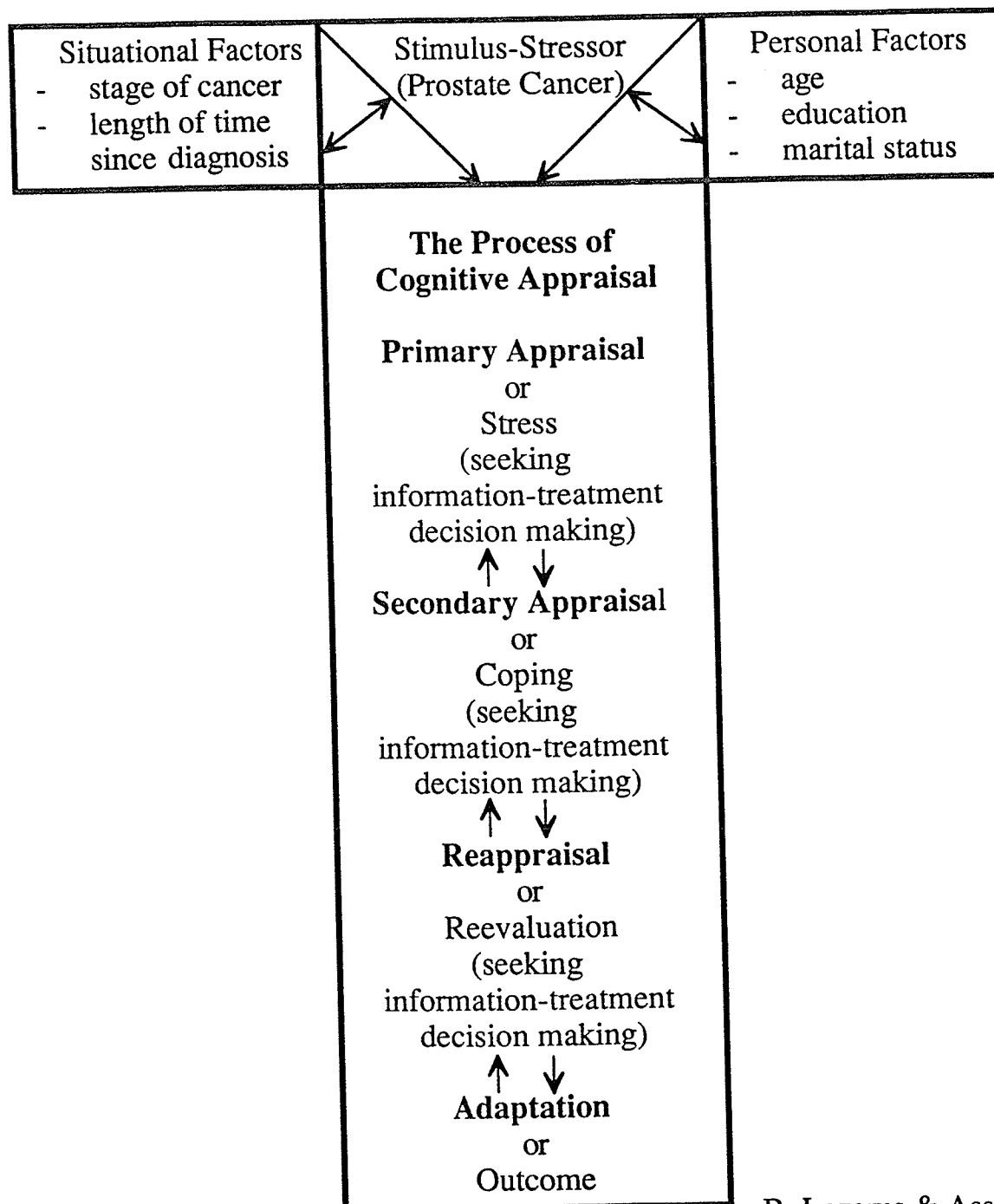
### **Lazarus' Conceptual Definitions**

**Psychological Stress-** refers to the "demands (or conflicts among them) that tax or exceed available resources (internal and external) as appraised by the person involved" (Lazarus, 1984, p. 193).

**Coping-** consists of efforts , both action-orientated and intrapsychic, to manage external and internal demands, and conflicts among them, which tax or exceed a person's resources.

**Cognitive Appraisal-** an interdependent process whereby an individual evaluates a specific stimulus-stressor with respect to their well-being (primary appraisal), assesses available resources or options to mediate the situation (secondary appraisal), evaluates how effective specific actions have been (reappraisal), and adjusts to the stimulus-stressor (adaptation/outcome). It is transactional because the interaction between the individual and his/her environment is seen as a two-way process.

# Appendix B Transactional Model of Stress and Coping



R. Lazarus & Assoc.



## **Appendix C**

### **Invitation and Explanation of the Study for Participants**

My name is Joyce Davison. I am a Registered Nurse and a student in the Master's of Nursing program at the University of Manitoba. As part of my nursing program, I am conducting a study to identify what types of information are important to men with prostate cancer, and determine the role they prefer to assume in treatment decisions.

Your physician suggested your name as someone who might be interested in learning more about this study. I would like to invite you to participate in this study.

If you agree to participate, it will take about 30 minutes of your time, and you will be asked to complete three measures. The first task will involve judging which of nine different types of information is most important to you. The second task will be a card sort procedure in which you will judge which of five different types of participation in decision making you prefer. The third measure will ask you some questions about yourself, such as age, education, and marital status. Your medical records may need to be reviewed to obtain selected information about your illness and treatment(s).

Your participation in this study is voluntary, and if you choose not to participate, it will in no way affect your medical or nursing care. If you decide to stop part way through completing the measures, you will be free to do so. Participation in this study will result in no direct benefits to you, but it may provide you with an opportunity to clarify some of the feelings and concerns you might have about assuming alternative roles in treatment decision making and the information you have received, or wish to receive. The only known risk of participating in this study is that it may make you think about your illness and treatment, and that may be uncomfortable for you.

Your involvement in this study will remain strictly confidential, and that the information will be kept in a locked filing cabinet in my home. Your identity and that the information that you provide me with will be identified by a code number. The written report and any further publication coming out of this study will describe only group information and will not identify you in any way. The data and code numbers will not be destroyed for a minimum of ten years. The only people who will have access to the data from this study are Dr. Leslie Degner (Advisor, University of Manitoba, Faculty of Nursing), and Dr. Jeff Sloan (Statistician, University of Manitoba).

If you choose to participate in this study, I will read a consent form with you and if you have any questions, please feel free to ask me about them. Your signature on the consent form will indicate your willingness to participate in the study.

If you have any questions about this study, I will be happy to answer them. I can be contacted at \_\_\_\_\_ If you wish to speak with my study supervisor, Dr. Leslie Degner, you can call her at \_\_\_\_\_ Thank you for your time and attention.

**Appendix D**  
**Consent Form**

I, \_\_\_\_\_ agree to participate in a study to identify the information needs and preferred role in treatment decision making of men with prostate cancer being conducted by Ms. Joyce Davison, who is a student in the Master's of Nursing program at the University of Manitoba. I understand that my name, as a potential participant, was given to Ms. Davison by my physician.

I understand that the purpose of this study is to better understand what types of information are important to men with prostate cancer, and determine the role they prefer in treatment decisions. This information will assist doctors and nurses to provide the information that is desired and support the role men prefer in making treatment decisions.

I understand it will take about 30 minutes of my time, and I will be asked to complete three measures. The first is a task will involve judging which of nine different types of information is most important to me. The second task will be a card sort procedure in which I will judge which of five different types of participation in decision making I prefer. The third measure will ask me some questions about myself, such as age, education, and marital status. I understand that my medical records may be reviewed to obtain selected information about my illness and treatment.

I understand that my participation in this study is voluntary, and if I choose not to participate, it will in no way affect my medical or nursing care. If I decide to stop part way through completing the measures, I will be free to do so. I understand that my participation in this study will result in no direct benefits to me, but it may provide me with an opportunity to clarify some of the feelings and concerns I might have about assuming alternative roles in treatment decision making and the information I have received, or wish

to receive. I also understand that the only known risk of participating in this study is that it may make me think about my illness and treatment, and that may be uncomfortable for me.

I have been assured that my involvement in this study will remain strictly confidential, and that the information will be kept in a locked filing cabinet in Ms. Davison's home. I understand that only the investigator will know my identity and that the information that I provide will be identified by a code number. I understand that the written report and any further publication coming out of this study will describe only group information and will not identify me in any way. The data and code numbers will not be destroyed for a minimum of ten years. The only people who will have access to the data from this study are Dr. Leslie Degner (Advisor, University of Manitoba, Faculty of Nursing), and Dr. Jeff Sloan (Statistician, University of Manitoba).

If I have any questions about this study, I am aware that I can contact Ms. Joyce Davison at \_\_\_\_\_, or Dr. Leslie Degner (Thesis Advisor) at \_\_\_\_\_

---

I agree to participate in the Information Needs/Treatment Decision Making Study, as described above.

Participant \_\_\_\_\_

Investigator \_\_\_\_\_

Date \_\_\_\_\_

I would like a summary of the results of this study: Yes \_\_\_\_\_ No \_\_\_\_\_

Mail to:

## Appendix E

### Part One: Profile of Information Needs Questionnaire

**From each of the following pairs, circle the one information need that is more important for you to know at this time.**

- 
1. Information about how advanced the disease is and how far it has spread.
  2. Information about the likelihood of cure from the disease.
- 
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
  9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
- 
4. Information about how my family and close friends may be affected by the disease.
  8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
- 
5. Information about caring for myself at home ( for example: diet, support groups, help at home, social worker, counsellor).
  7. Information about different types of treatments (surgery, chemotherapy, radiotherapy, hormone therapy), and the advantages and disadvantages of each treatment.
- 
6. Information about how the treatment may affect my usual sexual activity.
  1. Information about how advanced the disease is and how far it has spread.
- 
2. Information about the likelihood of cure from the disease.
  3. Information about how the treatment may affect my ability to carry on my usual social activities ( sports, or hobbies etc.).
- 
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
  4. Information about how my family and close friends may be affected by the disease.
- 
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
  5. Information about caring for myself at home ( for example: diet, support groups, help at home, social worker, counsellor).
- 
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy, hormone therapy), and the advantages and disadvantages of each treatment.
  6. Information about how the treatment may affect my usual sexual activity.

1. Information about how advanced the disease is and how far it has spread.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
4. Information about how my family and close friends may be affected by the disease.
2. Information about the likelihood of cure from the disease.
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
6. Information about how the treatment may affect my usual sexual activity.
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy, hormone therapy), and the advantages and disadvantages of each treatment.
1. Information about how advanced the disease is and how far it has spread.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
4. Information about how my family and close friends may be affected by the disease.
2. Information about the likelihood of cure from the disease.
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
6. Information about how the treatment may affect my usual sexual activity.
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy, hormone therapy), and advantages and disadvantages of each treatment.
1. Information about how advanced the disease is and how far it has spread.
4. Information about how my family and close friends may be affected by the disease.

5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
6. Information about how the treatment may affect my usual sexual activity.
2. Information about the likelihood of cure from the disease.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy, hormone therapy), and the advantages and disadvantages of each treatment.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
1. Information about how advanced the disease is and how far it has spread.
4. Information about how my family and close friends may be affected by the disease.
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
6. Information about how the treatment may affect my usual sexual activity.
2. Information about the likelihood of cure from the disease.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy, hormone therapy), and the advantages and disadvantages of each treatment.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
1. Information about how advanced the disease is and how far it has spread.
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
6. Information about how the treatment may affect my usual sexual activity.
4. Information about how my family and close friends may be affected by the disease.

7. Information about different types of treatments (surgical, chemotherapy, radiotherapy, hormone therapy), and the advantages and disadvantages of each treatment.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
2. Information about the likelihood of cure from the disease.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).
1. Information about how advanced the disease is and how far it has spread.
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
6. Information about how the treatment may affect my usual sexual activity.
4. Information about how my family and close friends may be affected by the disease.
7. Information about different types of treatments ( surgical, chemotherapy, radiotherapy, hormone therapy ), and the advantages and disadvantages of each treatment.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.
2. Information about the likelihood of cure from the disease.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).

Are there any other informational needs you may have?

---



---



---



---



**Appendix F**  
**Likert Scale of Information Needs**

**Please circle the number that shows how much you feel you need to know about each of the following types of information at this time.**

1. Information about how advanced the disease is and how far it has spread.  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything
  
2. Information about the likelihood of cure from the disease.  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything
  
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything
  
4. Information about how my family and close friends may be affected by the disease.  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything
  
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything
  
6. Information about how the treatment may affect my usual sexual activity.  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything
  
7. Information about different types of treatments (surgery, radiotherapy, hormone therapy, chemotherapy), and the advantages and disadvantages of each treatment.  

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything

8. Information about whether my spouse/partner or other members of the family are at risk of getting prostate cancer.

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything

9. Information about possible unpleasant side effects of treatment (for example: nausea, pain).

1	2	3	4
Almost nothing	A little bit	A fair bit	Almost everything

## **Appendix G**

### **Part Two: Control Preference Scale**

1. Preferred role in treatment decision making if you were given the amount of information that you identified on the previous nine categories of information: \_\_\_\_\_
2. Actual role in treatment decision making at present time: \_\_\_\_\_

**The following choices were presented to the patients using a card sort procedure, as outlined in the methodology section.**

1. I prefer to make the final selection about which treatment I will receive.
2. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
3. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
4. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
5. I prefer to leave all decisions regarding my treatment to my doctor.

**(This key was not included on actual survey questionnaire)**

**Choice 1 or 2 indicates an active role**

**Choice 3 indicates a collaborative role**

**Choice 4 or 5 indicates a passive role**

## Appendix H

### Part Three: Personal Sociodemographic Profile

1. ID Number \_\_\_\_\_
2. Age at last birthday \_\_\_\_\_
3. Highest education:   1) Eighth grade or less \_\_\_\_\_  
                                   2) Some high school \_\_\_\_\_  
                                   3) High school diploma \_\_\_\_\_  
                                   4) Greater than high school \_\_\_\_\_
4. Marital status: 1) Married \_\_\_\_\_  
                           2) Common Law/Cohabiting \_\_\_\_\_  
                           3) Widowed \_\_\_\_\_  
                           4) Divorced \_\_\_\_\_  
                           5) Separated \_\_\_\_\_  
                           6) Never Married \_\_\_\_\_
5. Employment Status: 1) Working Full-time \_\_\_\_\_  
                                   2) Working Part-time \_\_\_\_\_  
                                   3) Retired \_\_\_\_\_
6. Where you born in Canada? 1) Yes \_\_\_\_\_  
   2) No \_\_\_\_\_
7. Which one ethnic group do you identify with? (Please check one)  

___ Black	___ Italian	___ Polish
___ Chinese	___ Irish	___ Scottish
___ Dutch	___ Japanese	___ Ukrainian
___ English	___ Jewish	___ Other (Please State)
___ French	___ North American Indian	_____
___ German	___ Metis	
___ Greek	___ Pakistani	
___ Indian (India)	___ Philippine	
___ Inuit-Eskimo	___ Portuguese	
8. How strongly do you identify with this group? 1) Very Little \_\_\_\_\_  
   2) Somewhat \_\_\_\_\_  
   3) Fairly Strongly \_\_\_\_\_  
   4) Very Strongly \_\_\_\_\_
9. What language do you speak at home? (most often) \_\_\_\_\_

**Information to be obtained from Patient Record:**

10. Length of time since diagnosis (in weeks): \_\_\_\_\_
11. Length of time since diagnosis (in months): 1) 0-3 months \_\_\_\_\_  
2) 4-6 months \_\_\_\_\_
12. Stage of disease at time of testing: 1) Early (Stage A or B) \_\_\_\_\_  
2) Late (Stage C or D) \_\_\_\_\_  
3) Unknown \_\_\_\_\_
13. Past and/or current treatments: 1) Surgery (Orchiectomy, radical, TUR, LND) \_\_\_\_\_  
2) Hormone Therapy \_\_\_\_\_  
3) Radiation \_\_\_\_\_  
4) Chemotherapy \_\_\_\_\_  
5) Other \_\_\_\_\_
14. Time spent for data collection: \_\_\_\_\_ (minutes).

# **Appendix I** **Variable Dictionary**

<b>Variable Column Number/Name</b>	<b>Measurement Level</b>	<b>Values/ Tags</b>	<b>Number</b>
1. IDNO	Character	Special code	1-2
2. DR	Categorical	1= Dr. A 2= Dr. B	3
3. I12, I39, I48, I57, I61, I23, I94, I85, I76, I13, I42, I59, I68, I71, I34, I25, I96, I87, I14, I53, I62, I79, I81, I45, I36, I27, I98, I15, I64, I73, I82, I91, I56, I47, I38, I29	Categorical	1 = First number 0 = Second number  1= Disease advance 2= Likelihood of cure 3= Affect on social activities 4= Affect on family/close friends 5= Self care at home 6= Sexual activity 7= Types of treatments (adv. & disadv. of each) 8= Family at risk of disease 9= Side effects of treatment(s)	4-39
4. LIK1, LIK2, LIK3, LIK4, LIK5, LIK6, LIK7, LIK8, LIK9	Interval	1= Almost nothing 2= A little bit 3= A fair bit 4= Almost everything	40-48
5. PREROLE	Interval	1= A (active) 2= B (active) 3= C (collaborative) 4= D (passive) 5= E (passive)	49
6. ACTROLE	Interval	1= A (active) 2= B (active) 3= C (collaborative) 4= D (passive) 5= E (passive)	50
7. AGE	Ratio		51-52

8.	EDU	Ordinal	1= Eighth grade or less 2= Some high school 3= High school diploma 4= Greater than high school	117 53
9.	MARSTAT	Categorical	1= Married 2= Common law/cohab 3= Widowed 4= Divorced 5= Separated 6= Never married	54
10.	EMPSTAT	Categorical	1= Work full-time 2= Work part-time 3= Retired	55
11.	BORCAN	Categorical	1= Yes 2= No	56
12.	ETH	Categorical	1= Black 2= Chinese 3= Dutch 4= English 5= French 6= German 7= Greek 8= Icelandic 9= Indian (India) 10= Inuit-Eskimo 11= Italian 12= Irish 13= Japanese 14= Jewish 15= North American Indian 16= Metis 17= Pakistani 18= Philippine 19= Portuguese 20= Polish 21= Scottish 22= Swedish 23= Ukrainian	57-58
13.	IETH	Interval	1= Very little 2= Somewhat 3= Fairly strongly 4= Very strongly	59
14.	LANG	CategoricalL	1= English 2= Other	60

15. TIMEDIAG	Ratio	0-24 weeks	61-62
16. STG	Categorical	1 = Stage A 2 = Stage B 3 = Stage C 4 = Stage D 5 = Unknown	63
17. TX	Categorical	1 = Surgery 2 = Hormone 3 = Radiation 4 = Chemo 5 = Surgery & Hormone 6 = Surgery & Radiation 7 = None so far	64
18. TIME	Ratio	0-60 minutes	65-66



**Appendix J**  
**Frequency Matrix for All Subjects**  
**(n= 57)**

	1	2	3	4	5	6	7	8	9
1	0	31	43	47	47	46	39	44	50
2	26	0	38	50	46	55	44	51	51
3	14	19	0	32	29	44	18	31	31
4	10	7	25	0	23	43	11	30	21
5	10	11	28	34	0	43	16	33	27
6	11	2	13	14	14	0	6	15	9
7	18	13	39	46	41	51	0	41	41
8	13	6	26	27	24	42	16	0	21
9	7	6	26	36	30	48	16	36	0

**1= advance of disease**

**2= likelihood of cure**

**3= effect of treatment on social activities**

**4= effect of disease on family/friends**

**5= self-care**

**6= effect of treatment on usual sexual activity**

**7= types of treatment (adv. & disadv. of each)**

**8= risk of disease to family**

**9= side-effects of treatment**

**Appendix K**  
**Proportion Matrix for All Subjects**  
**(n= 57)**

	1	2	3	4	5	6	7	8	9
1	0	.544	.754	.825	.825	.807	.684	.772	.877
2	.456	0	.667	.877	.807	.965	.772	.895	.895
3	.246	.333	0	.561	.509	.772	.316	.544	.544
4	.175	.123	.439	0	.404	.754	.193	.526	.368
5	.175	.193	.491	.596	0	.754	.281	.579	.474
6	.193	.035	.228	.246	.246	0	.105	.263	.158
7	.316	.228	.684	.807	.719	.895	0	.719	.719
8	.288	.105	.456	.474	.421	.737	.281	0	.368
9	.123	.105	.456	.632	.526	.842	.281	.632	0
<b>Sum</b>									
	1.972	1.666	4.175	5.018	4.457	6.526	2.913	4.930	4.403

---

**1= advance of disease**

**2= likelihood of cure**

**3= effect of treatment on social activity**

**4= effect of disease on family/friends**

**5= self-care**

**6= effect of treatment on usual sexual activity**

**7= types of treatment (adv. &disadv. of each)**

**8= risk of disease to family**

**9= side-effects of treatment**

**Appendix L**  
**Z Score Matrix for All Subjects**  
**(n= 57)**

	1	2	3	4	5	6	7	8	9
1	0	.110	.688	.933	.933	.867	.480	.745	1.161
2	-.110	0	.431	1.161	.867	1.811	.745	1.252	1.252
3	-.688	-.431	0	.155	.022	.745	-.480	.110	.110
4	-.933	-1.161	-.155	0	-.244	.688	-.867	.066	-.336
5	-.933	-.867	-.022	.244	0	.688	-.581	.199	-.066
6	-.867	-1.811	-.745	-.688	-.688	0	-1.252	-.634	-1.003
7	-.480	-.745	.480	.867	.581	1.252	0	.581	.581
8	-.745	-1.252	-.110	-.066	-.199	.634	-.581	0	-.336
9	-1.161	-1.252	-.110	.336	.066	1.003	-.581	.336	0
<b>Sum</b>									
	-5.917	-7.409	.457	2.942	1.338	7.688	-3.117	2.655	1.363
<b>Mean</b>									
	-.657	-.823	.051	.327	.149	.854	-.346	.295	.151

---

**1= advance of disease**

**2= likelihood of cure**

**3= effect of treatment on social activity**

**4= effect of disease on family/friends**

**5= self-care**

**6= effect of treatment on usual sexual activity**

**7= types of treatment (adv. & disadv. of each)**

**8= risk of disease to family**

**9= side-effects of treatment**